Research Topics

Towards 2030: sustainable development goal 3: good health and wellbeing. A sociological perspective

Edited by
Sangeeta Chattoo, Chimaraoke Izugbara, Andrzej Klimczuk,
Magdalena Klimczuk-Kochańska, Piotr Toczyski, Ashwani Kumar,
Rubal Kanozia and Grzegorz Piotr Gawron

Coordinated by
Ahmad Ozair

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Towards 2030: sustainable development goal 3: good health and wellbeing. A sociological perspective

Topic editors
Sangeeta Chattoo — University of York, United Kingdom
Chimaraoke Izugbara — International Center for Research on Women, United States
Andrzej Klimczuk — Warsaw School of Economics, Poland
Magdalena Klimczuk-Kochańska — University of Warsaw, Poland
Piotr Toczyski — The Maria Grzegorzewska University, Poland
Ashwani Kumar — University of Allahabad, India
Rubal Kanozia — Central University of Punjab, India
Grzegorz Piotr Gawron — University of Silesia in Katowice, Poland

Topic coordinator
Ahmad Ozair — University of Maryland, United States

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Table of contents

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Ettore Recchi,
Sciences Po, Paris, France

*CORRESPONDENCE
Andrzej Klimczuk
✉ klimczukandrzej@gmail.com

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Editorial: Towards 2030: sustainable development goal 3: good health and wellbeing. A sociological perspective

Andrzej Klimczuk[1]*, Sangeeta Chattoo[2], Chimaraoke Izugbara[3,4], Magdalena Klimczuk-Kochańska[5], Piotr Toczyski[6], Ashwani Kumar[7], Rubal Kanozia[8], Grzegorz Piotr Gawron[9] and Ahmad Ozair[10,11]

[1]Department of Social Policy, Collegium of Socio-Economics, SGH Warsaw School of Economics, Warsaw, Poland, [2]Department of Sociology, University of York, York, United Kingdom, [3]International Center for Research on Women, Washington, DC, United States, [4]School of Public Health and Community Medicine, University of Gothenburg, Gothenburg, Sweden, [5]Faculty of Management, University of Warsaw, Warsaw, Poland, [6]Media and Communication Department, Institute of Philosophy and Sociology, The Maria Grzegorzewska University, Warsaw, Poland, [7]Metagenomics and Secretomics Research Laboratory, Department of Botany, University of Allahabad, Prayagraj, India, [8]Department of Mass Communication and Media Studies, School of Information and Communication Studies, Central University of Punjab, Bathinda, India, [9]Institute of Sociology, Faculty of Social Sciences, University of Silesia in Katowice, Katowice, Poland, [10]Faculty of Medical Sciences, King George's Medical University, Lucknow, India, [11]Bloomberg School of Public Health, Johns Hopkins University, Baltimore, MD, United States

KEYWORDS

SDG3, essential health services, public health, universal health coverage, health inequalities, wellbeing, global health

Editorial on the Research Topic
Towards 2030: Sustainable development goal 3: good health and wellbeing. A sociological perspective

Overview

This Research Topic explores the third Sustainable Development Goal (SDG) to "ensure healthy lives and promote wellbeing for all at all ages," highlighting the severe impact of the COVID-19 pandemic. The pandemic has threatened to reverse prior improvements in maternal and child health, immunization coverage, and reductions in communicable and non-communicable disease mortality while also disrupting essential health services, shortening life expectancy, and worsening mental health issues and healthcare access inequalities. This Research Topic contains studies examining how social stratification, geography, and culture affect health, aiming to inform policymakers on developing equitable public health policies to address disparities and improve wellbeing.

The Research Topic "*Towards 2030: sustainable development goal 3: good health and wellbeing. A sociological perspective*" includes 11 articles prepared in total by 52 authors from the following countries: Brazil, Canada, Ethiopia, India, Norway, Spain, Sweden, the United Kingdom, and the United States. "Frontiers in Sociology" and "Frontiers in Public Health" journals were responsible for organizing this project. The presented Research covering: six original research articles (Tripathi and Samanta; Zewude et al.; Teteh et al.; Engdawork et al.; Kåks et al.; Elung'ata), two hypothesis and theory papers (Sæbø and Lund; Field-Richards and Timmons), one conceptual analysis (Coca et al.), one review (Araújo et al.), and one study protocol (Martí-Lluch et al.). The Research Topic covers topics such as aging, community support, social determinants of health, digital health, health promotion and prevention, health-related stigma, and social innovation. The articles comprising this Research Topic are divided into three themes.

Theme I: advancements and challenges in health systems

The first paper of this Research Topic by Araújo et al. analyzes the alignment of Brazilian and international organizations' arguments for adopting digital health in primary health care during the COVID-19 pandemic to support achieving the SDGs. This study finds that both emphasize the applicability of information and communication technologies, but Brazil also underscores the need for regulatory frameworks to support these digital practices. Field-Richards and Timmons focus on specific cases of risk management related to cardiac arrest (CA) that lead to high mortality and morbidity, with many deaths in intensive care units due to neurological injury following out-of-hospital CA. Despite the uncertainty and risk in prognostication, post-cardiac arrest (P-CA) guidelines emphasize using prognosticators to manage professional risk, balancing the duty to prognosticate with the challenges of accurately predicting outcomes. Martí-Lluch et al.'s study argues that healthcare and wellbeing depend on multiple factors that must adapt to societal changes, including individuals' increasing participation in their care decisions. Their analysis focuses on the association between personal aptitudes related to behaviors and health outcomes. It contributes to improved health promotion and prevention strategies by examining their impact on morbidity, mortality, lifestyle adoption, quality of life, and healthcare utilization. Finally, Elung'ata's study examines healthcare systems as mesocosms to understand social disparities in spousal violence perceptions in sub-Saharan Africa, focusing on cohort differences in victim decision-making. Using data from 18 countries, it finds significant differences in spousal violence decisions and underlines the influence of healthcare system access, supporting socio-ecological theory in addressing these disparities.

Theme II: social determinants and innovations in health and wellbeing

The subsequent papers mainly focus on factors and innovations influencing health and wellbeing. Tripathi and Samanta's study explores how leisure activities can moderate the relationship between subjective wellbeing and depressive symptoms among older Indians, using data from the Longitudinal Aging Study in India. Results indicate that increased social engagement through leisure activities significantly improves wellbeing and reduces depressive symptoms, highlighting the need for age-friendly initiatives and social infrastructure to enhance involvement and wellbeing in older adults. Kåks et al. studied the adaptation of a South African social innovation based on peer support for mothers that was implemented in southern Sweden to help immigrant women access public health services. The research found that the intervention's success relied on trust-building and flexible, tailored support despite community mistrust and funding issues. The social determinants of health (SDOH) are also crucial in Sæbø and Lund's study of smoker stigma, an unintended consequence of tobacco policies in Norway that is influenced by personal values and socio-demographic factors. Their research found high levels of perceived public stigma against smokers, especially among women, young people, and high socio-economic status individuals, with smokers planning to quit feeling the most stigma. In another study, Teteh et al. examined how SDOH influences the quality of life (QOL) outcomes for lung cancer surgery patients. Their research found that financial challenges, education, healthcare access, environment, and social support impact QOL, highlighting the need for routine SDOH assessment and targeted interventions to improve care and survivorship.

Theme III: health-related strategies and interventions

The last section provides examples of specific case studies related to health-related public policies. Engdawork et al. focus on Ethiopia's response to the COVID-19 pandemic, which involved structural and social interventions, such as national policy development, community engagement, and mass communication strategies, which helped slow the virus spread in Addis Ababa. However, challenges such as competing interests, misconceptions, and capacity constraints hindered implementation, emphasizing the need for future interventions to address these issues in low- and middle-income settings. The team of Zewude et al. focused on Addis Ababa, particularly on the situation of street children, who are highly vulnerable to health risks and have limited access to healthcare services. This study found that while these children perceive their susceptibility to health risks and engage in preventive behaviors such as maintaining hygiene and physical exercise, they also frequently engage in risky behaviors such as smoking, sniffing glue, and unprotected sex, which necessitates targeted health interventions. Finally, Coca et al. examined the socio-historical importance of pharmacovigilance. The authors show that this scientific discipline has evolved significantly, as highlighted by the sulfonamide elixir case. The paper suggests that integrating pharmacovigilance with the social sciences could enhance its societal impact and promote a more democratic environment responsive to individual and group needs.

Conclusion

The research findings presented in this Research Topic facilitate the formulation of five directions for further research combined with SDG3. These are: (1) transformations of social determinants of health, covering new lifestyles and smart environments (see Missoni, 2022; Ozair and Singh, 2021); (2) new schemes in the health emergency preparedness and access to universal health coverage (see Okyere et al., 2024); (3) public health and health sector innovations in the post-COVID-19 pandemic period (see Raji and Demehin, 2023); (4) integrated innovation combining ideas from the fields the environmental policy, social policy, and health policy (see Klimczuk et al., 2022); and (5) privacy and ethical issues related to e-health solutions such as telemedicine platforms, mobile health apps, and wearable health devices (see Wyllie et al., 2022).

Author contributions

AKl: Methodology, Conceptualization, Investigation, Validation, Supervision, Project administration, Writing – review & editing, Writing – original draft. SC: Writing – review & editing, Validation, Supervision. CI: Supervision, Writing – review & editing, Validation. MK-K: Supervision, Validation, Writing – review & editing. PT: Validation, Supervision, Writing – review & editing. AKu: Validation, Writing – review & editing, Supervision. RK: Supervision, Validation, Writing – review & editing. GG: Validation, Writing – review & editing, Supervision. AO: Supervision, Validation, Writing – review & editing.

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Conflict of interest

The author declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Klimczuk, A., Klimczuk-Kochańska, M., and Felix, J. (2022). Editorial: Social, technological and health innovation: opportunities and limitations for social policy, health policy, and environmental policy. *Front. Polit. Sci.* 4:1020110. doi: 10.3389/fpos.2022.1020110

Missoni, E. (2022). "Global health determinants and limits to the sustainability of sustainable development goal 3," in *Transitioning to Good Health and Well-Being*, ed. A. Flahault (Basel: MDPI), 1–29. doi: 10.3390/books978-3-03897-865-7-1

Okyere, D. O., Lomazzi, M., Peri, K., and Moore, M. (2024). Investing in health system resilience: a scoping review to identify strategies for enhancing preparedness and response capacity. *Popul. Med.* 6, 1–21. doi: 10.18332/popmed/183661

Ozair, A., and Singh, K. K. (2021). Delivering high-quality, equitable care in India: an ethically-resilient framework for healthcare innovation after COVID-19. *Front. Public Health* 9:640598. doi: 10.3389/fpubh.2021.640598

Raji, S. A., and Demehin, M. O. (2023). "Long Walk to 2030": a bibliometric and systematic review of research trends on the UN sustainable development goal 3. *Dialog. Health* 2:100132. doi: 10.1016/j.dialog.2023.100132

Wyllie, J., Carlson, J., Heinsch, M., Kay-Lambkin, F., and McCoy, A. (2022). eHealth services and SDG3: increasing the capacity of care. *Austral. Market. J.* 30, 131–141. doi: 10.1177/18393349211069114

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A technical solution to a professional problem: The risk management functions of prognosticators in the context of prognostication post-cardiac arrest

Sarah Elizabeth Field-Richards[1]* and Stephen Timmons[2]

[1]School of Health Sciences, University of Nottingham, Nottingham, United Kingdom, [2]Nottingham University Business School, University of Nottingham, Nottingham, United Kingdom

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EDITED BY
Abdelouahab Bellou,
Wayne State University, United States

REVIEWED BY
Efstratios Photiou,
Hospital of Montebelluna "San Valentino", Italy
Linus Lilja,
Karlstad Central Hospital, Sweden

*CORRESPONDENCE
Sarah Elizabeth Field-Richards
sarah.fieldrichards@nottingham.ac.uk

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Cardiac arrest (CA) is a major cause of mortality and morbidity globally. Two-thirds of deaths among patients admitted to intensive care units following out-of-hospital CA are due to neurological injury, with most as a consequence of withdrawing life-sustaining treatment, following prognostication of unfavorable neurological outcome. Given the ramifications of prognosis for patient outcome, post-cardiac arrest (P-CA) guidelines stress the importance of minimizing the risk of falsely pessimistic predictions. Although prognosticator use is advocated to this end, 100% accurate prognosticators remain elusive, therefore prognostication P-CA remains pervaded by uncertainty and risk. Bioethical discourse notwithstanding, when located within a wider socio-cultural context, prognostication can be seen to present risk and uncertainty challenges of a professional nature. Such challenges do not, however, subvert the medical profession's moral and ethical prognostication obligation. We interpret prognosticator use as an attempt to manage *professional* risk presented by prognostication P-CA and demonstrate how through performing "risk work," prognosticators serve professional functions, mediating tension between the professional duty to prognosticate, and risk presented. We draw on sociological analyses of risk and uncertainty, and the professions to explicate these (hitherto less enunciated) professional risk management functions of prognosticators. Accordingly, the use of prognosticators is conceived of as a professional response – a technical/scientific solution to the problem of professional risk, inherent within the P-CA prognostication process.

KEYWORDS

prognostication, prognosticator, cardiac arrest, risk, professions, risk management, risk work, sociology of prognosis

Introduction

Cardiac arrest (CA) is a major cause of mortality and morbidity globally and outcomes for resuscitated patients are typically poor. Two-thirds of deaths amongst patients admitted to intensive care units following CA outside of hospital are due to neurological injury. Most of these deaths are a consequence of withdrawing life-sustaining treatment, following prognostication of an unfavorable neurological outcome - severe neurological injury, persistent vegetative state, or death (Nolan et al., 2015; Sandroni and Geocadin, 2015). Given the ramifications of prognosis for treatment decisions and patient outcome, post-cardiac arrest (P-CA) guidelines stress the importance of minimizing "the risk of a falsely pessimistic prediction" (Nolan et al., 2015). Prognostication P-CA is however challenging and inexact and the use of clinical indicators (prognosticators) is advocated to support medical professionals' decision-making (Horn et al., 2014; Sandroni and Geocadin, 2015). The various prognosticators employed by medical professionals can be classified as clinical examination (e.g., Glasgow Coma Scale score, corneal reflex, seizure presence), neurophysiological studies (e.g., electroencephalography, somatosensory evoked potentials), biochemical markers (e.g., neuron-specific enolase), and imaging studies (magnetic resonance imaging, brain computerized tomography) (Nolan et al., 2015).

The dominant biomedical narrative and rationale supporting prognosticator use P-CA is normatively framed in bioethical terms concerning patient "best interest," avoiding inappropriate treatment "in patients with no chance of recovery," whilst conversely avoiding prematurely withholding treatment for those with "a chance for good neurologic outcome" (Sandroni and Geocadin, 2015, p. 2). Further, bioethically, prognosticators should have a specificity of 100% or a false-positive rate of zero (i.e., when they predict a poor outcome, no patient should experience a long-term "good" outcome) (Nolan et al., 2015). However, despite an abundance of research (see Sandroni and Geocadin, 2015; Sandroni et al., 2018), definitive prognosticators remain elusive, with Nolan et al. (2015) concluding that none are adequate for the task asked of them. Though clinically varied, prognosticators can be considered equivalent as they are employed for a common purpose (prognostication) and one for which they are ultimately inadequate. As such, guidelines recommend a multi-modal approach involving multiple types of brain injury tests (Nolan et al., 2015), which might be interpreted as an attempt to triangulate prognosticator uncertainty. Although "Even the most robust predictors … do not guarantee an absolute certainty when predicting poor outcome" (Sandroni and Geocadin, 2015, p. 6), usage continues, creating tension between the bioethical imperative for prognostic certainty and the "probabilistic knowledge" (Gale et al., 2016, p. 1062) provided by uncertain prognosticators. Paradoxically, since 100% accurate prognosticators remain to be found, their use as a means of managing clinical and bioethical risk and uncertainty itself, constitutes an uncertain practice entailing the risk of error, reflecting tension between prognosticators as both creators and managers of risk and rendering the quest for certainty inherently uncertain.

Origins and nature of the paper

This paper presents a theoretical interpretation of the professional functions served by a documented empirical phenomenon (prognostication P-CA). The stimulus for the paper was a review of scientific biomedical research pertaining to prognostication P-CA, conducted in 2013, involving 185 returned papers. Through the literature review process, the authors became familiar with scientific and biomedical aspects of the P-CA prognostication process, which served as a point of departure for sociological thinking. The biomedical literature suggested that definitive prognosticators remained to be identified since the publication of the 2010 Resuscitation Council (UK) guidelines (Deakin et al., 2010). The review also demonstrated a significant and sustained research focus and professional interest in the identification of accurate P-CA prognosticators. This focus on the identification of accurate P-CA prognosticators remains today (e.g., Sandrioni et al., 2020; Andersson et al., 2021; Oh et al., 2021), reflecting their apparent importance in managing clinical and bioethical risk and uncertainty associated with patient outcome P-CA, as an important and pressing medical problem.

The bioethical rationale, function and research notwithstanding, as sociologists of the professions considering phenomena within a wider socio-cultural context, we theorized as to how the quest for certainty might be conceived of, and the professional functions that prognostication P-CA serves and to what effect. We also observed a tension created by the professional duty to engage in the process of prognostication on the one hand, as a process pervaded by uncertainty and professional risk stemming from the use of uncertain prognosticators, on the other. We considered how this tension might be managed by medical professionals and the overall salience of the prognostication P-CA process for the medical profession. During this process, we engaged with sociological literature relating to the professions (particularly the medical profession, including areas such as medical prognosis, death and dying), and risk and uncertainty, in informing and developing our theorizing, applying existing sociological knowledge to a new, specific context (prognostication P-CA). Accordingly, references to this literature are included throughout the paper to support the arguments presented. Although a theoretical rather than empirical paper in nature, the arguments presented herein can therefore be considered to be empirically grounded in considering a documented empirical phenomenon (prognostication P-CA) observed in the biomedical literature, and in applying empirically-based sociological theory to analyze how it can function for professional means.

Argument and structure of the paper

In this paper, we argue that prognosticator use P-CA can be interpreted as an attempt to manage not only clinical and bioethical risk but also *professional* risk presented by the prognostication process. Bioethical discourse notwithstanding, prognostication presents risk and uncertainty challenges of a *professional* nature. Such challenges do not however subvert the medical profession's moral and ethical prognostication obligation (Christakis, 1999). We demonstrate how although uncertain prognosticators can create risk, by negotiating professional challenges through performing "risk work" (Gale et al., 2016, p. 1046), prognosticators function to manage professional risk in multiple ways, with varying outcomes. In this way, we show how prognosticators serve professional functions, mediating tension between the professional duty to prognosticate on the one hand and the challenges it presents, in terms of professional risk and uncertainty, on the other. Their use constitutes a professional response - a technical/scientific solution to the professional problem of risk and uncertainty arising from the P-CA prognostication process. Whilst prognosticators have as yet failed to deliver certainty in relation to prognostication of patient outcome P-CA as their "primary" purpose, when considered within a wider socio-cultural context, their use can therefore be observed to serve other important professional risk and uncertainty management functions. In explicating our argument, we utilize extant theory and empirical work, applying and extending insights to an analysis of the P-CA prognostication context. In doing so, we contribute to knowledge and theorizing in the sociological areas of risk and uncertainty, and professions. Further, through a critique of the process and practice of prognostication more broadly, we contribute to the "emerging sociology of prognosis" (Timmermans and Strivers, 2018, p. 13).

In the sections that follow, firstly, we outline the theoretical positioning of the paper and locate the central argument within the perspectives introduced. We then identify professional risks presented by the P-CA prognostication process and the way prognosticators function to manage them, through various forms of risk work. We do this by presenting a series of inter-related arguments, each focusing on an area of professional risk and considering the nature of the risk work performed by prognosticators, how this functions to address the professional risk, and to what effect. Collectively, these arguments demonstrate the risk work role that prognosticators perform in managing professional risk presented by the prognostication process P-CA. Before concluding the paper, we summarize and provide a theoretical model of the arguments presented and discuss contributions to knowledge, caveats and opportunities for research.

Theoretical approach

The theoretical position adopted in this paper is informed by the sociology of professions and the sociology of risk and uncertainty. These approaches are now outlined and contextualized in terms of their relevance to the central argument of the paper.

Sociology of professions

Our paper considers the P-CA prognostication process within the specific professional context of medical professionals. Acknowledging different possible approaches to "profession" (Macdonald, 1995), we now outline our position. For us, "profession" is a socially constructed concept, serving as much to create a market shelter for an occupational group as it does to analytically delineate between types of work (Freidson, 1970). Within the sociology of professions, we align ourselves with the neo-Weberian but eclectic position of Saks (2016), which draws centrally on the work of authors including Larson (1977) (the professional project) and Abbott (1988) (the system of professions). Saks argues for the continued relevance of the neo-Weberian approach, despite the critique of, for instance, Evetts (2006). Professions are engaged in an ongoing professional project where they attempt to secure privileges (principally from the state), such as control over work and power to accredit members of their profession. The main strategy used by professionals to accomplish this is by defining a "jurisdiction" where they have an effective monopoly on professional knowledge, enabling control over work and limitation of interference from the state (and managers) (Abbott, 1988). Contemporary sociology of professions theory is dominated by questions around hybridity, where professionals also function as managers (Noordegraaf, 2015; Breit et al., 2017). As we shall see, medical professionals hold resource management responsibilities in P-CA contexts and can be seen as inhabiting these hybrid roles.

Informed by the sociology of professions, we focus on ways in which the P-CA prognostication process presents professional risks - to central tenets of professional status. We interpret the use of prognosticators to manage professional risk, as a form of professional defense mechanism - part of the medical profession's engagement in their ongoing professional project to gain and maintain professional status and power.

Sociology of risk and uncertainty

We draw on the broad and diverse sociology of risk and uncertainty as our other key theoretical approach. Consistent with our approach to "profession", we view risk as socially constructed. As it demonstrates "best fit" with the issues considered in this paper, focused as they are on medical professionals' practice of prognosticator use to manage risk, we employ the "risk work" approach of Gale et al. (2016). This approach "aims to make visible *working practices to assess or manage risk*, in order to subject these practices to sociological critique" (Gale et al., 2016, p. 1046). The risk work performed by prognosticators reflects all of Gale et al.'s (2016) aspects of risk work; translation of risk, minimizing risk, and caring in contexts of risk. In accordance with this approach, we consider prognosticator use itself to constitute a form of professional "risk work," a working practice employed by physicians to assess and manage (professional) risk presented by the P-CA prognostication process. We subject this practice to sociological critique by explicating the various discrete risk work roles and functions that prognosticators play in managing professional risk - how prognosticators perform risk work on behalf of medical professionals and to what effect.

The risk of "getting it wrong" – Managing risks to professional credibility, trust, power, and the role of scientific rationality

This section describes the role of prognosticators and their association with scientific rationality, in managing professional risks presented by the prognostication process, to professional credibility, trust and power. The specific mechanisms through which prognosticators perform the professional risk work characterizing this risk management are identified.

Prognostication is a central component of the medical profession's jurisdiction (Kellett, 2008). Consonant with knowledge and expertise forming part of the profession's social licensure and contract (Bhugra, 2014), there is a social expectation that prognostication will be accurate and consistent with outcome (Christakis, 1999, 2003). Competence in "getting it (prognosis) right" (an accurate prognosis) therefore plays an important role in maintaining professional credibility and trust afforded to the medical profession by society, and ultimately, in the maintenance of professional power and status (Cruess, 2006; Bhugra, 2014). However, the inexact and uncertain nature of prognostication P-CA in particular, can be seen to present the medical profession with an enhanced risk of "getting it (prognosis} wrong" (an inaccurate prognosis), resulting in the potential for inappropriate withdrawal of treatment, or conversely, prediction of a positive outcome where the actual outcome transpires as poor. Given the centrality of "getting it right" to notions of credibility, trust, and ultimately professional power, the risk of "getting it wrong" can in turn be interpreted as presenting a professional risk to these aspects of professional status - individually, amongst individual clinicians, or collectively, to the medical profession as a whole. These risks associated with "getting it wrong" are compounded by the high bioethical stakes associated with patient outcome in the P-CA context. Prognosticators can assist in managing these professional risks to credibility, trust and power, stemming from the risk of "getting it wrong," in a two-fold way - by performing risk work involving the *mitigation* of risk, and the facilitation of a *devolving-dispersing-diluting-delegating* process. How prognosticators act to allow the management of professional risk through the performance of risk work will now be elaborated upon in turn.

Managing professional risk through mitigation

"Prognosticators" in their various guises constitute an array of clinical data. When located and interpreted within the context of the wider P-CA scientific evidence base, however, the meaning and relevance of clinical data for P-CA outcomes become realized. "Clinical data" undergo a process of epistemological translation, becoming "prognostic markers" and allowing for the status of scientific "prognosticators" to be assigned. Considered in isolation from the wider evidence base, clinical data alone hold little relevance and utility for the prognostication process. Through the processes of interpretation and classification, however, prognosticators become imbued with powerful significance as "markers of meaning" and "scientific evidence" in the context of prognostication P-CA. In turn, once established, prognosticators act as technological (and epistemological) "keys," unlocking and granting medical professionals access to the scientific knowledge necessary to inform prognostic decision-making. In interpreting individual patient data within the context of existing scientific knowledge, a (probable) prognosis is indicated in accordance with the scientific knowledge relevant to outcomes P-CA. In this way, the certainty surrounding prognosis is increased ("getting it right"), and the risk of "getting it wrong" is reduced. Reducing the risk of "getting it wrong" in turn reduces associated professional risks to credibility, trust and power, inherent in the prognostication process. As part of their risk work, through reducing the risk of "getting it wrong," the use of prognosticators in conjunction with scientific knowledge (to which they facilitate access), therefore acts to manage the professional risk presented by the prognostication process, through the risk work mechanism of *mitigation.* Professional risks to credibility, trust and power are mitigated by reducing the risk of “getting it wrong.” Whilst reducing risk, owing to the technical indeterminacy of prognosticators, the risk of “getting it wrong” is not eliminated however and a prognosis, though legitimate, may be inaccurate.

Managing professional risk through devolving-dispersing-diluting-delegating

The above notwithstanding, in situations where “getting it wrong” materializes [despite the use of (inherently uncertain) science], the use of prognosticators in conjunction with science can function to manage professional risk through risk work in this situation also. This is done through (partially) *devolving* decision-making, *dispersing* attribution for “error,” and *diluting* and *delegating* the locus of responsibility, and professional risk, as a result.

The use of prognosticators, coupled with their scientific foundation, provides professionals with a clinical rationale that guides and underpins their prognostic decision-making, and which can be appealed to as justification, in instances where a professional might “get it wrong.” When adopting “evidence-based” decision-making, the individual decision-making becomes situated within, informed by, and is therefore partially attributable to, a wider knowledge community. “Scientific” decision-making, facilitated by prognosticator use, could therefore be interpreted as a form of partially devolved decision-making. In instances where an individual “gets it wrong,” attribution of “error” might be seen to be less concentrated on the “incorrect” prognostic decision-making of one clinician and instead be more dispersed and distributed amongst the more nebulous knowledge network. “Getting it wrong” is then at least partially attributable to the collective conglomerate of the scientific community and knowledge, to which the individuals’ decision-making was (at least partly) influenced and devolved. In turn, the locus of responsibility for “getting it wrong” might also be seen to be more diffuse and dilute, in terms of its concentration and attribution to individual professionals and professions, and partly relocated and delegated to prognosticators and science. In the process of delegating responsibility for "getting it wrong", so too are associated professional risks to credibility, trust, and power. As such, in instances where individuals “get it wrong,” the use of prognosticators in conjunction with “science” functions to manage professional risk via risk work. This risk work involves the facilitation of *devolved* prognostic decision-making as a means of *dispersing* attribution for “error,” *diluting* the professional locus of responsibility, and *delegating* it to prognosticators and science, and with it, professional risk (to credibility, trust and power) associated with “getting it wrong”.

The role of scientific rationality and dirty work

The mechanism by which the risk work of prognosticators can function to manage professional risk by devolving-dispersing-diluting-delegating, is illuminated by considering the nature and status of prognosticators and the evidence base, as *scientific* forms of knowledge and proxies for *scientific* rationality. As a socially and professionally trusted, hegemonic form of knowledge (Aronowitz, 1988), the “scientific” affinity of prognosticators affords them the power to function in these ways to manage professional risk. Since the clinical rationale guiding and underpinning a prognosis P-CA is derived from *scientific* evidence (a professionally endorsed, socially legitimate resource), when “getting it wrong,” this can be (at least partly) attributed to a “fault” inherent within the scientific prognostication process itself (the inexact science of prognosticators). As such, responsibility can be (partially) located within the scientific, rather than the professional realm, allowing for professional credibility, trust and power to be maintained. The scientific status of prognosticators, therefore, renders them both the means (a facilitator) and the object of professional risk delegation.

The risk work of prognosticators, in relation to the delegation of responsibility and professional risk, might be conceived of as a form of “boundary work” (Gieryn, 1983; Fournier, 2000), serving to delegate “dirty work” (Hughes, 1958) externally from the professional, to the scientific realm. Traditionally, “boundary work” is used within the sociology of professions to refer to the negotiation of inter- or intra-professional boundaries by the professions. In facilitating the delegation of responsibility and risk from the professional to the scientific realm, the risk work performed by prognosticators in the P-CA context might be considered as an enactment of boundary work by prognosticators *on behalf of* medical professionals - or boundary work by proxy. In addition, the uncertain, risky, and clinically, bioethically and professionally challenging nature of prognostication P-CA might allow the prognostication process to be conceived of as “dirty work.” In delegating responsibility and risk associated with prognostication to the scientific realm, we argue that boundary work performed as part of the prognosticators’ risk work role, functions to delegate professional dirty work. This delegation of dirty work constitutes a further affordance of the risk work role played by prognosticators in managing professional risk presented by the P-CA prognostication process. Medical professionals have been documented to use boundary work discursively as a means of removing their practice from legally and ethically contentious issues (dirty work) in other contexts (Miner, 2019). Here, with prognosticators constituting both the means and object of risk delegation, we show that boundary work can be both performed by prognosticators *on behalf of* medical professionals (boundary work *by proxy*), which *also* serves to delegate dirty work to prognosticators and science.

The risk of death, "getting it right" and the (unwanted) power of prophecy – Managing risks to professional power, control and identity

This section describes the role of prognosticators in managing risks to professional power, control and identity, presented by the prognostication process. The place of calculability, predictability and prophecy within this risk work is considered.

Patients' P-CA can be conceived of as occupying an uncertain, liminal space "'betwixt and between' living and dying" (Nicholson et al., 2012, p. 1426). In this context, prognostication presents a "particularly thorny form of uncertainty" since paradoxically it constitutes a medical situation with high levels of unpredictability, which both demands and subverts professional efforts to prognose (Christakis, 2003, p. 140). Further, where it includes the possibility of death, prognostication entails physicians considering and confronting uncertainty and risk in relation to patient (and personal) mortality (Christakis, 1999). With its high degree of uncertainty and high risk of death, together with heightened bioethical consequences, this is especially true of and intensified within the context of prognostication P-CA. To physicians, death can be considered a professionally "noxious and worrisome" stimulus, which impinges upon their social role (Christakis, 2003, p. 135). Since "cure" occupies a central place in the medical professional role and identity, death (as indicative of the absence or futility of cure) can be viewed as connoting professional failure, presenting challenges to this professional role and identity (Christakis, 2003; Apesoa-Varano et al., 2011). In addition, death serves as a stark reminder of the limits of medical knowledge, control and power, and as such, presents risks to professional power and control. Through association with death, the prognostication process can therefore be seen to confront professional power, control, and identity which are compounded and heightened by the high risk and highly uncertain nature of P-CA in relation to patient mortality. Although inherent within medical professionals' social role, through association with death, prognostication also presents challenges to it, which Christakis (2003, p. 140) suggests creates "sociological anxiety" amongst physicians. We argue that the use of prognosticators by medical professionals in the context of prognostication P-CA can function to manage professional risks presented indirectly, through introducing (a sense of) calculability and predictability surrounding death, and more directly (and less desirably) through the action of a self-fulfilling prophecy.

Indirect management of professional risks – The role of calculability and predictability

Section "The risk of "getting it wrong" – Managing risks to professional credibility, trust, power and the role of scientific rationality" identified that the use of prognosticators and wider scientific knowledge in the prognostication process is intended to increase certainty surrounding prognosis ("getting it right"), thereby reducing the risk of medical professionals "getting it wrong." Further, we argue that by increasing certainty surrounding prognosis, the use of prognosticators serves to introduce calculability and predictability surrounding death (both actual and/or a sense of) thereby rendering death more calculable. In cases where a professional ultimately "gets it right," prognosticators might be considered to have introduced both actual, and a sense of, calculability and predictability. Where patient outcome is consistent with prognosis, the calculability and predictability provided by prognosticators transpire and are confirmed "in actuality." In cases where a professional "gets it wrong," however, *a sense of* calculability and predictability surrounding outcomes is nonetheless introduced, despite the absence of calculability and predictability being realized "actually." Prognosticator use *in itself* confers a subjective sense of calculability and predictability regarding death, regardless of the objective accuracy of predictive capabilities of prognosticators (and the "actual" degree of calculability and predictability they provide) in relation to patient outcome. This sense of calculability and predictability is as significant as objective accuracy, in terms of the function of prognosticators in managing professional risk concerning death.

The act of prognostication alone does not allow medical professionals to (re)gain "power" over death directly (patient outcome remains the same). The (sense of) calculability and predictability introduced by prognosticators does however afford the (re)assertion and (re)establishment of medical power and control over death - either "felt" or more materially, by way of allowing for the initiation of palliative care and psychosocial preparatory rituals, for example. In these instances, although medical professionals do not directly influence *whether* patients die, they can influence *how* they die. Drawing on risk theory, which suggests that when risk becomes calculable, it becomes manageable (Streicher et al., 2018), in rendering death more calculable, it becomes more predictable, manageable and tolerable. Similarly, the calculability introduced by prognosticators might be interpreted as a means of "scientizing" death, medicalizing the uncertain and liminal space between living and dying, and increasing professionals' (sense of) controllability. In affording medical professionals (a sense of) calculability and predictability, and in turn (a perception of) control over death, through their risk work, the use of prognosticators functions to allay professional risks to power, control and identity stemming from the confrontation with death, presented by the P-CA prognostication process.

Direct management of professional risks – (unwanted) professional power and the self-fulfilling prophecy

We have argued that the act of prognostication alone does not change patient outcome and therefore medical professionals do not (re)gain power over death directly through the act of prognostication. We acknowledge however that in the case of prognostication P-CA particularly, a prognosis of death (futility) can lead to subsequent withdrawal of artificial life-sustaining treatment. This likely leads to the outcome of death predicted, therefore becoming a self-fulfilling prophecy (Christakis, 1999; Nolan et al., 2015); the prophecy of death becomes fulfilled by the course of action warranted by the prognosis of futility. In these instances, prognosticators have more direct implications for professional power concerning death – their use allows medical professionals to (re)gain power and control over death more directly and concretely. Although within the sociology of professions, power is commonly analyzed in a professionally desirable way, this is an instance where power and its exercise are more professionally problematic and somewhat less palatable. The risk work performed by prognosticators in relation to managing professional risks to power, control and identity, associated with confronting death as part of the prognostication process, can be seen, therefore, to serve in two ways. It can serve indirectly, through instilling (a sense of) predictability, calculability, and thus power and control over death indirectly, and more directly (and uncomfortably), by affording professionals more direct power and control over death, through the mechanism of a self-fulfilling prophecy.

The risk of managerialism and new professionalism – Managing risks to professional norms, integrity, and identity

This section describes the protective and mediating role of prognosticators in managing risks to professional fundamental norms, integrity and identity, presented by the P-CA prognostication process, when considered in the context of managerialism.

Medical professionals are becoming increasingly managerialized in the context of contemporary healthcare (Numerato et al., 2012). Physicians act as front-line "gatekeepers" to finite healthcare resources (Kluge, 2007, p. 57) and have been tasked with and responsibilized for resource management, symptomatic of a "'new' professionalism" accompanying the managerialist milieu (Evetts, 2011, p. 406). Managerially-driven resource allocation responsibilities, however, present professional and ethical challenges (Christakis, 1999; Kluge, 2007; Mechanic, 2008). This is especially true in instances where managerial responsibilities might come into conflict with a patient's interest. In medical ethics literature, this is referred to as "bedside rationing" (e.g., see Ubel and Goold, 1997).

Medical intervention is a costly and finite resource. A prognosis of futility ["a fundamental assertion about the intractability of the patient's disease or about the impotence of the doctor's treatment to alter the course" (Christakis, 1999, p. 205)] can legitimately justify a case for withdrawing life-sustaining (costly) treatment P-CA (Christakis, 1999; Luchetti, 2013) and therefore holds resource management implications. Medical professionals' withdrawal of treatment in cases of futility, is determined and underpinned by the professional principle and ethical priority of patient "best interest" (British Medical Association, 2007). However, the resource management connotations of prognostication can present professional dis-ease, challenging what Mechanic (2008) describes as the essential and fundamental norms of medical professionalism. In turn, physicians' resource management role might be interpreted to threaten aspects of medical professional integrity and identity, predicated on the ethical principle of "best interest" in the P-CA prognostication context. Within this milieu, we argue that prognosticators perform risk work by way of serving a dual role in relation to managing these risks to professional norms, integrity and identity, stemming from the potential managerialist connotations of prognostication. Where they indicate a prognosis of futility, and (costly) life-sustaining treatment is consequently withdrawn, prognosticators afford professionals the ability to meet managerialist demands and discharge managerial responsibilities, in a way consistent with their professional best interest principles. When treatment is withdrawn in the name of best interest owing to futility, the need for further (costly) treatment is negated, and without the requirement for medical professionals to deliberate on a more overtly financially informed decision, thus leaving their professional and ethical integrity and identity intact. Prognosticators can therefore be observed to mediate tension between hybrid managerial-professional imperatives, and in turn, risks to professional norms, integrity and identity. Further, since prognosticators provide an "objective" and "scientific" indication of likely futility, the decision to withdraw life-sustaining treatment on this basis is deemed professionally defensible, justifiable and ethically acceptable. Here, decision-making might be considered biologically and scientifically "preordained" or "fixed" (Christakis, 1999, p. 206) since, as identified in "Managing professional risk through devolving-dispersing-diluting-delegating", it is devolved (and responsibility for it delegated) to prognosticators and science. Scientific and "objective" prognosticators in effect "speak for themselves," objectifying decision-making and negating the need for a more subjective prognosis and decision-making surrounding the continuation of treatment. In turn, resource management might therefore be interpreted as a further example of professional delegation to prognosticators and science. It is through these mediating mechanisms that the risk work performed by prognosticators serves to manage the risk presented to professional norms, integrity and identity, by the P-CA prognostication process and its managerialist associations.

Psychosocial risk and individual professionals – Affective and protective functions of prognosticators

In this final section, we argue for the affective and protective role that prognosticators play in managing professional psychosocial risk presented by the prognostication process, as a component of their risk work.

Demonstrating the relationship between the individual *professional* and collective *profession* (Kluge, 2007), prognostication is a practice undertaken by the medical profession on behalf of society, entailing collective professional risk. However, it is individual professionals who engage in and enact the process of prognostication and who are subject to these professional risks at an individual professional level. The "obligations of the profession" collectively translate to professional obligations individually (Kluge, 2007, p. 57), transferring professional risk in the process. Prognostication is difficult, uncertain, emotionally distressing, and highly clinically, bioethically and professionally consequential (Christakis, 1999). As such, medical professionals find prognostication concerning death, in particular, to be psychologically and intra-personally stressful and troubling (Christakis, 1999). Owing to the multitude of professional risks that it presents and the emotive context in which it is situated, we argue that prognostication P-CA carries with it a potentially significant psychosocial burden for individual medical professionals engaged in the process and practice - it presents *psychosocial* professional risk. By managing some of the initial professional risks that contribute to the psychosocial risk associated with prognostication however, through the ways of risk work described thus far, we argue that prognosticators simultaneously serve affective and protective professional functions; their use allays the professional impact of prognostication, and psychosocial risk as a consequence. In instances where an individual clinician "gets it wrong" for example, prognosticator use functions not only to manage professional risks to credibility, trust and power (by devolving-dispersing-diluting-delegating), but it also allays the psychosocial impact of "getting it wrong" on individual professionals [engendering, for example, potential guilt, anxiety, sense of moral burden, and responsibility (Christakis, 1999)] in the process. Thus, risk work performed by prognosticators includes an affective and professionally protective role, reducing psychosocial risk presented by the prognostication process P-CA.

Discussion – A theoretical model, caveats and contributions

The prognostication process P-CA is challenging and suffused with clinical, bioethical and professional uncertainty and risk. Underpinned by sociological analyses of risk and uncertainty, and professions, we have argued that the medical profession's advocation for and use of prognosticators to guide the prognostication process, can be interpreted as a professional attempt to manage *professional* risk presented by the prognostication process P-CA. We have introduced the conceptualization of prognosticators as serving professional functions through the performance of "risk work," mediating tension between the professional duty to prognosticate and professional risks presented. In explicating the (hitherto less enunciated) professional risk management functions of prognosticators, we have identified areas of professional risk presented by the P-CA prognostication process, the nature of risk work performed by prognosticators, how this functions to address professional risk and to what effect. Namely, we have identified the role that prognosticators and scientific rationality play in managing professional risks to professional credibility, trust and power, stemming from the risk of "getting it wrong." Through performing risk work involving the *mitigation* of risk and the facilitation of a *devolving* (decision-making)-*dispersing* (attribution for error)-*diluting-delegating* (the locus of responsibility) process, prognosticator use serves to allay these professional risks (*dirty work*). We have illustrated how risks to professional power, control and identity presented by the requirement to confront death during prognostication, are managed directly and indirectly by the risk work of prognosticators. We detailed how this management is achieved through prognosticator use introducing (a sense of) *calculability* and *predictability*, and power and control over death *indirectly*, and also by affording professionals power and control over death more *directly* (and less desirably), through the action of a *self-fulfilling prophecy*. Further, we explained the *mediating* role that prognosticator risk work

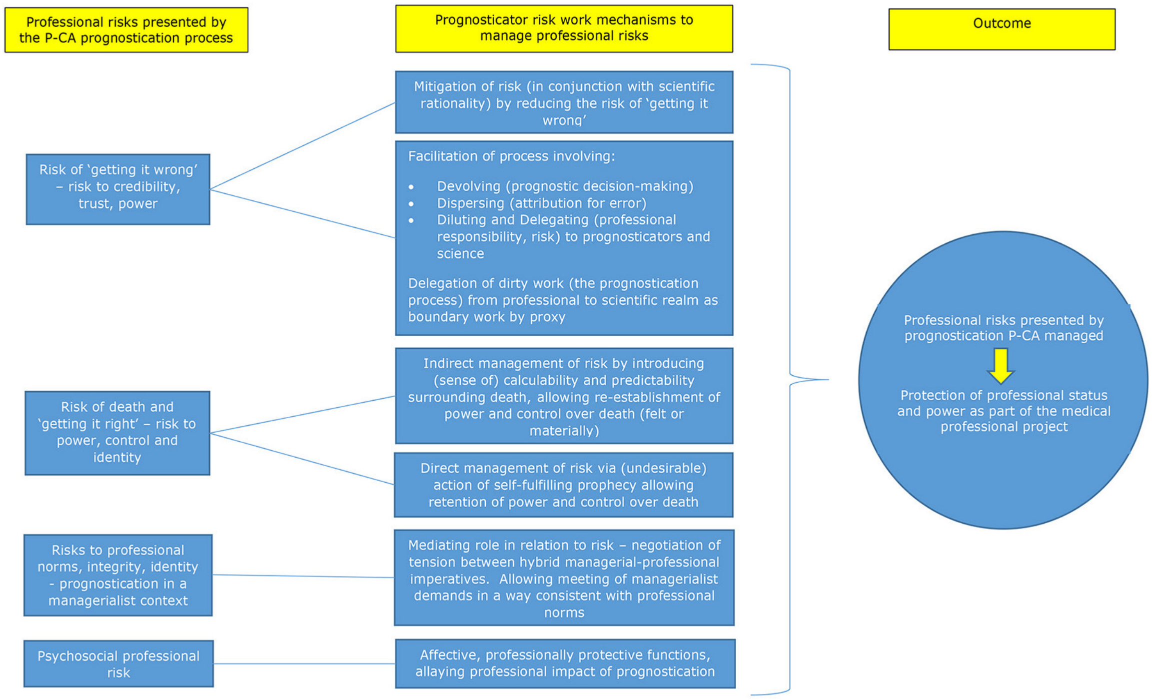

FIGURE 1
Theoretical model of the professional risk management functions of prognosticators in the context of prognostication post-cardiac arrest.

performs in managing risks to professional fundamental norms, integrity and identity, when considered in the context of managerialism. This mediating role affords professionals the ability to negotiate hybridity and meet managerialist demands in a way consistent with professional norms. Finally, we argued for an *affective* and *protective component* to prognosticator risk work, in relation to the management of individual psychosocial professional risk presented by the challenging, uncertain and highly consequential nature of the prognostication process. Here, by managing professional risks which contribute to the genesis of psychosocial risk and reducing the professional impact of the prognostication process, through their risk work, prognosticators simultaneously serve *affective* and *professionally protective* professional functions, managing psychosocial risk as a consequence. These arguments are summarized in Figure 1, which presents a theoretical model of the professional risk management functions of prognosticators in the context of prognostication P-CA.

Caveats and opportunities

We caveat our argument and analysis, firstly by acknowledging their theoretical nature *a priori*. Empirical work exploring prognostication P-CA as a situated practice might utilize these theoretical ideas and conceptual arguments as a framework to explore the nature of professional risk and the risk work role of prognosticators, in the context of their manifestation and enactment in the "everyday" reality of clinical practice. In this way, the arguments presented may be further developed, refined and augmented. Secondly, our aim in this paper was to provide a theoretical analysis and interpretation of the professional functions of prognosticators in relation to the management of risk and uncertainty presented by the P-CA prognostication process. We acknowledge that prognostication P-CA is inherently complex and that the view we have presented here, necessarily for analytical purposes, constitutes a simplification of the process, its variables and implications. Although we have attempted to incorporate consideration of different eventualities, possibilities and outcomes in the development of arguments, we do not intend to deny this inherent complexity and suggest that studies of applicability and difference across situational contexts, constitute a fruitful area for further theoretical and empirical work.

Contributions to knowledge

The analysis presented has drawn upon extant sociological theory, applying and extending it to the context of the medical profession's practice of prognostication P-CA. In doing so, this paper contributes to sociological theorizing surrounding risk and uncertainty, and professions. Through our critique of the process and practice of prognostication more broadly, we contribute to and inform "an emerging sociology of prognosis" (Timmermans and Strivers, 2018, p. 13).

With regard to the sociology of professions, firstly, we contribute to theorizing the hitherto less enunciated *professional* functions of prognosticators in relation to the management of risk and uncertainty, and locate this within a specific (P-CA) context. As a component of risk work performed by prognosticators P-CA, we also introduce the notion of "boundary work by proxy" as the performance of boundary work by prognosticators, on behalf of medical professionals. Further, we identify its nature and purpose in delegating the dirty work of professional risk and responsibility associated with the prognostication process, to outside of the professional and toward the (inexact) scientific realm, to maintain professional credibility, trust and power, consistent with the medical profession's professional project. In doing so, we demonstrate how "dirty work" functions to defend and maintain facets of professional status, as part of the medical profession's professional project, which has tended to be overlooked in prior conceptualizations of dirty work (Miner, 2019). Furthermore, we identify the potential for medical professional prognoses of death to operate as a self-fulfilling prophecy, highlighting an instance in which power and its exercise can be analyzed as professionally problematic and undesirable in the context of the professions. Finally, we contribute to understanding surrounding the nature, practice and social organization of professional risk work, potentially as an aspect and/or consequence of "new professionalism" in the context of managerially-driven healthcare.

Gale et al. (2016, p. 1046, 1065) identify a series of neglected areas of knowledge surrounding risk work, to which we contribute theoretically. We have considered, for example, the "impact of risk on the nature…of healthcare work" using risk work to "develop our understanding of these practices." We have considered what risk work is *doing* in the context of a broader sociological framework, and have incorporated consideration of the issues of professional credibility and identity in the context of risk work. Further, in exploring *professional* risk work, we have identified a specific *type* of risk work (along with discrete functions), contributing to understanding surrounding the impact of risk work on the professions, how professional identity is mediated in the context of risk, and in particular, micro (prognostication P-CA) and macro (managerialist, healthcare) risk contexts. Indeed, to our knowledge, this is the first analysis of risk work applied to the context of distinctly *professional* risks and its management broadly, and particularly, within medical professional, prognostication, and P-CA contexts.

Conclusion

Collectively, the arguments presented in this paper demonstrate the risk work role that prognosticators perform in managing professional risk - risk to central tenants of medical professional status, presented by the prognostication process P-CA. As such, we conceive of the use of prognosticators as a professional response - a technical solution to the professional problem of risk inherent within the P-CA prognostication process, employed as part of the medical professions' engagement in their ongoing professional project to gain and maintain professional status and power. Whilst prognosticators have as yet failed to deliver certainty in relation to prognostication P-CA as their primary purpose, when considered within a wider socio-cultural context, their use can be observed to serve other important *professional* functions relating to the management of risk and uncertainty presented by the prognostication process, particularly in the P-CA context.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author/s.

Author contributions

SF-R wrote the first and subsequent drafts of the manuscript. Both authors contributed to the conception, development of the manuscript content, revision, read, and approved the submitted version.

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Conflict of interest

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References

Abbott, A. (1988). *The System of Professions*. Chicago, IL: Chicago University Press. doi: 10.7208/chicago/9780226189666.001.0001

Andersson, P., Johnsson, J., Bj?rnsson, O., Cronberg, T., Hassager, C., Zetterberg, H., et al. (2021). Predicting neurological outcome after out-of-hospital cardiac arrest with cumulative information; development and internal validation of an artificial neural network algorithm. *Crit. Care.* 25:83. doi: 10.1186/s13054-021-03505-9

Apesoa-Varano, E. C., and Barker, J. C., and Hinton, L. (2011). Curing and caring: the work of primary care physicians with dementia patients. *Qual. Health Res.* 21, 1469–1483. doi: 10.1177/1049732311412788

Aronowitz, S. (1988). *Science as Power. Discourse and Ideology in Modern Society.* Minneapolis, MN: University of Minnesota Press doi: 10.1007/978-1-349-19636-4

Bhugra, D. (2014). Medicine's contract with society. *J. R. Soc. Med.* 107, 144–147. doi: 10.1177/0141076814525068

Breit, E., Fossestøl, K., and Andreassen, T. (2017). From pure to hybrid professionalism in post-NPM activation reform: the institutional work of frontline managers. *J. Prof. Organ.* 5, 28–44. doi: 10.1093/jpo/jox013

British Medical Association (2007). *Withholding and Withdrawing Life-Prolonging Medical Treatment. Guidance for Decision Making.* 3rd ed. Oxford: Blackwell Publishing.

Christakis, N. A. (1999). Prognostication and bioethics. *Daedalus* 128, 197–214.

Christakis, N. A. (2003). "On the sociological anxiety of physicians," in: *Society & Medicine. Essays in Honor of Renée C.Fox*, eds C. M. Messikomer, J. P. Swazey, and A. Glicksman (London: Transaction publishers), 135–144. doi: 10.4324/9781315129891-9

Cruess, S. R. (2006). Professionalism and medicine's social contract with society. *Clin. Orthop. Relat. Res.* 449, 170–176. doi: 10.1097/01.blo.0000229275.66570.97

Deakin, C., Nolan, J., and Perkins, G., and Lockey, A. (2010). "Adult advanced life support," in: *Resuscitation Council UK Resuscitation Guidelines*, ed J. Nolan (London: Resuscitation Council), 58–80.

Evetts, J. (2006). Short note: the sociology of professional groups. *Curr. Sociol.* 54, 133–143. doi: 10.1177/0011392106057161

Evetts, J. (2011). A new professionalism? Challenges and opportunities. *Curr. Sociol.* 59, 406–422. doi: 10.1177/0011392111402585

Fournier, V. (2000). "Boundary work and the (un)making of the professions," in: *Professionalism, Boundaries and the Workplace*, ed N. Malin (London: Routledge), 67–86.

Freidson, E. (1970). *Profession of Medicine: A Study of the Sociology of Applied Knowledge*. New York, NY: Harper and Row

Gale, N. K., Thomas, G. M., Thwaites, R., and Greenfield, S., and Brown, P. (2016). Towards a sociology of risk work: a narrative review and synthesis. *Sociol. Compass* 10, 1046–1071. doi: 10.1111/soc4.12416

Gieryn, T. F. (1983). Boundary-work and the demarcation of science from non-science: strains and interests in professional ideologies of scientists. *Am. Sociol. Rev.* 48, 781–795. doi: 10.2307/2095325

Horn, J., and Cronberg, T., and Taccone, F. S. (2014). Prognostication after cardiac arrest. *Curr. Opin. Crit. Care* 20, 280–286. doi: 10.1097/MCC.0000000000000085

Hughes, E. C. (1958). *Men and Their Work*. London: The Free Press of Glencoe, Collier-Macmillan Limited.

Kellett, J. (2008). Prognostication – the lost skill of medicine. *Eur. J. Intern. Med.* 19, 155–164. doi: 10.1016/j.ejim.2007.09.002

Kluge, E.-H. W. (2007). Resource allocation in healthcare: Implications of models of medicine as a profession. *Medscape Gen. Med.* 9, 57.

Larson, M. S. (1977). *The Rise of Professionalism. A Sociological Analysis*. Los Angeles, CA: University of California Press. doi: 10.1525/9780520323070

Luchetti, M. (2013). Intensive care resource allocation: when difficult choices have to be made. *Br. J. Med. Pract.* 6, a633–4.

Macdonald, K. (1995). *The Sociology of the Professions*. London: Sage.

Mechanic, D. (2008). Rethinking medical professionalism: the role of information technology and practice innovations. *Milbank Q.* 86, 327–358. doi: 10.1111/j.1468-0009.2008.00523.x

Miner, S. A. (2019). Demarcating the dirty work: Canadian fertility professionals' use of boundary-work in contentious egg donation. *Soc. Sci. Med.* 221, 19–26. doi: 10.1016/j.socscimed.2018.11.039

Nicholson, C., Meyer, J., Flatley, M., and Holman, C., and Lowton, K. (2012). Living on the margin: understanding the experience of living and dying with frailty in old age. *Soc. Sci. Med.* 75, 1426–1432. doi: 10.1016/j.socscimed.2012.06.011

Nolan, J., Deakin, C., Lockey, A., and Perkins, G., and Soar, J. (2015). "Post-resuscitation care – prognostication," in: *Resuscitation Guidelines. Resuscitation Council (UK).* Available online at: https://www.resus.org.uk/resuscitation-guidelines/post-resuscitation-care/ (accessed June 20, 2018).

Noordegraaf, M. (2015). Hybrid professionalism and beyond: (New) forms of public professionalism in changing organizational and societal contexts. *J. Prof. Organ.* 2, 187–206. doi: 10.1093/jpo/jov002

Numerato, D., and Salvatore, D., and Fattore, G. (2012). The impact of management on medical professionalism: a review. *Sociol. Health Illn.* 34, 626–644. doi: 10.1111/j.1467-9566.2011.01393.x

Oh, S. H., Kim, H. S., Park, K. N., Ji, S., Park, J. Y., Choi, S. P., et al. (2021). The levels of circulating microRNAs at 6-hour cardiac arrest can predict 6-month poor neurological outcome. *Diagnostics* 11, 1905. doi: 10.3390/diagnostics11101905

Saks, M. (2016). A review of theories of professions, organizations and society: the case for neo-Weberianism, neo-institutionalism and eclecticism. *J. Prof. Organ.* 3, 170–187. doi: 10.1093/jpo/jow005

Sandrioni, C., D'Arrigo, S., Cacciola, S., Hoedemaekers, C. W. E., Kamps, M. J. A., Oddo, M., et al. (2020). Prediction of poor neurological outcome in comatose survivors of cardiac arrest: a systematic review. *Intensive Care Med.* 46, 1803–1851. doi: 10.1007/s00134-020-06198-w

Sandroni, C., and D'Arrigo, S., and Nolan, J. P. (2018). Prognostication after cardiac arrest. *Crit. Care* 22, 150. doi: 10.1186/s13054-018-2060-7

Sandroni, C., and Geocadin, R. G. (2015). *Neurological prognostication after cardiac arrest.* HHS public access, 1–11. Available online at: https://europepmc.org/backend/ptpmcrender.fcgi?accid=PMC4955580&blobtype=pdf (accessed June 20, 2018).

Streicher, B., and Eller, E., and Zimmerman, S. (2018). "Risk culture: an alternative approach to handling risks," in: *Psychological Perspectives on Risk and Risk Analysis: Theory, Models, and Applications*, eds. M. Raue, E. Lermer, and B. Streicher (Switzerland: Springer International Publishing AG), 217–247. doi: 10.1007/978-3-319-92478-6_10

Timmermans, S., and Strivers, Y. (2018). Clinical forecasting: towards a sociology of prognosis. *Soc. Sci. Med.* 218, 13–20. doi: 10.1016/j.socscimed.2018.09.031

Ubel, P. A., and Goold, S. (1997). Recognizing bedside rationing: clear cases and tough calls. *Ann. Intern. Med.* 126, 74–80. doi: 10.7326/0003-4819-126-1-199701010-00010

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EDITED BY
Andrzej Klimczuk,
Warsaw School of Economics, Poland

REVIEWED BY
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Patrick Maison,
Agence Nationale de Sécurité du
Médicament et Des Produits de Santé
(ANSM), France

*CORRESPONDENCE
Juan R. Coca
juanr.coca@uva.es

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Socio-historical analysis of the social importance of pharmacovigilance

Juan R. Coca[1]*, Raquel Coca-Asensio[2] and
Gema Esteban Bueno[3]

[1]Unit for Social Research in Health and Rare Diseases, Faculty of Education of Soria, University of Valladolid, Soria, Spain, [2]Department of Neurosciences (Pharmacology), University of Cadiz, Cadiz, Spain, [3]Almeria Periphery Clinical Management Unit, Almería Health District, Andalusian Health Service, Almeria, Spain

Pharmacovigilance is a scientific discipline that has changed a lot in recent years and is of great social importance. The case of the so-called sulfonamide elixir showed society the importance of this discipline. Since then, pharmacovigilance has evolved into a scientific discipline with a strong social character. In this paper, a historical review is made of several paradigmatic examples of this discipline to reflect on what pharmacovigilance could be like finally. We conclude that this discipline could be more closely related to other areas of the social sciences, which would help to promote a more democratic social environment taking into account the needs of individuals and social groups.

KEYWORDS

pharmacovigilances, sulfonamides, thalidomide, rofecoxib, biosocial

Introduction

The development of pharmaceutical legislation began in the early 19th century in the United States, and by 1820 the *US Pharmacopeia* had published monographs that regulated compounding in the US (Haller, 1982). One of the earliest studies on the pharmacovigilance of the effects of chloroform was conducted by Gustave Darin (Caron et al., 2016). On the other hand, the first edition of the *British Pharmacopeia* was also published in the 19th century, specifically in 1864, in Europe. This pharmacopeia is the official collection of quality standards with which medicines in the UK must comply. It is produced by the *British Pharmacopeia Commission Secretariat* and depends on the British Medicines Agency (*Medicines and Healthcare Products Regulatory Agency*). The *British Pharmacopeia* incorporates monographs from the *European Pharmacopeia*, it is updated annually (the latest edition is dated 1st January 2015) and contains 3.000 monographs of substances and articles used in the practice of medicine. At the beginning of the 20th century, in 1906, the *US Pharmacopeia* and the *National Formulary* acquired the status of legal pharmaceutical legislation in the United States (Kremers and Urdang, 1976). In the same year, the *US Food and Drugs Administration* (FDA), which was created in 1848, was established as a federal agency of the US government with the approval of the *Pure Food and Drugs Act* (Barkan, 1985), which was the first ratified law on drug regulation and consumer protection. This federal law prohibited the manufacture, sale or transportation of intoxicating medical products, among others, and it also required that certain substances such as alcohol, cocaine, heroin, morphine and cannabis would be appropriately labeled in terms of quality and quantity. The enforcement of this provision was only ensured in 1914, when the Harrison Narcotic Drugs Act was passed, prohibiting the sale of some narcotic drugs (Hansen and Dusenbury, 2007). Currently, the FDA is responsible for the regulation of food, drugs, medical devices (human and veterinary), cosmetics, biological products and blood derivatives. Its main function is to regulate medical products in a way that ensured the safety of US consumers and the effectiveness of marketed drugs (Weaver et al., 2008).

Pharmacovigilance (PV) is a disciplinary field that is often linked to epidemiological and pharmacological studies. This is because it is primarily seen as a discipline focused on assessments in the field of drugs approval and safety (Rocca et al., 2019). However, Rocca et al. (2019) are aware that this discipline has given rise to a number of new insights related to epistemology and epidemiology. Nevertheless, the generation of new strategies, methodologies and standards of evidence to enable the implementation of risk assessment is becoming increasingly relevant.

In this line, we wonder whether it is not somewhat limited to restrict pharmacovigilance to the aspects indicated by Rocca et al. (2019). They refer to social aspects, but they circumscribe them to the medical and scientific community. On the other hand, we consider that there are social phenomena (e.g., self-medication) that are related to the social understanding of reality and social perceptions. For this reason, we believe that PV is a broader concept and that it is closely related to social psychology, sociology and other disciplines. On this basis, we consider that historical studies allow us to analyse the processes that have been taking place in this field and, thus, to make decisions in this regard. Hence, the aim of this paper is to take a socio-historical look at some outstanding cases in order to understand the evolution of pharmacovigilance. We have focused our analysis on pharmacy professionals, being aware that the patient-partner is also an extremely important agent. However, in this research we believe that pharmacists play an important role in the social processes related to pharmacovigilance.

The first pharmaceutical control systems: The case of sulfonamides

Domagk (1895–1964) demonstrated in 1932 the efficacy of sulfonamides for the treatment of streptococci. Subsequently, in 1935, the trademark patent Protonsil was established, allowing the subsequent marketing of the first drug with this active ingredient, which led to the production and marketing of the first sulfonamide (Morales and Bosch, 2007). The media dissemination of the efficacy of the first sulfonamides generated a great social impact. In fact, there was an imaginary element that conditioned the positive opinions of the drug. In 1936, the publication of news in the New York Times showing that President Roosevelt's son, after being admitted to hospital with a severe tonsil infection caused by *Streptococcus*, was cured by *Prontylin*, a dispensing form of Protonsil (Morales and Bosch, 2007). The commercial success of this drug led the *Food and Drug Administration* (FDA) to recognize the growing regulatory problem that was being generated by the expansion of sulfonamides (Cooper, 2002).

The success of sulfonamides led to widespread sales and the generation of commercial alternatives. One of the latter was the so-called "Sulfanilamide Elixir." This preparation was developed in the use of 72% diethylene glycol (Wax, 1995). The issue was that the producing company (Massengill Corporation), as stated in a report of the Secretary of Agriculture of the United States of America published in 1937, did not test the toxicity of the ingredients and focused on evaluating the taste, color and labeling (Secretary of Agriculture, 1937). Furthermore, the company did not disseminate the presence of diethylene glycol in the product (Wax, 1995). This resulted in at least 107 deaths from ingestion of the product. Besides, the FDA was only able to blame Massengill with a trivial problem related to mislabeling of the product, since it was claimed to be an elixir when in fact it had an alcoholic content (Cooper, 2002). At the end of 1937, an editorial was published in (The British Medical Journal, 1937) reflecting on the sulfonamide problem. The text begins by stating: "A recent outbreak of poisoning in the USA has sensationally and tragically demonstrated the unexpected dangers which may arise in the introduction of the therapeutic use of chemical compounds without adequate preliminary testing of their possible toxic actions." As a result of this problem and, because of the lack of regulations to control the production process, the United States congress enacted the United States Federal Food Drug and Cosmetic Act, a set of laws that granted the FDA authority to demand the safety of food, drugs and cosmetics. However, and despite the attempts to establish an analysis process and verification of pharmaceutical products, it was not until the end of the 20th century that well-established processes for defending society against the negative effects of certain drugs were in place. In fact, for Abraham (2008), the pharmaceutical sector escaped social scrutiny for many years, since in the later part of the 19th and 20th centuries, industrialized countries and society were seen as a kind of market for the products of an expanding scientific-medical industry. The fact that Massengill was only concerned with the commercial elements of his product is a proper evidence of this issue.

The United States Federal Food, Drug and Cosmetic Act is the beginning of a different perspective, as well as the intertwining of the social and the pharmaceutical. In fact, this regulation is the seed of the current pharmaceutical legislation focused on a preventive process that conditions the marketing of industrial products, and that requires tests on the safety of pharmaceutical products and also it grants the FDA surveillance powers after the products have been authorized for marketing (Silva-Ortiz, 2011). Nevertheless, and despite the implementation of a regulation that gave the US FDA more power, this did not prevent other similar events from occurring. As a matter of fact, on 19th March 1941, George Adams, the head of the Food and Drug Administration's Boston Station, found that three girls in his area went into a coma after taking fifteen grams of sulfathiazole (Swann, 1999). The problem was caused by a deficiency in manufacturing and in quality control related to the production of the drug. On 24th December 1940, analysts at the marketing company "Winthrop," confirmed that some of their sulfathiazole, specifically the batch MP 29, was contaminated with Luminal, which was the brand of phenobarbital they produced (Swann, 1999). This issue arose because the company did not alert the FDA about the contamination, and thus, there was an inefficient recall of the affected batch. William Weiss, who was the chairman of the board of Sterling Products at that time, told the FDA that he thought Winthrop had not tried to conceal the contamination, but that it was possibly due to poor decision-making resulting from a misjudgement of the seriousness of the situation (Swann, 1999). Around 120.000 tablets of Winthrop's contaminated sulfathiazole were circulating in the United States with a subsequent risk to the population. Although the Sulfanilamide Elixir tragedy, which was the event that marked the beginning of the Food, Drug and Cosmetic Act of 1938, was still remembered by American society, Winthrop did not alert the FDA about the contamination.

It is possible to affirm that, in these early years of the development of the pharmaceutical industry, there were a series of events related to the lack of control processes and regulatory systems for production and marketing. These events were preceded by a positive image of the potential in the healing process of several pathologies (Morales and Bosch, 2007). This act could possibly have led to a certain over-optimism among the public regarding the benefits of chemical products, which on the other hand, they were not being controlled. Once the "Sulfanilamide Elixir" event occurred, social perception changed again, partly as a result of the information exposed in the various articles of the media at that time. It is conceivable to consider that, although the media played an important role, it cannot be forgotten other relevant element which explains the social behavior toward sulfanilamides: the economic crisis.

In 1929, a severe economic crisis emerged in the United States under the name of "The Great Depression," whose effects had an impact on the life of American citizens and on their social perception. The socio-economic transformations of that time led to an increase in the number of suicides, although there was also a notable increase in the economy. On this account, President Roosevelt generated several measures aimed at greater state intervention in investment and the implementation of public works in order to relieve the effects of the crisis (Comín, 2012). During those years, the life expectancy at birth of US citizens varied substantially, showing very marked peaks. In 1936, specifically, a notable drop was shown in the life expectancy of women and men regardless of their origin (Tapia and Diez, 2009). Nevertheless, health indicators of the US population show that the collective health condition of the population improved at that time. However, for most older age groups, mortality tended to peak during the years of strong economic expansion (such as 1936–1937).

This social, economic and health reality has led to the current welfare state, in which the control of commercial products, that could have a negative impact on society, is of vital importance. Hence, it was at this historical moment that the seeds of the pharmaceutical controls that are known today were sown, but it was necessary to wait a few years for the germ of such systems to take full shape.

The maturity of pharmaceutical control systems: The case of thalidomide

In 1954, the German company Chemie Grünenthal succeeded in obtaining the molecule alpha-phthalimido-glutarimide, known as thalidomide. This drug was classified as a sedative and hypnotic, and was used in 1957 for the treatment of anxiety, insomnia, nausea and vomiting in pregnant women (Martínez-Frías, 2012). In 1956, the first isolated case of phocomelia was documented after the exposure of thalidomide, and in the following 5 years, 3.000 cases of dysmelias, congenital malformations such as amelias, phocomelia or absence/hypoplasia of the thumb or fingers, among others, were gradually reported worldwide (Papaseit et al., 2013). However, in a short letter to the British Medical Journal, Florence (1960) indicates that patients treated with thalidomide for extended periods (8 months to 2 years) reported negative effects of thalidomide intake complaining of: (1) Paresthesia affecting first the feet and then the hands. (2) Coldness of the extremities and marked paleness of the toes. (3) Occasional slight ataxia. (4) Nocturnal cramps in the leg muscles. When the treatment was eliminated and the patients stopped taking the substance, the negative effects subsided. This led Leslie Florence to suspect the toxicity of thalidomide. Subsequently, in January 1962, The Lancet magazine published a series of letters of the effects of thalidomide. The first of these letters, which was signed by Lenz (1962), describing 52 children with malformations caused by the ingestion of this substance by their mothers during pregnancy. However, in this letter Lenz states that at a conference held on 18th November 1961, in which the author took part, they had already discussed the role of this substance in the development of human malformations. The same issue of The Lancet also published another letter by Pfeiffer and Kosenow (1962) in which he indicated the existence of a high statistical significance between the intake of thalidomide during the first trimester of pregnancy and the occurrence of defects. The third letter, which is signed by Hayman (1962), the managing director of the Distillers Company, begins by thanking them for the expressions of appreciation they received, and in which thalidomide is highlighted. He goes on to say that due to the small amount of data and official statistics, it is particularly difficult to establish the harmful effects of this substance. Irrespective of one's personal assessment of Hayman's writing, the objective data of the various researchers showed that thalidomide was not as harmless as it was claimed to be.

Papaseit et al. (2013) state that it was the Lenz letter that led to the withdrawal of thalidomide from the German market and its gradual elimination from the market worldwide (1961–1962). Salvador Coderch et al. (2014) state that this withdrawal was caused by an article published in the *Welt am Sonntag* newspaper on the 26th November 1961 discussing this issue. Grünental's action took place the following day, on the 27th November. It is difficult to establish a specific cause, since social reality is more complex than that and every social action is the result of a concatenation of events. Regardless of its origin, the process took time to reach Spain, which was one the last regions to officially ban its marketing as this took place in January 1963 (Papaseit et al., 2013). In Spain, a Ministerial Order was published on 18th May 1962 (Salvador Coderch et al., 2014) prohibiting the marketing of medicines containing thalidomide. Despite this, the Royal Decree 1006/2010 of the 5th of August states that there may have been some instances in the period between 1960 and 1965 in which "substances containing thalidomide could still be in circulation or in the possession of private individuals."

In Spain, the social process generated by thalidomide has been particularly dramatic. This was caused by the denial of thalidomide sales by the Spanish authorities for more than 30 years. At that time this implied that there were supposedly no cases in Spain and, for this reason, it put those affected individuals in a situation of institutionalized helplessness, exclusion and marginalization. Currently, it has been estimated that there are between 1.500 and 3.000 newborns with malformations (Papaseit et al., 2013). The seriousness derives from the lack of official registry, which has prevented affected individuals and families from accessing political and social recognition, as well as any financial compensation or health assistance.

The opposite pole to Spain is the United States. In that territory, no thalidomide patients were affected thanks to the caution of the FDA supervisor, Dr. Kelsey, who rejected the application for authorization to market such drugs. In view of conflicting information, the decision was made to wait for more data on its safety. For this reason, Dr. Kelsey was decorated by President Kennedy on 7th August 1962 with the "President's Award for Distinguished Federal Civilian Service" (Rajkumar, 2004). As a consequence of these events, on 10th October 1962, the United States Congress unanimously passed the Judiciary Committee's bill on amendments to the United States Federal Food, Drug and Cosmetic Act. In this amendment, an administrative procedure was established (Silva-Ortiz, 2011) for the authorization of clinical trials and the need to demonstrate the therapeutic efficacy of medicines before applying for marketing authorization (Silva-Ortiz, 2011). This regulation puts health before marketing, substantially institutionalizes the production of pharmaceuticals in the social context and strengthens what later became known as social medicine (Ryle, 1943, p. 635):

> "In short, social medicine means what it says. It is to embody the idea of medicine applied to the service of man as *socius*, as companion or comrade, with a view to a better understanding and a more lasting help to all fundamental problems and contributing to the avoidance of active health, and not the mere removal or relief of a present pathology. Social medicine also embodies the idea of medicine applied to the service of the *societas*, or community of men, with a view to reducing the incidence of all preventable diseases and raising the general level of human physical fitness."

The worldwide tragedy of thalidomide generated such a social effect that it led to a second sept toward the strengthening of voluntary adverse reaction reporting systems, which gave rise in 1963 to the International Pharmacovigilance Programme of the World Health Organization (WHO) with centers in 10 countries in that year. Since 1971, they have been under the authority of the world pharmacovigilance center (Caron et al., 2016). In Spain, the spontaneous adverse reaction reporting programme began in 1982 and, 2 years later, it joined the WHO programme.

A third prominent example: Rofecoxib (Vioxx®)

Rofecoxib is a non-steroidal anti-inflammatory drug that functions as a selective inhibitor of the enzyme cyclo-oxygenase-2 (COX-2) and thus of prostacyclin synthesis (Karha and Topol, 2004). Vioxx® was a drug marketed by Merck Sharp & Dohme (MSD) and it was indicated for the symptomatic treatment of rheumatoid arthritis and osteoarthritis. In the United States of America, the FDA considered the benefit-risk assessment of the drug to be favorable and it granted marketing authorization on 20th May 1999 (Presley, 2009). In February 2001, the FDA prepared two reports on notifications of possible cardiovascular adverse events associated with Vioxx®. The FDA required only Merck to incorporate precautions in its labeling (Horton, 2004). The scientific community urged the FDA to request further clinical safety testing, but the FDA did not do so (Horton, 2004; Topol, 2004). The scientific community therefore considered that the FDA's actions were insufficient to prevent possible adverse drug reactions (ADRs). In this regard, studies and critical comments were published in various prestigious international scientific journals on the methodological deficiencies of the clinical studies carried out on Vioxx®, warning of its link to serious cardiovascular risks. The FDA only required Merck to incorporate a series of precautions in this respect in its labeling. Despite the doubts and deficiencies, on 20th July 2001, Merck Sharp & Dohme obtained marketing authorization for another drug with rofecoxib as an active ingredient, Ceoxx®, indicated for the symptomatic treatment of short-term acute pain and primary dysmenorrhoea. Publications warning about Vioxx® ADRs were published from 2000 (Horton, 2004) to 2004. (Mukherjee et al., 2001; Horton, 2004; Jüni et al., 2004) In 2004, the serious ADRs associated with this drug became undisputedly evident. Merck notified the FDA of these findings and on 30th September 2004 voluntarily withdrew Vioxx® and Ceoxx® 100.

The unethical problem of the corporation is highlighted by a Wall Street Journal investigate journalism report revealing the existence of emails confirming the knowledge of the adverse cardiovascular effects of Vioxx® by some Merck executives (Horton, 2004). On the other hand, harsh criticism of the FDA's performance led to calls for more power, control and independence for the FDA (The Lancet, 2005). In addition, Horton (2004) questioned the very structure of the institution, stating the too often the FDA considers the pharmaceutical industry to be its client and, therefore, a vital sources of funding for its activities. Then, this fact undermines the FDA's performance by failing to act as a sector of society in need of sound regulation.

The social importance of pharmacovigilance

Pharmacovigilance (PV) in Spain, according to Royal Decree 577/2013 of 26th July, is defined as the public health activity whose objective is the identification, quantification, evaluation and prevention of risks associated with the use of medicinal products (RAM) once authorized. This implied that PV is a biomedical risk control activity and, potentially, it could be also a pharmacological social risk minimization activity. Additionally, it is an inherent part of the clinical use of medicines, and it starts during the pre-marketing phase of medicines, as well as it reaches its peak after their authorization and marketing. In fact, PV has been a discipline focused on the post-authorization and post-marketing period (Hartford et al., 2006). Nevertheless, this has gradually changed. PV, under the influence of biological disciplines, has evolved toward an anticipatory and proactive approach to the potential risks/benefits of medicines in the pre- and post- approval stages of drug development (Hartford et al., 2006).

Pharmacovigilance is of great relevance today. In fact, during the recent pandemic caused by the SARS-CoV-2 virus, it was crucial for the rapid commercialization of new drugs against this virus (Ellis and Toklu, 2020). Other outstanding examples of the importance of this discipline today are related to the use of opioids in the USA, to Levothyrox in New Zealand and France, or to the use of Ibuprofen in regions such as New Zealand or Spain. Likewise, the perspectives of analysis offered by the subsections of pharmacovigilance, such as cosmetovigilance and herbavigilance, are also remarkable (Toklu, 2016; Toklu et al., 2019). The examples are numerous and the challenges for this and other disciplines are proven to be enormous by negative consequences of ADRs.

ADRs are a major cause of morbidity and mortality, making the avoidance of ADRs extremely important for the population. In a classic study, Lazarou et al. (1998) analyzed 39 prospective studies conducted in US hospitals between 1966 and 1996. They found that ADRs accounted for 6.7% of hospital admissions and that they represented the sixth leading cause of death in the United States. On the other hand, currently the World Health Organization (Esteban et al., 2017) has established that adverse drug reactions (ADRs) are one of the 10 leading causes of death in the world.

Pharmacovigilance has undergone major changes since the thalidomide case. These changes were made mainly in the management of suspected cases of AMR (standardization of the processes for obtaining information, independence of sources, etc.), in the management of signals that raise suspicion for the detection of possible links between a given drug and its administration, and finally, in the management of the risk/benefit balance to implement processes that reduce risks for patients (Beninger, 2008).

Therefore, twenty-first century pharmacovigilance is not a discipline that simply discovers, reports and manages adverse events associated with approved and marketed drugs, but it is concerned with the systematic monitoring of the pre-marketing review process and post-marketing surveillance, which includes the use of drugs in everyday practice. However, all these considerations about pharmacovigilance are focused on the biomedical domain. Nonetheless, there are other actors involved in the systemic PV process that need to be taken into account and even explicitly incorporated into the PV process.

The first of these agents are pharmacists themselves. Obviously, as we have already indicated, in addition to pharmacists, physicians also have a preponderant role that should not be overlooked, especially general practitioners. Kumar (2017) notes that pharmacists' involvement in AMR reporting is, as he states, largely unknown. In fact, in the United States of America, a survey of 377 pharmacists in Texas found that 67.7% of the pharmacists surveyed had inadequate knowledge of the process of reporting to competent authorities (Gavaza et al., 2011).

The second major player that cannot be ignored in PV is society itself, which, through its interactions, could offer new opportunities for the management of PV-related information (Harpaz et al., 2014). This is because a large proportion of patients are often active participants in the exchange and dissemination of health-related information through social networks and, in particular, health social networks (Sarker et al., 2015). However, although the potential for obtaining useful information for PV is high, it is also necessary to bear in mind that the incorporation of data from social networks or everyday interactions between people generates serious drawbacks: credibility, timeliness, frequency, relevance, etc. (Sarker et al., 2015). On the other hand, the same author indicates that when trying to process natural language into computer language, it is found that consumers tend to use misspelled words, terms without medical correspondence and descriptive expressions to refer to health problems. Sarker et al. (2015) also indicate that a small proportion of drug-related data collected through social networks tends to contain information associated with AMR.

Therefore, pharmacovigilance also has an inescapable social component as it identifies previously unrecognized adverse events or changes in the patterns of these same effects, as well as the quality and adequacy of drug supply, and ensures effective communication with the public, healthcare professionals and patients about the risk/benefit balance and use of drugs (Pitts et al., 2016). Another important aspect of pharmacovigilance is centered around patient reports. These are often incomplete or unclear. In addition, there is also the possibility of reporting adverse drug effects *via* social networks (Paola and Claudio, 2020). Given this reality, we wonder if pharmacy professionals could play a more active role in regard to this by obtaining information directly from patients. Now, this aspect of pharmacovigilance has been traditionally done by relying on post-marketing spontaneous reporting systems (SRSs), such as: the EudraVigilance system (operated by the European Medicines Agency) or the Adverse Event Reporting System (US Food and Drug Administration, FDA). These systems gather voluntary reports produced by healthcare professionals, marketing authorization holders (MAHs) or consumers. However, the reporting rate of such systems is low, causing delays in the detection of ADRs (Pappa and Stergioulas, 2019). In this regard, several authors (Lardon et al., 2015; Bagheri et al., 2016; Sinha et al., 2018, among many others) have studied the usefulness of social media in pharmacovigilance. These works, together with other ones, show the enormous possibilities that exist in this social sphere. Sinha et al. (2018) even conclude that the FDA could develop strategies to more actively disseminate drug safety information through these social networks. They even argue that the FDA could benefit from information dumped on websites such as Wikipedia, which are frequently accessed for drug-related information. Most critical of such strategies, Lardon et al. (2015) suggest that there is a sufficient volume of pharmacovigilance data on social media to work with. However, they are aware that the quality of this information is variable and that further studies are needed to improve the process. For all these reasons, it could be concluded that these mechanisms are not yet sufficiently developed to be used with complete efficiency and reliability.

The use of social media to improve pharmacovigilance is one of the possible strategies of what has been called social pharmacology (Montastruc et al., 2021). This discipline, according to these authors, is the study of interactions between pharmaceuticals and society. In line with this Knight et al. (2017), a study on the pharmacovigilance of opioids, showed that social elements, mainly structural ones, affected opioid access. Similarly, in Canada, social groups have been found to be more prone to AMR. In fact, women have a lower proportion of ADRs (53.5%) compared to 60.9% of men. Furthermore, these authors also indicate that AMR have a direct social impact, i.e., they directly affect people's lives. For this reason, Castillon et al. (2019) suggest that social dimensions such as social and family functioning, psychological functioning, functioning related to daily life, and functioning at work or school should be included and assessed in AMR reporting. This gives an idea of the importance of the social aspects in pharmacovigilance. On the other hand, a study previously conducted (Pottie et al., 2008) found that the development of collaborative professional practices between pharmacists and physicians was beneficial because, among other things, it provided clinical safety for physicians. Well, we believe that, in a similar way, the collaboration of pharmacy professionals (but also of medicine) would allow us to broaden our understanding of the social world. One possibility would be to develop strategies for ongoing collaboration and communication when analyzing human behavior or social perceptions. Another more recent and enlightening study shows how it is possible to develop virtual forums (cyber-forums) to share information, motivate and understand the practical constraints that influence pharmacovigilance (Rochoy et al., in press). The question would then be similar: wouldn't it be desirable that sociologists could actively participate to help better understand the social and practical determinants of pharmacovigilance?

Conclusion

For all these reasons, we believe that it is essential that the biomedical, pharmacological and social research fields interrelate in a more effective way. This would require a different strategy to the current one. In this sense, we could say that there would be several main actors involved: those who report ADRs, those who investigate ADRs, and those who study the mechanisms of prevention, education and social perception of medicines in order to understand ADRs and, if possible, reduce them. In addition, we believe that this interaction would allow the information obtained and issued by pharmacists (as well as other health professionals) to be previously filtered and have greater reliability than that coming, for example, from social networks.

On the other hand, the way in which the misperception of medicines, vaccines, etc., is generated in the citizenship would be better understood, and also the behaviors that promote or facilitate AMR could be more effectively reduced. We also assume that it would be easier to reduce the likelihood of self-medication or, at least, to increase the decision-making of those who choose to self-medicate.

Hence, and in this context, pharmacy would become an agent of socio-biomedical democratization, since it would act as a "translator" of citizens' impressions. However, in this hypothetical process of interrelation between pharmacists and society, it would also be of vital importance to establish mechanisms for dialogue with social scientists. The latter have a better understanding of social conditioning factors and could encourage better vigilance and greater social acceptance of pharmaceutical vigilance itself.

In any case, the challenges of PV in today's society are numerous and, in our opinion, it is clear that they require the incorporation of the greatest number of social agents that make possible a dynamic of constant information in order to implement flexible and appropriate control and management strategies. Finally, we believe that further research would be necessary to encourage the development and structuring of this process of interrelation that we are discussing.

Author contributions

JC has written the definite article, and participated in the search for information and in the analysis. RC-A has written a first draft, and participated in the information search and analysis. GE has corrected the final article and has participated in the analysis of the information. All authors contributed to the article and approved the submitted version.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Abraham, J. (2008). Sociology of pharmaceuticals development and regulation: a realist empirical research programme. *Sociol. Health Illness* 30, 869–885. doi: 10.1111/j.1467-9566.2008.01101.x

Bagheri, H., Lacroix, I., Guitton, E., Damase-Michel, C., and Montastruc, J. L. (2016). Cyberpharmacovigilance: les réseaux siaux sont-ils utiles en pharmacovigilance? *Therapi* 71, 229–233. doi: 10.1016/j.therap.2015.09.001

Barkan, I. D. (1985). Industry invites regulation: the passage of the Pure Food and Drug Act of 1906. *Am. J. Public Health* 75, 18–26. doi: 10.2105/AJPH.75.1.18

Beninger, P. (2008). Pharmacovigilance: an overview. *Clin. Ther.* 40, 1991–2004. doi: 10.1016/j.clinthera.2018.07.012

Caron, J., Rochoy, M., Gaboriau, L., and Gautier, S. (2016). The history of pharmacovigilance. *Therapie* 71, 129–134. doi: 10.1016/j.therap.2015.12.007

Castillon, G., Salvo, F., and Moride, Y. (2019). The social impact of suspected adverse drug reactions: an analysis of the canada vigilance spontaneous reporting database. *Drug Saf.* 42, 27–34. doi: 10.1007/s40264-018-0713-8

Comín, F. (2012). *Historia Económica Mundial*. Madrid: Alianza.

Cooper, D. E. (2002). Adequate controls for new drugs: good manufacturing practice and the 1938 Federal Food, Drug and Cosmetic Act. *Pharm. Hist.* 44, 12–23.

Ellis, H., and Toklu, H. Z. (2020). Importance of awareness of adverse drug reaction reporting during the COVID-19 pandemic. *HCA Healthc. J. Med.* 1, 1. doi: 10.36518/2689-0216.1206

Esteban, O., Navarro, C., González, F., Lanuza, F. J., and Montesa, C. (2017). Análisis de la incidencia y de las características clínicas de las reacciones adversas a medicamentos de uso humano en el medio hospitalario. *Rev. Española Salud Pública* 91, e201712050.

Florence, A. L. (1960). Is thalidomide to blame? *Br. Med. J.* 2, 1954. doi: 10.1136/bmj.2.5217.1954

Gavaza, P., Brown, C. M., Lawson, K. A., Rascati, K. L., Wilson, J. P., and Steinhardt, M. (2011). Texas pharmacists' knowledge of reporting serious adverse drug events to the Food and Drug Administration. *J. Am. Pharm. Assoc.* 51, 397–403. doi: 10.1331/JAPhA.2011.10079

Haller, J. S. (1982). The United States Pharmacopoeia: its origin and revision in the 19^{th} century. *Bull. N. Y. Acad. Med.* 58, 480–492.

Hansen, W. B., and Dusenbury, L. (2007). Ciencia, política y práctica: lecciones desde Estados Unidos de América. *Adicciones* 19, 117–124. doi: 10.20882/adicciones.309

Harpaz, R., Callahan, A., Tamang, S., Low, Y., Odgers, D., Finlayson, S., et al. (2014). Text mining for adverse drug events: the promise, challenges, and state of the art. *Drug Saf.* 37, 777–790. doi: 10.1007/s40264-014-0218-z

Hartford, C. G., Petchel, K. S., Mickail, H., Perez-Gutthann, S., McHale, M., Grana, J. M., et al. (2006). Pharmacovigilance during the pre-approval phases. an evolving pharmaceutical industry model in response to ICH E2E, CIOMS VI, FDA and EMEA/CHMP risk-management guidelines. *Drug Saf.* 29, 657–673. doi: 10.2165/00002018-200629080-00003

Hayman, D. J. (1962). Thalidomide and congenital abnormalities. *Lancet* 46, 45–46.

Horton, R. (2004). Vioxx, the implosion of Merck, and aftershocks at the FDA. *Lancet* 364, 1995–1996. doi: 10.1016/S0140-6736(04)17523-5

Jüni, P., Nsrtey, L., Reichenbach, S., Sterchi, R., Dieppe, P. A., and Egger, M. (2004). Risk of cardiovascular events and rofecoxif: cumulative meta-analysis. *Lancet* 364, 2021–2029. doi: 10.1016/S0140-6736(04)17514-4

Karha, J., and Topol, E. J. (2004). The sad story of Vioxx, and what we should learn from it. *Cleve. Clin. J. Med.* 71, 933–939. doi: 10.3949/ccjm.71.12.933

Knight, K. R., Kushel, M., Chang, J. S., Zamora, K., Ceasar, R., Hurstak, E., et al. (2017). Opioid pharmacovigilance: a clinical-social history of the changes in opioid prescribing for patients with co-occurring chronic non-cancer pain and substance use. *Soc. Sci. Med.* 186, 87–95. doi: 10.1016/j.socscimed.2017.05.043

Kremers, E., and Urdang, G. (1976). *Kremers and Urdang's History of Pharmacy*. Philadelphia, PA: American Institute of History of Pharmacy, Philadelphia.

Kumar, A. (2017). Pharmacovigilance: importance, concepts, and processes. *Am. J. Health Syst. Pharm.* 74, 606–612. doi: 10.2146/ajhp151031

Lardon, J., Abdellaoui, R., Bellet, F., Asfari, H., Souvignet, J., Texier, N., et al. (2015). Adverse drug reaction identification and extraction in social media: a scoping review. *J. Med. Internet Res.* 17, e171. doi: 10.2196/jmir.4304

Lazarou, J., Pomeranz, B. H., and Coreyn, P. N. (1998). Incidence of adverse drug reactions in hospitalized patients: a meta-analysis of prospective studies. *JAMA* 279, 1200–1205. doi: 10.1001/jama.279.15.1200

Lenz, W. (1962). Thalidomide and congenital abnormalities. *Lancet* 46, 45.

Martínez-Frías, M. L. (2012). Talidomida: 50 años después. *Med. Clín.* 139, 25–32. doi: 10.1016/j.medcli.2011.10.011

Montastruc, J. L., Lafaurie, M., de Canecaude, C., Montastruc, F., Bagheri, H., Durrieu, G., et al. (2021). COVID-19 vaccines: a perspective from social pharmacology. *Therapies* 76, 311–315. doi: 10.1016/j.therap.2021.05.010

Morales, P., and Bosch, F. (2007). Hechos históricos de las sulfamidas divulgados por la prensa: el caso de *The New York Times*. *Med. Clín.* 128, 660–664. doi: 10.1157/13102052

Mukherjee, D., Nissen, S. E., and Topol, E. J. (2001). Risk of cardiovascular events associated with selective cox-2 inhibitors. *JAMA* 286, 954–959. doi: 10.1001/jama.286.8.954

Paola, K., and Claudio, G. (2020). The value of direct patient reporting in pharmacovigilance. *Ther. Adv. Drug Saf.* 11, 2042098620940164. doi: 10.1177/2042098620940164

Papaseit, E., García-Algar, O., and Farré, M. (2013). Talidomida: una historia inacabada. *Anales Pediatría* 78, 283–287. doi: 10.1016/j.anpedi.2012.11.022

Pappa, D., and Stergioulas, L. K. (2019). Harnessing social media data for pharmacovigilance: a review of current state of the art, challenges and future directions. *Int. J. Data Sci. Anal.* 8, 113–135. doi: 10.1007/s41060-019-00175-3

Pfeiffer, R. A., and Kosenow, W. (1962). Thalidomide and congenital abnormalities. *Lancet* 46, 45–46.

Pitts, P. J., LeLouet, H., Moride, Y., and Conti, R. M. (2016). 21st century pharmacovigilance: efforts, roles, and responsibilities. *Lancet Oncol.* 17, e486–e492. doi: 10.1016/S1470-2045(16)30312-6

Pottie, K., Farrell, B., Haydt, S., Dolovich, L., Sellors, C., Kennie, N., et al. (2008). Integrating pharmacists into family practice teams. Physicians' perspectives on collaborative care. *Can. Family Phys.* 54, 1714–1717.e1-5.

Presley, H. (2009). *Vioxx and the Merck Team Effort*. Duke: Duke University/Kenan Institute for Ethics.

Rajkumar, S. V. (2004). Thalidomide: tragic past and promising future. *Mayo Clin. Proc.* 79, 899–903. doi: 10.4065/79.7.899

Rocca, E., Copeland, S., and Ralph Edwards, I. (2019). Pharmacovigilance as scientific discovery: an argument for trans-disciplinarity. *Drug Saf.* 42, 1115–1124. doi: 10.1007/s40264-019-00826-1

Rochoy, M., Danel, A., Chazard, E., Gautier, S., and Berkhout, C. (in press). Doping with aromatase inhibitors and oestrogen receptor modulators in steroid users: analysis of a forum to identify dosages, durations and adverse drug reactions. *Therapie*. doi: 10.1016/j.therap.2022.03.004

Ryle, J. A. (1943). Social medicine: its meaning and its scope. *Br. Med. J.* 2, 633–636. doi: 10.1136/bmj.2.4324.633

Salvador Coderch, P., Gómez Ligüerre, C., Rubí Puig, A., Ramos González, S., and Terra Ibáñez, A. (2014). *Daños tardíos. Avite©. Grünenthal. Comentario a la SJPI n° 90 Madrid, 19 de noviembre de 2013, sobre los daños causados por la talidomida*. InDret. Revista para el análisis del derecho 01/2014. Avaliable online at: http://www.indret.com/pdf/1036_revisado.pdf (accessed June 10, 2022).

Sarker, A., Ginn, R., Nikfarjama, A., O'Connor, K., Smith, K., Jayaraman, S., et al. (2015). Utilizing social media data for pharmacovigilance: a review. *J. Biomed. Inform.* 54, 202–212. doi: 10.1016/j.jbi.2015.02.004

Secretary of Agriculture (1937). Deaths due to elixir of sulf-anilamide-massengill: report of Secretary of Agriculture submitted in response to House Resolution 352 of nov. 18, 1937, and senate resolution 194 of nov. 16, 1937. *JAMA* 109, 1985–1988. doi: 10.1001/jama.1937.92780500008012

Silva-Ortiz, A. (2011). *El régimen de autorización de nuevos medicamentos en Estados Unidos de América y la Unión Europea* (Ph.D. thesis). Servicio de Publicaciones de la Universidad de Navarra, Navarra. Avaliable in: http://dadun.unav.edu/bitstream/10171/20689/1/Tesis%20Doctoral%20Alejandro%20Silva%20Ortiz.pdf (accessed June 10, 2022).

Sinha, M. S., Freifeld, C. C., Brownstein, J. S., Donneyong, M. M., Rausch, P., Lappin, B. M., et al. (2018). Social media impact of the food and drug administration's drug safety communication messaging about zolpidem: mixed-methods analysis. *JMIR Public Health Surveill* 4, e1. doi: 10.2196/publichealth.7823

Swann, J. P. (1999). The 1941 Sulfathiazole disaster and the birth of good manufacturing practices. *Pharm. Hist.* 41, 16–25.

Tapia, J. A., and Diez, A. V. (2009). Life and death during the Great Depression. *Proc. Nat. Acad. Sci.* 106, 17290–17295. doi: 10.1073/pnas.0904491106

The British Medical Journal (1937). Poisoning by elixir sulfanilamide (editorial). *Br. Med. J.* 2, 1129–1130.

The Lancet (2005). Safety concerns at the FDA (editorial). *Lancet* 365, 727–728. doi: 10.1016/S0140-6736(05)17994-X

Toklu, H. Z. (2016). Pharmacovigilance of herbal medicine: herbavigilance. *Adv. Pharmacoepidemiol. Drug Saf.* 5, 4. doi: 10.4172/2167-1052.1000208

Toklu, H. Z., Antigua, A., Lewis, V., Reynolds, M., and Jones, J. (2019). Cosmetovigilance: a review of the current literature. *J. Family Med. Prim. Care* 8, 1540–1545. doi: 10.4103/jfmpc.jfmpc_447_18

Topol, E. J. (2004). Failing the public health—rofecoxib, Merck, and the FDA. *N. Engl. J. Med.* 351, 1707–1709. doi: 10.1056/NEJMp048286

Wax, P. M. (1995). Elixirs, Diluents, and the passage of the 1938 federal food, drug and cosmetic act. *Ann. Intern. Med.* 122, 456–461. doi: 10.7326/0003-4819-122-6-199503150-00009

Weaver, J., Willy, M., and Avigan, M. (2008). Informatic tools and approaches in postmarketing pharmacovigilance used by FDA. *AAPS J.* 10, 35–41. doi: 10.1208/s12248-007-9004-5

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EDITED BY
Andrzej Klimczuk,
Warsaw School of Economics, Poland

REVIEWED BY
Ricardo Batista,
Ottawa Hospital Research Institute (OHRI), Canada
Jorge Homero Rodríguez-Castro,
Technological Institute of Ciudad Victoria, Mexico
Hamza Khalifa Ibrahim,
Higher Institute of medical sciences and Technology Bani Waleed-Libya, Libya

*CORRESPONDENCE
Rafel Ramos
✉ rramos.girona.ics@gencat.cat

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Role of personal aptitudes as determinants of incident morbidity, lifestyles, quality of life, use of health services, and mortality (DESVELA cohort): quantitative study protocol for a prospective cohort study in a hybrid analysis

Ruth Martí-Lluch[1,2,3,4], Bonaventura Bolíbar[3,4,5], Joan Llobera[4,6,7], José A Maderuelo-Fernández[4,8,9,10], Rosa Magallón-Botaya[4,11,12], Álvaro Sánchez-Pérez[4,13,14], Mª José Fernández-Domínguez[4,15,16,17], Emma Motrico[4,18], Enric Vicens-Pons[4,19], Blanca Notario-Pacheco[4,20,21], Lia Alves-Cabratosa[1,4], Rafel Ramos[1,2,4,22,23]* and the DESVELA Cohort Investigators

[1]Vascular Health Research Group of Girona, Institut Universitari per a la Recerca a l'Atenció Primària Jordi Gol i Gurina (IDIAPJGol), Girona, Spain, [2]Parc Hospitalari Martí Julià, Institut d'Investigació Biomèdica de Girona (IDIBGI), Salt, Spain, [3]Universitat Autònoma de Barcelona, Cerdanyola del Vallès, Spain, [4]Network for Research on Chronicity, Primary Care, and Health Promotion (RICAPPS), Tenerife, Spain, [5]Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina (IDIAPJGol), Barcelona, Spain, [6]Balearic Islands Health Service (Ib-Salut), Primary Care Research Unit of Mallorca, Palma, Spain, [7]Hospital Universitari Son Espases, GrAPP-caIB—Health Research Institute of the Balearic Islands (IdISBa), Palma, Spain, [8]Unidad de Investigación en Atención Primaria de Salamanca (APISAL), Salamanca, Spain, [9]Instituto de investigación Biomédica de Salamanca (IBSAL), Salamanca, Spain, [10]Gerencia Regional de salud de Castilla y León (SACyL), Gerencia de Atención Primaria de Salamanca, Salamanca, Spain, [11]Primary Health Care Research Group of Aragón (GAIAP), Institute for Health Research Aragón (IIS Aragón), Zaragoza, Spain, [12]Department of Medicine, Psychiatry and Dermatology, University of Zaragoza, Zaragoza, Spain, [13]Unidad de Investigación Atención Primaria de Bizkaia. Subdirección para la Coordinación de la Atención Primaria, Dirección General Osakiadetza, Vitoria, Spain, [14]Grupo de Investigación en Ciencias de la Diseminación e Implementación en Servicios Sanitarios Instituto Investigación Biocruces, Baracaldo, Bizkaia, Spain, [15]Ourense Health Area, SERGAS, Ourense, Spain, [16]Centro de Saúde de Leiro, SERGAS, Leiro, Spain, [17]I-Saúde Group, Hospital Álvaro Cunqueiro Bloque Técnico, South Galicia Health Research Institute, Vigo, Spain, [18]Departamento de Psicología, Universidad Loyola Andalucía, Sevilla, Spain, [19]Health Technology Assessment in Primary Care and Mental Health (PRISMA) Research Group, Parc Sanitari Sant Joan de Deu, Institut de Recerca Sant Joan de Deu, St Boi de Llobregat, Catalunya, Spain, [20]Faculty of Nursing, Universidad de Castilla-La Mancha, Cuenca, Spain, [21]Social and Health Research Center, Universidad de Castilla-La Mancha, Cuenca, Spain, [22]Department of Medical Sciences, School of Medicine, Campus Salut, Universitat de Girona, Girona, Spain, [23]Atenció Primària, Institut Català de la Salut, Girona, Catalonia, Spain

Introduction: The healthcare and well-being of the population depend on multiple factors and should adapt to societal changes. The opposite is also occurring; society has evolved concerning the individuals' approach to their care, which includes participation in decision-making processes. In this scenario, health promotion and prevention become crucial to provide an integrated perspective in the organization and management of the health systems. Health status and well-being depend on many aspects, determinants of health, which in turn may be modulated by individual behavior. Certain models and frameworks try to study the determinants of health and individual human behaviors, separately. However, the interrelation between these two aspects has not been examined in our population. Our main objective is to analyze whether personal aptitudes related to behaviors are independently associated with the incidence of morbidity. A secondary objective will enquire whether these personal aptitudes are independently associated with lower all-cause mortality, enhanced adoption of healthy lifestyles, higher quality of life, and lower utilization of health services during follow-up.

Methods: This protocol addresses the quantitative branch of a multicenter project (10 teams) for the creation of a cohort of at least 3,083 persons aged 35 to 74 years from 9 Autonomous Communities (AACC). The personal variables to evaluate are self-efficacy, activation, health literacy, resilience, locus of control, and personality traits. Socio-demographic covariates and social capital will be recorded. A physical examination, blood analysis, and cognitive evaluation will be carried out. Several sets of six Cox models (one for each independent variable) will analyze the incidence of morbidity (objective 1); all-cause mortality and the rest of the dependent variables (objective 2). The models will be adjusted for the indicated covariates, and random effects will estimate Potential heterogeneity between AACC.

Discussion: The analysis of the association of certain behavioral patterns and determinants of health is essential and will contribute to improving health promotion and prevention strategies. The description of the individual elements and interrelated aspects that modulate the onset and persistence of diseases will allow the evaluation of their role as prognostic factors and contribute to the development of patient-tailored preventive measures and healthcare.

Clinical Trial Registration: ClinicalTrials.gov, NCT04386135. Registered on April 30, 2020.

KEYWORDS

primary health care, health promotion, chronicity, determinants of health, health behavior, morbidity, lifestyles, quality of life

1. Introduction

In Spain, the population over 65 years of age is expected to increase by 10% in the next 50 years (1); and the total dependency ratio to grow from the current 54.2 to 72.2%. The aging of the population is associated with an increase in the number of people with chronic diseases (osteoarticular, cardiovascular, respiratory, mental, neurodegenerative, and cancer) and the resulting higher multimorbidity (two or more concurrent conditions) (2). This poses a great challenge to the health systems because the demand for health and social services escalates (3).

Chronic diseases are the leading cause of overall mortality and premature mortality in the world (they are related to 42% of the deaths occurring before 70 years of age). These conditions have an enormous impact on people's daily life and their families, and represent a heavy burden on society (4). Among chronic diseases, the high prevalence of mental disorders is worth mentioning (5). Major depression, specifically, holds second place worldwide in terms of disability and disease burden (6). Mortality rates in people with mental health problems are up to double those in people without them. But importantly, most chronic diseases and their complications could be prevented through health promotion and primary prevention strategies; approximately 80% of cardiovascular diseases and 30% of all cancers could be averted (4).

Health promotion and prevention interventions play an essential role when considering the wellbeing of the population from a comprehensive perspective. According to the World Health Organization (WHO), health is a state of physical, mental, and social well-being that includes the ability to function, and not only the absence of disease or infirmity (7). From the perspective of health promotion, the Ottawa Charter defines health as a resource that allows people to lead individual, social, and economically productive lives (8). The general practitioner Jordi Gol stated that 'health is an

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Abbreviations: AACC, Autonomous Communities; ABI, Ankle-brachial index; BFI-10, 10-Item Big Five Inventory; BMI, Body Mass Index; COM-B, Capability, Opportunity and Motivation (COM-B) Model; IDIAPJGOL, Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina; IPAQ, International Physical Activity Questionnaire; LOC, Locus of Control; PAM, Patient Activation Measure; PHC, Primary Health Care; SNS, Spanish National Health System; SOGI, Sex orientation and gender identity; TDF, Theoretical Domains Framework; WHO, World Health Organisation.

autonomous, supportive, and happy way of living' (9). Furthermore, changes in society have also implied evolution in the role of the population concerning their care and decision making about their health.

In such a framework, health promotion is the process of equipping people with the necessary means to improve their health and exercise greater control over it (10, 11). According to the World Health Promotion Conference in Shanghai (2016), three areas within health promotion need priority: (1) good governance for health, (2) the promotion of healthy cities and communities, and (3) the reinforcement of health knowledge. These areas substantially coincide with the aims of the Strategy for Health Promotion and Prevention from the Spanish National Health System (SNS): to build healthy public policies, to create environments that support health and well-being, to support the empowerment of the individual through the development of personal skills, to reinforce community action, and to reorient the health services (12).

The health and well-being of both individuals and communities depends on the combination of many factors like where we live, our environment, genetics, income and education level, and family and social relationships. Notably, the access to and use of health care services have a limited impact; 80% of determinants of health are outside the influence of the health system (13).

These factors or determinants of health have been analyzed using various models. The Dahlgren-Whitehead model is one of the most widely used (14); it presents the main determinants of health as a range of concentric hierarchical layers where each layer determines the successive layers towards the center. Individuals are located in the center, with their non-modifiable characteristics such as age, sex, and genetic load. Around them, there are various layers of influences over health, such as lifestyles, social and community networks, living and working conditions, and socioeconomic, cultural and environmental conditions. Those factors that enhance the capacity of individuals to maintain health and well-being are defined as "Health Assets" according to the theory of salutogenesis (15). According to Marmot, control over one's life and opportunities for full social participation are crucial aspects for health, well-being, and longevity (16).

Despite the endorsement of certain elements to improve the future well-being of the population (participation in the decision-making processes, the way people experience and cope with the diseases; and the ability to self-manage their own health and care), little is known about the role of personal determinants and individual aptitudes on the capacity to adopt health-promoting behaviors and respond appropriately to adverse situations. Several classic health-related behavior models and theories and the more recent integrative frameworks try to explain human behavior, the most widely used being the Theoretical Domains Framework (TDF) (17). This framework includes 12 domains derived from 33 theories and covers the main factors that influence behavior, namely knowledge, skills, social/professional role and identity, beliefs about capacities and consequences, memory, attention and decision processes, and social influences. Nevertheless, population-based studies on the predictive validity of the behavioral frameworks applied to health and well-being are lacking.

The importance of the development of personal aptitudes is stated in the Ottawa Charter (8) as one of the bases for establishing health public policies. The efforts to attain such a development should be directed towards providing information and health education and improving the abilities essential for life. This, in turn, would increase the options available for the population so they could exercise higher control over their health and the environment that influences it (8). The evaluation of personality traits includes a whole set of psychological and behavioral characteristics and the internal organization, which make different persons act differently when facing a similar circumstance (18). Certain personality traits are related to harmful behaviors, physical and mental health problems, lower longevity, and more mortality from all causes (19–23).

Some personal aptitudes stand out among those with higher potential impact on health improvement, quality of life, or reduced use of health services: personality traits, locus of control (LOC), self-efficacy, resilience, activation, and health literacy.

The locus of control (LOC) is defined as the extent to which individuals hold agency regarding the events that occur in their life. It can be internal—when the individuals believe that events in their lives are due to their own actions, attitudes, or behaviors; or external—when people believe it is the result of luck, chance, destiny, or the decisions of others (24). The presence of an internal LOC has been associated with a better perception of general health, a lower perceived burden of the diseases (25, 26), and a positive attitude towards health promotion and primary prevention activities (27). Regarding the workplace, the presence of an internal LOC is associated with higher job satisfaction and well-being, better job performance, and lower levels of stress (28). An external LOC has been associated with a worse health status (29), more use of the emergency services and hospital admissions (30), a higher risk of developing cardiovascular diseases (25) and other chronic diseases (31), and a worse physical and psychological health status (32).

Self-efficacy refers to the feeling of confidence in one's abilities to adequately manage certain stressors in life (33). High self-efficacy was related to better mental function (34); better memory levels, speed of thought, and intelligence (35, 36); and a higher probability of acquiring healthy lifestyles (37). Low self-efficacy has been associated with anxious personality disorder (38).

Resilience is a dynamic process of positive adaptation to stress and adversity regarded as a protective factor against mental problems (39). A high degree of resilience has been considered a protective factor against mental diseases (40). Some authors have even suggested that it is a form of "mental immunity" (41). Resilience is also related to better cognitive function in older adults, specifically, greater verbal fluency and speed of perception (42).

Activation is defined as the capacity and ability to manage one's personal condition, collaborate with the health provider to maintain one's own health and wellbeing, access adequate and high-quality care, and prevent health deterioration (43). The Patient Activation Measure (PAM) allows evaluation of the self-knowledge, motivation, and aptitude to manage one's own health (43). Activation is a tool that allows individuals to reach and maintain healthy lifestyles, and optimize their quality of life (44). Higher activation levels are associated with people with better self-healing capacity, better health status, and lower use of health services (45, 46).

Health literacy refers to the health knowledge of the population, their motivation and individual abilities to understand and make decisions related to the promotion and maintenance of their health (47). Adequate health literacy levels have been associated with healthy lifestyle behaviors, such as eating five servings of fruit and vegetables per day or being a non-smoker-regardless of age, educational level, sex, ethnicity, or income (48, 49). Low health literacy can hinder health self-care and be related to a higher incidence of chronic diseases (50). From a health and social perspective, the improvement of health literacy is an unavoidable challenge.

To date, we have not identified longitudinal studies that delve into the analysis of all these personal aptitudes and their impact on health in our population. And yet, consideration of the interrelation of personal aptitudes and determinants of health is essential. Even more, there is solid evidence to support the association of socioeconomic, cultural, and environmental determinants with lifestyles, certain risk factors, and diseases (51). In the framework of the WHO 25 × 25 strategy, a recent meta-analysis of 48 cohorts that included 1.7 million people compared persons with low versus high socioeconomic status. Overall mortality rates were higher in the first group (hazard ratio, 95% confidence interval of 1.42, 1.38–1.45 in men, and 1.34, 1.28–1.39 in women), who also had those lifestyles that caused higher premature mortality (52). Other recent findings have shown that social and emotional support can protect health and well-being. However, further research should explain the reasons for this association, and understand its context and mechanisms (53). One of the most highlighted social determinants is the social capital, which refers to the resources available to individuals and groups through social networks (54, 55). Greater social capital has been associated with a better subjective perception of health and well-being (56, 57). Several observational studies indicated that higher social capital is a protective factor against mental and physical health, and mortality (58–60). Another conditioning factor is the working environment (13). Work stress has been associated with worse health status (61), increased risk of depressive disorders (62, 63), sleep disturbances (64), coronary heart disease (65), musculoskeletal pathology (66), alterations of lipid metabolism, and increased metabolic syndrome markers (67).

We believe that the analysis of the causal relationship between personal aptitudes and the adoption of healthy lifestyles, improvements in self-management of chronic conditions, quality of life, incidence and control of risk factors, incidence of chronic diseases and mortality is of special interest, and the creation of a cohort from Primary Health Care (PHC) is a most appropriate framework.

This project will contribute to provide essential knowledge for enabling and promoting the design of individualized interventions adapted to personal abilities and the evaluation of their role as prognostic factors. The interventions would also aim at improving the aptitudes that can be modified, such as health literacy, and the impact of these modifications may be assessed. Identification of the key determinants of multimorbidity is essential for the development of effective strategies for the healthcare and well-being of the person (2).

Accordingly, we propose to conduct an extensive investigation, with a holistic approach, on the determinants of health. Special focus will be given to the influence and effects of factors that determine individual behavior; a gender perspective and other aspects of social inequality will be included in the design and analysis. The description of these individual determinants involved in behaviors and their relation to social determinants, lifestyles, risk factors, chronic diseases and mortality are of paramount interest to our evolving societies and health systems.

1.1. Study objectives and hypotheses

This project was designed as a hybrid study, composed of a quantitative part (exposed in this article) and a qualitative part (published in another article).

The quantitative part of the DESVELA cohort has the following objectives:

1. To analyze whether personal aptitudes related to certain behaviors (self-efficacy, activation, health literacy, resilience, locus of control, and personality traits) are independently associated with the incidence of morbidity.
2. To analyze whether personal aptitudes related to certain behaviors (self-efficacy, activation, health literacy, resilience, locus of control, and personality traits) are independently associated with lower all-cause mortality, improved engagement in healthy lifestyles, higher quality of life, and lower utilization of the health services during follow-up.

We hypothesize that personal aptitudes that are related to positive behaviors (a higher self-efficacy, activation, health literacy, resilience, an internal locus of control, and positive personality traits) will be independently associated with a lower incidence of morbidity. We also hypothesize that personal determinants related to positive behaviors (a higher self-efficacy, activation, health literacy, and resilience, an internal locus of control, and positive personality traits) will be independently associated with all-cause mortality, engagement in healthy lifestyles, higher quality of life, and more optimal use of the health services during follow-up.

2. Materials and methods

2.1. Aim, design and study setting

We aim to evaluate the influence of personal aptitudes on lifestyles and quality of life, the incidence of the most relevant health problems, the utilization of the health services, and all-cause mortality (Figure 1).

This is a multicenter study for the creation of a prospective cohort of persons assigned to Primary Healthcare (PHC) centers within nine autonomous communities (AACC; Catalonia, the Basque Country, Castilla y León, Aragón, Galicia, the Balearic Islands, Castilla La Mancha, Andalusia and Madrid). Follow-up examinations and evaluations will be at 5 and 10 years from the entry date.

2.2. Participants

We will include persons aged 35–74 years assigned to the above-mentioned PHC centers, selected by random sampling. Exclusion criteria will apply to persons with a terminal condition or institutionalized at the time of recruitment; persons with intellectual

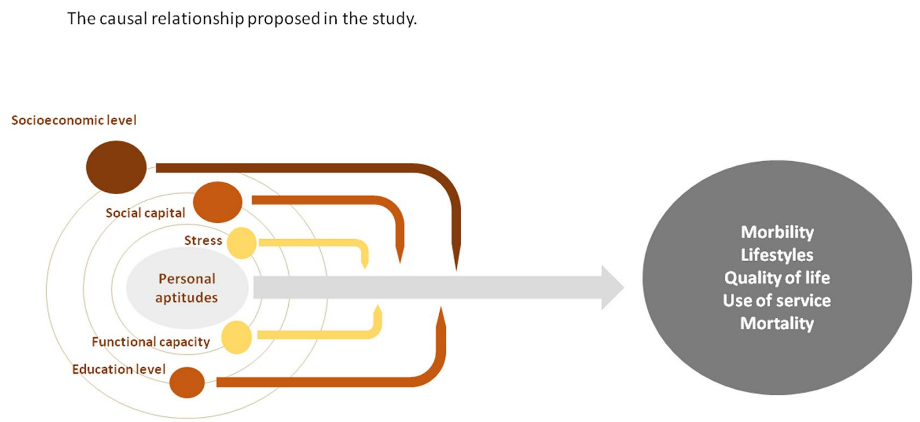

FIGURE 1
Diagram showing the causal relationship proposed in the study between the independent variables (personal aptitudes), the dependent variables (morbidity, lifestyles, quality of life, use of services and mortality) and the modulating effect of the covariates.

disabilities, dementia, or language difficulties; and persons who plan to move out of Spain within 5 years from study initiation.

2.3. Sample size

The sample size was computed using the GRANMO sample size calculator. We considered the estimation of the relative risk (RR) for a cohort study (using the Poisson approximation), with 10 years of follow-up and a rate of loss to follow-up of 30%, accepting an alpha risk of 0.05 and a beta risk of 0.2 in a bilateral contrast. The incidence of morbidity was considered as the main dependent variable and was around 60% in a previous analysis with 10.14 years follow-up (2). Health literacy was considered as the main independent variable. According to the questionnaire HLS-EU, 58,3% of the Spanish population has an inadequate or problematic level of health literacy (47). Low levels of health literacy have been linked to poorer physical and mental health outcomes, increased use of health services (68–70), and higher all-cause mortality (71, 72). Taking all these parameters into account, a sample of 3,083 persons is required, 1,793 in the exposed group (inadequate or problematic health literacy, HLS-EU-Q16 score between 0 and 12) and 1,290 in the non-exposed group (HLS-EU-Q16 score between 13 and 16). The sample size has been calculated to detect a minimum RR of 1.1 at 10 years, and will allow the detection of a minimum RR of 1.2 at 5 years, which is lower than some of the figures reported in the literature (73).

2.4. Variables

All the questionnaires used in the study are validated in Spanish except for the LOC, which will be assessed by a single question not yet validated. Table 1 shows the name of the questionnaire, the number of items, and the citation.

The independent variables in this study refer to personal aptitudes, will be measured at baseline, and are listed as follows with the corresponding measurement tools: self-efficacy, which will be measured with the Sherer's general self-efficacy scale (74); activation, measured with the Patient Activation Questionnaire (PAM) (46); resilience, measured with the abbreviated version of the 10-item Connor-Davidson scale (75); health literacy, evaluated with the HLS-EU-Q16 literacy questionnaire (76); LOC, assessed with the statement "I feel that events in my life are often determined by factors that are beyond my control" which has 6 response options in a Likert-type scale; personality characteristics will be examined using the 10-Item Big Five Inventory (BFI-10) for determination of personality traits (77).

The dependent variables in this study are morbidity, all-cause mortality, adoption of healthy lifestyles, quality of life, and utilization of health services. The information regarding the main dependent variables will be recorded at baseline and during the follow-ups at 5 and 10 years through surveys, physical examination and review of the medical records. The presence of morbidities will be assessed through the diagnoses in the medical records and physical examination. The medical records will also be the source to assess all-cause mortality.

Regarding the physical examination, blood pressure of participants will be measured and hypertension defined following the recommendations and criteria of the Spanish Hypertension Society. The ankle-brachial index (ABI) will be measured with a Vasera device (Fukuda Denshi), and peripheral arterial disease considered when $ABI < 0.9$. Weight and height will be measured to obtain the body mass index (BMI), and overweight and obesity will be considered if $25 \leq BMI < 30$ and $BMI > 30$, respectively. Waist circumference will also be measured. Blood testing will be performed to measure fasting glucose levels, glycated hemoglobin (HbA1c), total, low and high-density lipoprotein cholesterol, triglycerides, and creatinine.

For each participant, morbidity will be recorded at baseline and during follow-up by considering all the active conditions in the medical records at the time of the visit. We will define incident morbidity as the onset of any of the following 17 group conditions, provided they are not present at baseline: hypertension, ischemic heart disease (angina or acute myocardial infarction), heart failure, cardiac arrhythmias, diabetes mellitus, ischemic stroke, peripheral arterial disease, chronic obstructive pulmonary disease, asthma, any type of arthritis, osteoporosis, any type of cancer, Parkinson's disease, one or more affective disorders (depression, anxiety), one or more psychotic disorders (schizophrenia, psychosis, bipolar disorder), dementia (including Alzheimer's disease), and obesity. If we detect any frequent

TABLE 1 Validated questionnaires used in the study.

Optional self-administration in our study	Questionnaires	Number of items	Reference of validated version in Spanish
	Independent variables (Personal aptitudes)		
Yes	Sherer's general self-efficacy scale (GSES-12)	12	(74)
No	Patient Activation Measure (PAM)	13	(46)
Yes	10-item Connor-Davidson Scale	10	(75)
No	Health Literacy (HLS-EU-Q16)	16	(76)
No	10-Item Big Five Inventory (BFI-10)	10	(77)
	Covariables		
Yes	Functional social support (Duke-UNC-11)	11	(78)
Yes	WHO Disability Assessment Schedule (WHODAS 2.0)	12	(79)
Yes	List of Threatening Events (LTE)	12	(80)
Yes	Effort-Reward Imbalance questionnaire (DER/ERI)	16	(81)
	Dependent variables		
No	Adherence to the Mediterranean diet (Predimed and Predimed Plus)	23	(82, 83)
Yes	International Physical Activity Questionnaire (IPAQ)	4	(84)
Yes	Pittsburgh Sleep Quality Index (PSQI)	11	(85)
Yes	Quality of Life (EuroQol 5D–5 L)	5	(86)
No	Generalized anxiety disorder (GAD-7)	7	(87)
No	Depression Test Questionnaire (PHQ-9)	9	(88)
No	Depression Risk Calculator (PredictD)	2 + 12	(89)

condition at follow-up that has not already been included in these 17 proposed groups, we will add a new group category.

The evaluation of the participants' mental health will also include the following: a questionnaire on the generalized anxiety disorder (GAD-7) (87), which evaluates the presence of symptoms; examination of the diagnostic criteria for major depression, using the PHQ-9 (88); and estimation of the risk of depression (89), in participants with no diagnosis of a major depressive episode.

We will evaluate the several lifestyles: adherence to the Mediterranean diet, assessed with the PREDIMED (82) and PREDIMED plus (83) questionnaires; type of diet, determined by asking the participants if they follow any specific diet (e.g., vegetarian, vegan); level of physical activity, assessed with the International Physical Activity Questionnaire (84); smoking habit, measured with the 4-question scale adapted from the WHO MONICA study (90); alcohol consumption, considering the total units during the past week and a question on the monthly frequency of excessive consumption (binge drinking) over the past year; and sleep, evaluated using the Pittsburgh Sleep Quality Index (85), the overall number of sleeping hours, usual bedtime, and waking-up time.

The quality of life will be determined using the EUROQol 5D-5L health questionnaire (86), and a question on self-perceived well-being. Finally, the utilization of health services for the last 12 months previous to inclusion into the study will be extracted from electronic health records. Where the research team may have no access to electronic health records, the utilization of health services will be assessed with a survey answered by the participants. The items will enquire on the number of visits (to the emergency department, primary care, and other specialties), hospital admissions, diagnostic tests, and pharmacological treatment (medication, dose, total daily dose, and duration).

Additionally, we will consider the following groups of covariates: sociodemographic, social, functional capacity, and stress level.

We will register the following sociodemographic variables: date of birth, sex, sex orientation, and gender identity (SOGI questions), marital status, nationality, and employment status. We will also consider occupational social class, defined with the educational level and occupation. Participants will answer questions on employment conditions (six items), domestic and care work (six items), income level and economic situation (four items), and housing and material situation.

The two social variables included in this study are the social capital and the functional social support questionnaire. To assess the social capital, we will use the harmonized questionnaire proposed by Blaxter et al. (91) where five dimensions are identified: perspectives about the local area, civic engagement, social and support networks, social participation, and reciprocity and trust (91, 92). To assess the functional social support we will use the validated Spanish version of DUKE-UNC-11 (78). The questionnaire evaluates two sub-scales: confidential support (7 items) and affective support (4 items).

The functional capacity of participants will be evaluated using the WHO Disability Assessment Schedule (WHODAS 2.0) (79), a 12-item self-administered questionnaire.

The stress level will be assessed by taking into account stressful life events, using the List of Threatening Experiences questionnaire (80); and also occupational stress, determined in employed persons at the time of recruitment using the Effort-Reward Imbalance questionnaire (81). There will also be five questions regarding the impact of COVID-19.

2.5. Data collection process

Once the project has been approved by the pertinent ethics committees, informative meetings will be held at the PHC centers to explain the project to health professionals so they can address any questions that may arise. Subsequently, assigned personnel (may vary according to the AACC) will be asked to prepare a list with the people ascribed to the PHC center who meet the inclusion criteria of the study and make a random selection of the necessary sample, oversampling by 30%, in order to be able to substitute participants that should be excluded. In some PHC centers, professionals will directly call possible participants to invite them to be included in the study. In other centers, permission will be requested from the professionals so that a person linked to the study makes the calls on their behalf in a centralized manner.

Participants recruitment: a letter will be sent by mail to the candidates with the study information sheet and 10 self-administered questionnaires: (1) the self-efficacy scale; (2) the resilience scale; (3) level of physical activity; (4) quality of life; (5) the sleep quality index; (6) a disability assessment; (7) occupational stress; (8) stressful life events; (9) the functional social support questionnaire; and (10) the SOGI questions. This letter will be sent to participants before or after the phone contact, as decided by each AACC. The person in charge of calling the participants will invite them to participate in the study and schedule a day and time to attend their PHC centers. If they accept, they will be asked to fill out the self-administered questionnaires and deliver them to a nurse at the PHC.

During the face-to-face visit, the person will be invited to sign the informed consent and clarify doubts, if any, about the information sheet and the study in general. In a confidential sheet, separate from the rest of the variables, the name, surnames, postal address, and contact telephone numbers will be recorded. A case identification number will be given. Study data will be collected and managed using REDCap (93, 94) electronic data capture tools hosted at *Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina* (IDIAPJGol).

During the visit, participants will be invited to answer the questionnaires and the physical examination will be performed. The information collected in the self-administered questionnaires will be reviewed; if someone has not been able to fill them out, they will do it during the visit. On this first visit, a fasting blood sample extraction will be scheduled to determine (on a second visit) the parameters explained before. Finally, a letter with the examination results will be sent to each participant to allow consultation with the professionals from their health center if any abnormalities were detected. Figure 2 shows the data collection process with the actions that will affect the participants included in the study.

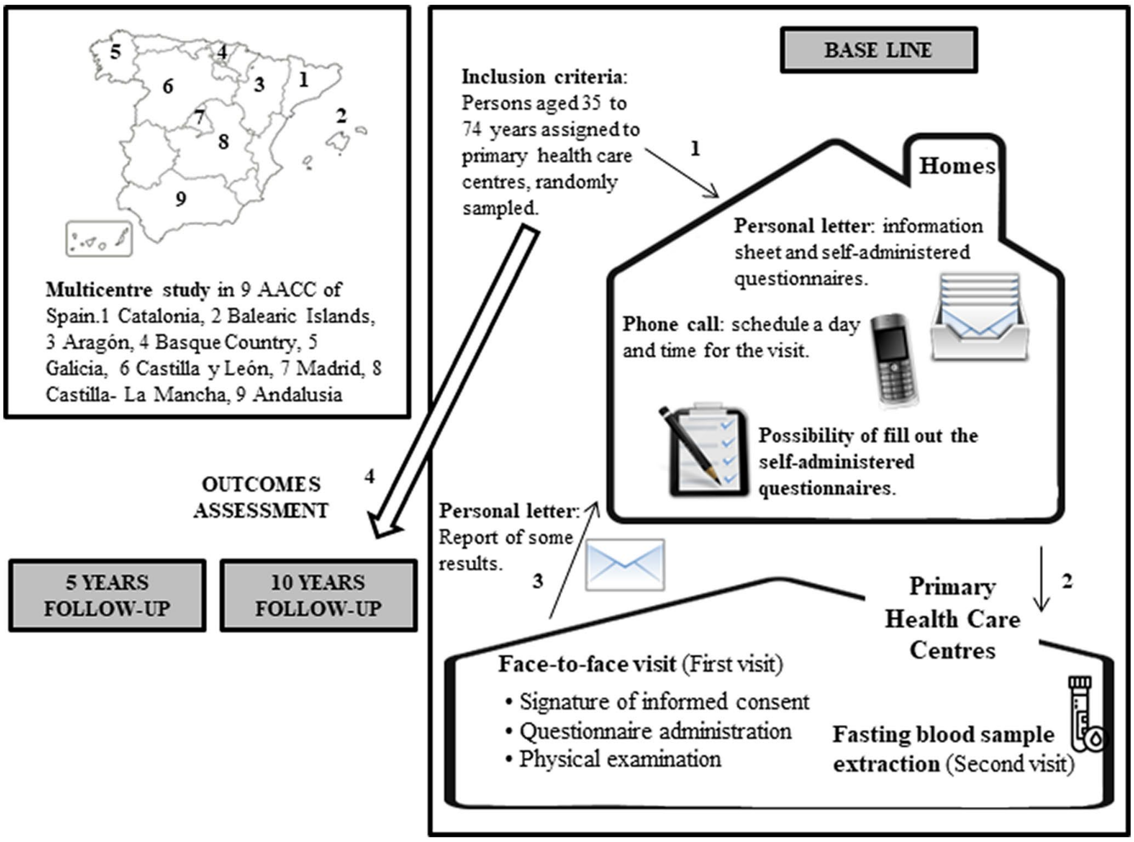

FIGURE 2
Data collection process with the actions that will affect the participants included in the study.

2.6. Statistical analysis

The statistical analysis will include a descriptive analysis. Percentages of the categorical variables will be calculated for each AACC. Continuous variables with a normal distribution will be described with the mean (standard deviation, SD); otherwise, the median (first and third quartile) will be used. The analyses will be stratified by sex. Bivariate analyses will be performed using the *t*-test for independent samples, or the Mann–Whitney test when required, to analyze continuous variables; and the Chi-squared test for proportions.

Objective one will analyze the incidence of morbidity, defined as the onset of any new condition out of the 17 considered. To this end, a Cox model will be built for each independent variable, and adjusted for the above-mentioned covariates. Potential heterogeneity between AACC will be estimated by introducing random effects in the model. Sensitivity analyses will examine loss to follow-up rates. Objective two will analyze the incidence of the rest of the dependent variables (except incidence of morbidity) using also Cox models, one for each of the six independent variables, adjusted for the covariates. We will calculate the incidence of all-cause mortality and its Kaplan–Meier, stratified by the categorical variables and AACC. Potential heterogeneity will be estimated, and sensitivity analyses performed as in objective one.

Before obtaining the follow-up information at 5 and 10 years, we will describe and analyze the gathered data at baseline. To this end, general linear multilevel models will be used to examine the association of the dependent variables (lifestyles, quality of life, and use of services), with the six independent variables, adjusted for the registered covariates (age, sex, occupational social class, social capital, functional capacity, and stress level). Potential disparities between AACC will be captured by including random effects in the models.

Statistical significance will be considered at p-values < 0.05. The analyses will be carried out using the Statistical Package for the Social Sciences (SPSS) version 26.0, and the R-software.

3. Discussion

Highly prevalent serious conditions should be one of the targets of research efforts. This is the case of chronic diseases, the leading cause of death in our population, and a major cause of disease burden, number of life-years lost, and resource consumption in our society. Chronic diseases and their consequences will be aggravated by an ongoing demographic trend that is predicted to linger on: the progressive ageing of the population (95, 96).

Health promotion and the strategies for disease prevention are particularly effective in the context of chronic diseases, because many of their associated risk factors could certainly be modified and prevented. This project aims to contribute to a framework on which efficient and safe interventions on health promotion and prevention could be developed, and the number of persons suffering these diseases in the future could be reduced. We need to promote and encourage the autonomy of people to carry out their activities, a constant care and improvement of their physical and psychological abilities, a delayed onset of early dependence, and the maintenance of their social environment. This would lead to a reduction in the burden of disease on society, a huge improvement in people's quality of life, and also a reduction of the enormous cost on overloaded health systems.

The evidence generated in this study will add new knowledge to previous attempts at establishing comprehensive theoretical frameworks that explain people's health behaviors, such as TDF (17) or the capability, opportunity, and motivation (COM-B) model (97, 98). The Primary Care context is the ideal environment to start this research due to the almost total similarity with the characteristics of the reference population. Moreover, it is where many of the indicators that we intend to analyze are developed and undertaken. Additional to the identification of the subjects, collection of all the baseline information and initial cross-sectional analysis, the longitudinal follow-up will explore the influence of these factors as predictors of lifestyles and the impact on multimorbidity, as reported in several systematic reviews (99, 100).

The conduct of this project will lay the basis for pioneering new methods in clinical practice, particularly for tailoring interventions according to the individual characteristics of each person, aiming to improve their acceptance and efficiency. Indeed, the project is directed towards extending personalized medicine, caring for and treating the person as a whole, and not only the disease. At the same time, it offers an opportunity to optimize the resources and sets a sustainable strategy that can be transferred into clinical practice through recommendations.

3.1. Study limitations

One of the chief difficulties in this study could be a low participation rate. A strategy to achieve adequate participation rates is to invite via phone call on behalf of the physician or nurse from their health center. Another approach would be to send an informative mail previous to the phone call so that when researchers contact potential participants, they already know the objective of the call and are more willing to listen to the invitation. In this project, we will follow both strategies. We have previous experience in carrying out cohort studies, with successful participation rates. Some of the measurements and administration of the questionnaires of this study require previous training, to ensure precise, comparable, and high-quality results. This challenge will be minimized by training the professionals that will perform them and controlling the quality of the periodically collected data. The measure of LOC in this study will be a single non-validated question. Finally, the survey will ask a considerable amount of questions, and thus the visits are at risk of being too long and tedious. To avoid this, some of the self-administered questionnaires will be attached to the above-mentioned informative mail. At home, participants will have plenty of time to answer them, before the visit. In previous studies, 60% of participants came to the visit with the questionnaires already answered, and this percentage could be higher if a reminder is given at the recruitment call.

4. Conclusion

Health promotion is a priority within the public health policy of developed and developing countries. Current knowledge describes the association of genetic, socioeconomic, cultural, and environmental determinants with lifestyles, risk factors, and diseases. However, little is known about the real effect of personal determinants on individual behaviors; these aptitudes may be connected with our personal capacity to adopt healthy lifestyles and respond suitably in the face of adverse situations. This project will fulfill the need for cohort studies on behavioral changes, maintenance of healthy behaviors, reduction of harmful habits, improvement in the self-management of chronic conditions, and increase in the quality of life related to health determinants. The collaborators in charge of this study present a holistic approach to examine health determinants with a special focus on individual behaviors. Description of these individual factors, their relation with social factors, lifestyles, and chronic diseases will be highly interesting and useful to the society and the national health system. This knowledge will allow the evaluation of their role as prognostic factors and the interaction with the rest of determinants to tailor interventions, and the design of interventions directly aimed at improving these individual capacities.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving human participants were reviewed and approved by Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina (reference number 19/150-P); Comité de Ética de la Investigación con medicamentos del Área de Salud de Salamanca (reference number PI 2020 02424); Andalusian Ministry of Health, Spain (reference number: 1260-M1-21); Comité de Ética de la Investigación de medicamentos de Euskadi (CEIm-E; reference number: PI2020185); Hospital Virgen de la Luz Clinical Reasearch Ethics Comiitte, Cuenca, Spain (Reference number 2019/PI2119). Research Central Commission of the Primary Care Assistance Management, Madrid, Spain. (Reference Number 07/21); Comité de Ética de la Investigación de la Comunidad Autónoma de Aragón (reference number: PI20/302); Galician Ministry of health, Spain: high impact study authorization (Reference number: 2021/047). The patients/participants provided their written informed consent to participate in this study.

DESVELA Cohort Investigators

Andalucía. Universidad Loyola Andalucía: Emma Motrico, Irene Gómez-Gómez. Instituto de Investigación Biomédica de Málaga: Patricia Moreno-Peral, Sonia Conejo-Cerón, Juan Ángel Bellón. ***Aragón***. Fundación Instituto de Investigación Sanitaria Aragón: Rosa Magallon-Botaya, Fátima Méndez-López, Alejandra Aguilar-Latorre, Maria Beltrán-Ruiz, Bárbara Oliván-Blázquez, Marta Dominguez-García, Maria Isabel Rabanaque Hernandez, Eva María Andrés Esteban. ***Castilla-La Mancha***. Centro de estudios sociosanitarios: Blanca Notario Pacheco, Montserrat Solera Martínez, Lidia Lucas-de la Cruz, Miriam Garrido Miguel, María Martínez Andrés, María Eugenia Visier Alfonso, Irene Marcilla Toribio. ***Castilla y León***. Unidad de Investigación de Atención Primaria de Salamanca. José A Maderuelo-Fernández, Leticia Sierra-Martínez, Olaya Tamayo-Morales, Miriam Daniela García-Cubillas, Ana B Castro-Rivero, María D Martín-Santos, Carmen Castaño-Sánchez, Luis García-Ortiz. ***Catalunya***. Fundació Institut Universitari per a la recerca a l'Atenció Primària de Salut Jordi Gol i Gurina: Bonaventura Bolíbar, Ruth Martí-Lluch, Rafel Ramos, Marc Casajuana-Closas, Anna Berenguera, Constanza Jacques-Aviñó, Yudy Young-Silva, Lia Alves-Cabratosa, Lluís Zacarías-Pons, Anna Ponjoan, Eva Espigulé-Ribas, Francesc Ribas-Aulinas, Jordi Blanch, Èric Tornabell-Noguera, Anna Moleras-Serra. Parc Sanitari Sant Joan de Déu: Enric Vicens-Pons, Montserrat Gil-Girbau, Mari Carmen Olmos Palenzuela, María del Carmen Gallardo González, Mª Teresa Peñarrubia-María, Paula Arroyo-Uriarte. ***Comunidad de Madrid***. Centro de Salud Infanta Mercedes, Servicio Madrileño de Salud. Francisco Camarelles Guillem. ***Euskadi***. Instituto para la Investigación Sanitaria Biocruces Bizkaia. Jose María Aiarzaguena, Álvaro Sánchez Pérez, Sandra Garcia-Martinez, Usue Elizondo Alzola, Mónica Miranda de la Maza, Ainhoa Abrisketa Ullibarri, Mikel Rueda-Etxebarria. ***Galicia***. Instituto de de investigación Galicia Sur: Mª José Fernández Domínguez, Sabela Couso Viana, Roberto Fernández Alvarez, Ana Claveria Fontan, Ana Isabel Castaño Carou, Clara González Formoso, María Victoria Martín Miguel, Clara Guede Fernández, Macarena Chacón Docampo. ***Illes Balears***. Gerencia de atención primaria de Mallorca, Instituto de investigación sanitaria de las Islas Baleares: Joan Llobera Cànaves, Caterina Vicens, Maria J. Serrano-Ripoll, Laura Gallardo-Alfaro, Oana Bulilete, Christian Jean-Mairet Soler, David Medina-Bombardó, T Coll Benejam.

Author contributions

RR and RM-L conceived the quantitative part of the study. RM-L and LA-C led the drafting of this manuscript. RM-L, JL, JM-F, RM-B, ÁS-P, MD, EM, EV-P, and BN-P obtained ethical approval from each institution. RM-L, RR, BB, JL, JM-F, RM-B, ÁS-P, MD, EM, EV-P, and BN-P advised and contributed to the study design. RM-L contributed to design the training program on the questionnaires and measurements. RR, RM-L, and JM-F developed the statistical analysis plan. RM-L, RR, and EV-P designed the economic components of the study and developed the economic analysis. All authors have revised the draft substantively, given approval of the submitted version (and any substantially modified version involving their contribution to the study), and agreed to be accountable for their own contributions and to ensure that all aspects of the study, including those in which they were not personally involved, are appropriately addressed.

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Conflict of Interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

1. Instituto Nacional de Estadística. Proyecciones de Población 2020-2070. (2020).

2. Mounce LTA, Campbell JL, Henley WE, Tejerina Arreal MC, Porter I, Valderas JM (2018). Predicting incident multimorbidity. *Ann Fam Med* 16:322–9. doi: 10.1370/afm.2271

3. World Health Organization. *Noncommunicable diseases Country profiles 2018*. Geneva: WHO (2018).

4. World Health Organization. *Global Status Report On Noncommunicable Diseases 2014*. Geneva: WHO (2014).

5. Kessler RC, Aguilar-Gaxiola S, Alonso J, Chatterji S, Lee S, Ormel J, et al (2009). The global burden of mental disorders: an update from the WHO World Mental Health (WMH) surveys. *Epidemiol Psichiatr Soc Il Pensiero Scientifico Editore srl* 18:23–33. doi: 10.1017/s1121189x00001421

6. O'Neil A, Jacka FN, Quirk SE, Cocker F, Taylor CB, Oldenburg B, et al (2015). A shared framework for the common mental disorders and Non-Communicable Disease: Key considerations for disease prevention and control. *BMC Psychiatry BioMed Central Ltd* 5:15. doi: 10.1186/s12888-015-0394-0

7. World Health Organisation. *Constitution of the World Health Organization*. Geneva: WHO (1948).

8. World Health Organization. *Ottawa Charter for Health Promotion*. Geneva: WHO (1986).

9. Bigorda J. (1986) *Jordi Gol i Gurina (1924-1985). Els grans temes d'un pensament i d'una vida*. Barcelona: La Llar del Llibre.

10. World Health Organisation. *The Jakarta Declaration on Leading Health Promotion into the 21st Century*. Geneva: WHO (1997).

11. Rosenzveig A, Kuspinar A, Daskalopoulou SS, Mayo NE. (2014) *Toward Patient-centered Care: A Systematic Review of How To Ask Questions That Matter to Patients. (Baltimore)* 93:e120. doi: 10.1097/MD.0000000000000120

12. Spanish Ministry of Health (2013). The Prevention and Health Promotion Strategy of the Spanish NHS. *Executive Summary*

13. Lalonde M. (1974). *A new perspective on the health of Canadians. Ottawa, ON: Minister of Supply and Services Canada. Retrieved from Public Health Agency of Canada website*. Available at: http://www.phac-aspc.gc.ca/ph-sp/pdf/perspect-eng.pdf

14. Dahlgren G, Whitehead M. *Policies and strategies to promote social equity in health. Background document to WHO – Strategy paper for Europe*. Stockholm: Institute for Futures Studies (1991). 69 p.

15. Antonovsky A (1996). The salutogenic model as a theory to guide health promotion 1. *Health Promot Int* 11:11–8. doi: 10.1093/heapro/11.1.11

16. Marmot MG. *The Status Syndrome: How Social Standing Affects Our Health and Longevity*. New York: Henry Holt; (2004), 150–154.

17. Atkins L, Francis J, Islam R, O'Connor D, Patey A, Ivers N, et al (2017). A guide to using the Theoretical Domains Framework of behaviour change to investigate implementation problems. *Implement Sci* 12:77. doi: 10.1186/s13012-017-0605-9

18. Rammstedt B, John OP (2007). Measuring personality in one minute or less: a 10-item short version of the Big Five Inventory in English and German. *J Res Pers* 41:203–12. doi: 10.1016/j.jrp.2006.02.001

19. Goodwin RD, Friedman HS (2006). Health status and the five-factor personality traits in a nationally representative sample. *J Health Psychol* 11:643–54. doi: 10.1177/1359105306066610

20. Chapman BP, Fiscella K, Kawachi I, Duberstein PR (2010). Personality, socioeconomic status, and all-cause mortality in the United States. *Am J Epidemiol Am J Epidemiol* 171:83–92. doi: 10.1093/aje/kwp323

21. Jokela M, Pulkki-Råback L, Elovainio M, Kivimäki M (2014). Personality traits as risk factors for stroke and coronary heart disease mortality: pooled analysis of three cohort studies. *J Behav Med* 37:881–9. doi: 10.1007/s10865-013-9548-z

22. Jokela M, Batty GD, Nyberg ST, Virtanen M, Nabi H, Singh-Manoux A, et al (2013). Personality and all-cause mortality: individual-participant meta-analysis of 3,947 deaths in 76,150 adults. *Am J Epidemiol* 178:667–75. doi: 10.1093/aje/kwt170

23. Hengartner MP, Kawohl W, Haker H, Rössler W, Ajdacic-Gross V (2016). Big Five personality traits may inform public health policy and preventive medicine: Evidence from a cross-sectional and a prospective longitudinal epidemiologic study in a Swiss community. *J Psychosom Res* 84:44–51. doi: 10.1016/j.jpsychores.2016.03.012

24. Rotter JB (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychol Monogr* 80:1–28. doi: 10.1037/h0092976

25. Berglund E, Lytsy P, Westerling R (2014). The influence of locus of control on self-rated health in context of chronic disease: a structural equation modeling approach in a cross sectional study. *BMC Public Health* 14:492. doi: 10.1186/1471-2458-14-492

26. Stürmer T, Hasselbach P, Amelang M (2006). Personality, lifestyle, and risk of cardiovascular disease and cancer: follow-up of population based cohort. *BMJ* 332:1359. doi: 10.1136/bmj.38833.479560.80

27. Moreno-Peral P, Conejo-Cerón S, Fernández A, Berenguera A, Martínez-Andrés M, Pons-Vigués M, et al (2015). Primary care patients' perspectives of barriers and enablers of primary prevention and health promotion-a meta-ethnographic synthesis. *PLoS One* 10:e0125004. doi: 10.1371/journal.pone.0125004

28. Wilski M, Chmielewski B, Tomczak M (2015). Work locus of control and burnout in Polish physiotherapists: The mediating effect of coping styles. *Int J Occup Med Environ Health* 28:875–89. doi: 10.13075/ijomeh.1896.00287

29. Poortinga W, Dunstan FD, Fone DL (2008). Health locus of control beliefs and socio-economic differences in self-rated health. *Prev Med (Baltim)* 46:374–80. doi: 10.1016/j.ypmed.2007.11.015

30. Mautner D, Peterson B, Cunningham A, Ku B, Scott K, Lanoue M (2017). How Multidimensional Health Locus of Control predicts utilization of emergency and inpatient hospital services. *J Health Psychol* 22:314–23. doi: 10.1177/1359105315603468

31. Henninger DE, Whitson HE, Cohen HJ, Ariely D (2012). Higher medical morbidity burden is associated with external locus of control. *J Am Geriatr Soc* 60:751–5. doi: 10.1111/j.1532-5415.2012.03904.x

32. Keedy NH, Keffala VJ, Altmaier EM, Chen JJ (2014). Health locus of control and self-efficacy predict back pain rehabilitation outcomes. *Iowa Orthop J* 34:158–65.

33. Sherer M, Maddux JE, Mercandante B, Prentice-Dunn S, Jacobs B, Rogers RW (1982). The Self-Efficacy Scale: Construction and Validation. *Psychol Rep* 51:663–71. doi: 10.2466/pr0.1982.51.2.663

34. Groffen DAI, Bosma H, Tan FES, Van Den Akker M, Kempen GIJM, Van Eijk JTM (2012). Material vs. psychosocial explanations of old-age educational differences in physical and mental functioning. *Eur J Pub Health* 22:587–92. doi: 10.1093/eurpub/ckr063

35. Windsor TD, Anstey KJ (2008). A longitudinal investigation of perceived control and cognitive performance in young, midlife and older adults. *Neuropsychol Dev Cogn B Aging Neuropsychol Cogn* 15:744–63. doi: 10.1080/13825580802348570

36. Zahodne LB, Nowinski CJ, Gershon RC, Manly JJ (2014). Which psychosocial factors best predict cognitive performance in older adults? *J Int Neuropsychol Soc* 20:487–95. doi: 10.1017/s1355617714000186

37. Bardach SH, Schoenberg NE, Howell BM (2016). What Motivates Older Adults to Improve Diet and Exercise Patterns? *J Community Health* 41:22–9. doi: 10.1007/s10900-015-0058-5

38. Olsson I, Dahl AA (2012). Avoidant personality problems—their association with somatic and mental health, lifestyle, and social network. A community-based study. *Compr Psychiatry*. Elsevier Inc. 53:813–21. doi: 10.1016/j.comppsych.2011.10.007

39. Dolores Serrano-Parra M, Garrido-Abejar M, Notario-Pacheco B, Bartolomé-Gutiérrez R, Solera-Martínez M, Martínez-Vizcaíno V (2013). Validity of the Connor-Davidson resilience scale (10 items) in a population of elderly. *Enferm Clin* 23:14–21. doi: 10.1016/j.enfcli.2012.11.006

40. Norris FH, Stevens SP, Pfefferbaum B, Wyche KF, Pfefferbaum RL (2008). Community resilience as a metaphor, theory, set of capacities, and strategy for disaster readiness. *Am J Community Psychol* 41:127–50. doi: 10.1007/s10464-007-9156-6

41. Davydov DM, Stewart R, Ritchie K, Chaudieu I (2010). Resilience and mental health. *Clin Psychol Rev* 30:479–95. doi: 10.1016/j.cpr.2010.03.003

42. Lang FR, Heckhausen J (2001). Perceived control over development and subjective well-being: differential benefits across adulthood. *J Pers Soc Psychol* 81:509–23. doi: 10.1037//0022-3514.81.3.509

43. Hibbard JH, Stockard J, Mahoney ER, Tusler M (2004). Development of the patient activation measure (PAM): conceptualizing and measuring activation in patients and consumers. *Health Serv Res* 39:1005–26. doi: 10.1111/j.1475-6773.2004.00269.x

44. Vernooij RWM, Willson M, Gagliardi AR, Armstrong M, Brouwers M, Bussières A, et al (2016). Characterizing patient-oriented tools that could be packaged with guidelines to promote self-management and guideline adoption: A meta-review. *Implement Sci* 11:52. doi: 10.1186/s13012-016-0419-1

45. Blakemore A, Hann M, Howells K, Panagioti M, Sidaway M, Reeves D, et al (2016). Patient activation in older people with long-term conditions and multimorbidity: correlates and change in a cohort study in the United Kingdom. *BMC Health Serv Res* 16:582. doi: 10.1186/s12913-016-1843-2

46. Moreno-Chico C, González-de Paz L, Monforte-Royo C, Arrighi E, Navarro-Rubio MD, Gallart F-PA (2017). Adaptation to European Spanish and psychometric properties of the Patient Activation Measure 13 in patients with chronic diseases. *Fam Pract* 34:627–34. doi: 10.1093/fampra/cmx022

47. Sørensen K, Pelikan JM, Röthlin F, Ganahl K, Slonska Z, Doyle G, et al (2015). Health literacy in Europe: Comparative results of the European health literacy survey (HLS-EU). *Eur J Public Health Oxford University Press* 25:1053–8. doi: 10.1093/eurpub/ckv043

48. Dewalt DA, Berkman ND, Sheridan S, Lohr KN, Pignone MP (2004). Literacy and health outcomes: a systematic review of the literature. *J Gen Intern Med* 19:1228–39. doi: 10.1111/j.1525-1497.2004.40153.x

49. Berkman ND, Dewalt DA, Pignone MP, Sheridan SL, Lohr KN, Lux L, et al (2004). Literacy and health outcomes. *Evid Rep Technol Assess (Summ)* 87:1–8.

50. Dennis S, Williams A, Taggart J, Newall A, Denney-Wilson E, Zwar N, et al (2012). Which providers can bridge the health literacy gap in lifestyle risk factor modification education: a systematic review and narrative synthesis. *BMC Fam Pract* 13:44. doi: 10.1186/1471-2296-13-44

51. Marmot M, Allen J, Bell R, Bloomer E, Goldblatt P (2012). Consortium for the European Review of Social Determinants of Health and the Health Divide. WHO European review of social determinants of health and the health divide. *Lancet (London, England)* 380:1011–29. doi: 10.1016/s0140-6736(12)61228-8

52. Stringhini S, Carmeli C, Jokela M, Avendaño M, Muennig P, Guida F, et al (2017). Socioeconomic status and the 25×25 risk factors as determinants of premature mortality: a multicohort study and meta-analysis of 1·7 million men and women. *Lancet (London, England)* 389:1229–37. doi: 10.1016/s0140-6736(16)32380-7

53. Reblin M, Uchino BN (2008). Social and emotional support and its implication for health. *Curr Opin Psychiatry* 21:201–5. doi: 10.1097/yco.0b013e3282f3ad89

54. Moore S, Kawachi I (2017). Twenty years of social capital and health research: A glossary. *J Epidemiol Community Health* 71:513–7. doi: 10.1136/jech-2016-208313

55. Villalonga-Olives E, Kawachi I (2017). The dark side of social capital: A systematic review of the negative health effects of social capital. *Soc Sci Med Elsevier* 194:105–27. doi: 10.1016/j.socscimed.2017.10.020

56. Poortinga W (2006). Social relations or social capital? Individual and community health effects of bonding social capital. *Soc Sci Med* 63:255–70. doi: 10.1016/j.socscimed.2005.11.039

57. Kim D, Subramanian SV, Kawachi I (2006). Bonding versus bridging social capital and their associations with self rated health: a multilevel analysis of 40 US communities. *J Epidemiol Community Health* 60:116–22. doi: 10.1136/jech.2005.038281

58. House JS, Landis KR, Umberson D (1988). Social relationships and health. *Science Science* 241:540–5. doi: 10.1126/science.3399889

59. Holt-Lunstad J, Smith TB, Layton JB (2010). Social relationships and mortality risk: a meta-analytic review. *PLoS Med* 7:e1000316. doi: 10.1371/journal.pmed.1000316

60. Ehsan AM, De Silva MJ (2015). Social capital and common mental disorder: A systematic review. *J Epidemiol Community Health* 69:1021–8. doi: 10.1136/jech-2015-205868

61. Siegrist J, Starke D, Chandola T, Godin I, Marmot M, Niedhammer I, et al (2004). The measurement of effort-reward imbalance at work: European comparisons. *Soc Sci Med* 58:1483–99. doi: 10.1016/s0277-9536(03)00351-4

62. Rugulies R, Aust B, Madsen IEH, Burr H, Siegrist J, Bültmann U (2013). Adverse psychosocial working conditions and risk of severe depressive symptoms. Do effects differ by occupational grade? *Eur J Pub Health* 23:415–20. doi: 10.1093/eurpub/cks071

63. Rugulies R, Aust B, Madsen IEH (2017). Effort-reward imbalance at work and risk of depressive disorders. A systematic review and meta-analysis of prospective cohort studies. *Scand J Work Environ Health* 43:294–306. doi: 10.5271/sjweh.3632

64. Fahlén G, Knutsson A, Peter R, Akerstedt T, Nordin M, Alfredsson L, et al (2006). Effort-reward imbalance, sleep disturbances and fatigue. *Int Arch Occup Environ Health* 79:371–8. doi: 10.1007/s00420-005-0063-6

65. Dragano N, Siegrist J, Nyberg ST, Lunau T, Fransson EI, Alfredsson L, et al (2017). Effort-reward imbalance at work and incident coronary heart disease: a multicohort study of 90,164 individuals. *Epidemiology* 28:619–26. doi: 10.1097/ede.0000000000000666

66. Burgel BJ, White MC, Gillen M, Krause N (2010). Psychosocial work factors and shoulder pain in hotel room cleaners. *Am J Ind Med* 53:n/a–56. doi: 10.1002/ajim.20832

67. Siegrist J, Li J (2017). Work stress and altered biomarkers: a synthesis of findings based on the effort-reward imbalance model. *Int J Environ Res Public Health* 14:1373. doi: 10.3390/ijerph14111373

68. Baker DW, Parker RM, Williams MV, Clark WS (1998). Health literacy and the risk of hospital admission. *J Gen Intern Med* 13:791–8. doi: 10.1046/j.1525-1497.1998.00242.x

69. Schillinger D, Grumbach K, Piette J, Wang F, Osmond D, Daher C, et al (2002). Association of health literacy with diabetes outcomes. *JAMA* 288:475–82. doi: 10.1001/jama.288.4.475

70. Wolf MS, Gazmararian JA, Baker DW (2005). Health literacy and functional health status among older adults. *Arch Intern Med* 165:1946–52. doi: 10.1001/archinte.165.17.1946

71. Berkman ND, Sheridan SL, Donahue KE, Halpern DJ, Crotty K (2011). Low health literacy and health outcomes: an updated systematic review. *Ann Intern Med* 155:97–107. doi: 10.7326/0003-4819-155-2-201107190-00005

72. Baker DW, Wolf MS, Feinglass J, Thompson JA, Gazmararian JA, Huang J (2007). Health literacy and mortality among elderly persons. *Arch Intern Med* 167:1503–9. doi: 10.1001/archinte.167.14.1503

73. Moser DK, Robinson S, Biddle MJ, Pelter MM, Nesbitt TS, Southard J, et al (2015). Health Literacy Predicts Morbidity and Mortality in Rural Patients With Heart Failure. *J Card Fail* 21:612–8. doi: 10.1016/j.cardfail.2015.04.004

74. Herrero R, Espinoza M, Molinari G, Etchemendy E, Garcia-Palacios A, Botella C, et al. *Psychometric properties of the General Self Efficacy-12 Scale in Spanish: General and clinical population samples*. Compr Psychiatry. Elsevier Inc.; 2014;*55*: 1738–1743. doi: 10.1016/j.comppsych.2014.05.015

75. Notario-Pacheco B, Solera-Martínez M, Serrano-Parra MD, Bartolomé-Gutiérrez R, García-Campayo J, Martínez-Vizcaíno V (2011). Reliability and validity of the Spanish version of the 10-item Connor-Davidson Resilience Scale (10-item CD-RISC) in young adults. *Health Qual Life Outcomes BioMed Central Ltd* 9:63. doi: 10.1186/1477-7525-9-63

76. Nolasco A, Barona C, Tamayo-Fonseca N, Irles MÁ, Más R, Tuells J, et al (2020). Health literacy: psychometric behaviour of the HLS-EU-Q16 questionnaire. *Gac Sanit* 34:399–402. doi: 10.1016/j.gaceta.2018.08.006

77. Benet-Martínez V, John OP (1998). Los Cinco Grandes across cultures and ethnic groups: Multitrait-multimethod analyses of the Big Five in Spanish and English. *J Pers Soc Psychol* 75:729–50. doi: 10.1037/0022-3514.75.3.729

78. Bellón-Saameño J, Delgado S, Luna del Castillo JD, Lardelli CP (1996). Validez y fiabilidad del cuestionario de apoyo social funcional Duke-UNC-11. *Aten Primaria* 42:181–63. doi: 10.4040/jkan.2012.42.2.181

79. WHO. Disability Assessment Schedule (WHODAS 2.0).

80. Motrico E, Moreno-Küstner B, de Dios Luna J, Torres-González F, King M, Nazareth I, et al (2013). Psychometric properties of the List of Threatening Experiences-LTE and its association with psychosocial factors and mental disorders according to different scoring methods. *J Affec Disord* 150:931–40. doi: 10.1016/j.jad.2013.05.017

81. Macías-Robles MD, Fernández-López JA, Hernández-Mejía R, Cueto-Espinar A, Rancaño I, Siegrist J (2003). Evaluación del estrés laboral en trabajadores de un hospital público español. Estudio de las propiedades psicométricas de la versión española del modelo «Desequilibrio Esfuerzo-Recompensa». *Med Clín* 120:652–7. doi: 10.1016/S0025-7753(03)73799-3

82. Martínez-González MA, García-Arellano A, Toledo E, Salas-Salvadó J, Buil-Cosiales P, Corella D, et al (2012). A 14-item mediterranean diet assessment tool and obesity indexes among high-risk subjects: The PREDIMED trial. *PLoS One Public Library Sci* 7:e43134. doi: 10.1371/journal.pone.0043134

83. Martínez-González MA, Corella D, Salas-salvadó J, Ros E, Covas MI, Fiol M, et al (2019). Cohort profile: design and methods of the PREDIMED study. *Int J Epidemiol* 48:387–388o. doi: 10.1093/ije/dyy225

84. Cancela JM, Ayán C, Vila H, Gutierrez JM, Gutierrez-Santiago A (2019). Validez de constructo del cuestionario internacional de actividad física en universitarios españoles. *Rev Iberoam Diagnóstico Evaluación-E Avaliação Psicológica* 52:5–14. doi: 10.21865/RIDEP52.3.01

85. Hita-Contreras F, Martínez-López E, Latorre-Román PA, Garrido F, Santos MA, Martínez-Amat A (2014). Reliability and validity of the Spanish version of the Pittsburgh Sleep Quality Index (PSQI) in patients with fibromyalgia. *Rheumatol Int* 34:929–36. doi: 10.1007/s00296-014-2960-z

86. Herdman M, Badia X, Berra S (2001). EuroQol-5D: a simple alternative for measuring health-related quality of life in primary care. *Aten Primaria* 28:425–9. doi: 10.1016/S0212-6567(01)70406-4

87. García-Campayo J, Zamorano E, Ruiz MA, Pardo A, Pérez-Páramo M, López-Gómez V, et al (2010). Cultural adaptation into Spanish of the generalized anxiety disorder-7 (GAD-7) scale as a screening tool. *Health Qual Life Outcomes* 8:8. doi: 10.1186/1477-7525-8-8

88. Muñoz-Navarro R, Cano-Vindel A, Medrano LA, Schmitz F, Ruiz-Rodríguez P, Abellán-Maeso C, et al (2017). Utility of the PHQ-9 to identify major depressive disorder in adult patients in Spanish primary care centres. *BMC Psychiatry* 17:291–9. doi: 10.1186/s12888-017-1450-8

89. Bellón JÁ, Moreno-Küstner B, Torres-González F, Montón-Franco C, Gildegómez-Barragán MJ, Sánchez-Celaya , et al (2008). Predicting the onset and persistence of episodes of depression in primary health care. The predictD-Spain study: Methodology. *BMC Public Health* 8:256. doi: 10.1186/1471-2458-8-256

90. Molarius A, Parsons RW, Dobson AJ, Evans A, Fortmann SP, Jamrozik K, et al (2001). Trends in cigarette smoking in 36 populations from the early 1980s to the mid-1990s: findings from the WHO MONICA Project. *Am J Public Health* 91:206–12. doi: 10.2105/ajph.91.2.206

91. Social capital for health. Insights from qualitative research (2002). Edited by Catherine Swann, Antony Morgan. Health Development Agency.

92. Harper R. The measurement of Social Capital in the United Kingdom. (2002).

93. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG (2009). Research electronic data capture (REDCap)-A metadata-driven methodology and workflow process for providing translational research informatics support. *J Biomed Inform* 42:377–81. doi: 10.1016/j.jbi.2008.08.010

94. Harris PA, Taylor R, Minor BL, Elliott V, Fernandez M, O'Neal L, et al (2019). The REDCap consortium: Building an international community of software platform partners. *J Biomed Inform* 95:103208. doi: 10.1016/j.jbi.2019.103208

95. World Health Organization. Regional Office for Europe (2013). The European health report 2012: charting the way to well-being. World Health Organization. Regional Office for Europe. Available at: https://apps.who.int/iris/handle/10665/326381

96. Dégano IR, Elosua R, Marrugat J (2013). Epidemiology of acute coronary syndromes in Spain: estimation of the number of cases and trends from 2005 to 2049. *Rev Esp Cardiol (Engl Ed) Rev Esp Cardiol (Engl Ed)* 66:472–81. doi: 10.1016/j.rec.2013.01.018

97. Michie S, van Stralen MM, West R (2011). The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci BioMed Central* 6:42. doi: 10.1186/1748-5908-6-42

98. Jabbour M, Newton AS, Johnson D, Curran JA (2018). Defining barriers and enablers for clinical pathway implementation in complex clinical settings. *Implement Sci. BioMed Central* 13:139. doi: 10.1186/s13012-018-0832-8

99. Violan C, Foguet-Boreu Q, Flores-Mateo G, Salisbury C, Blom J, Freitag M, et al (2014). Prevalence, determinants and patterns of multimorbidity in primary care: A systematic review of observational studies. *PLoS One* 9:3–11. doi: 10.1371/journal.pone.0102149

100. Le Reste J, Nabbe P, Lingner H, Kasuba Lazic D, Assenova R, Munoz M, et al (2015). What research agenda could be generated from the European General Practice Research Network concept of Multimorbidity in Family Practice? *BMC Fam Pract* 16:125. doi: 10.1186/s12875-015-0337-3

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EDITED BY
Rubal Kanozia,
Central University of Punjab, India

REVIEWED BY
Dev Vrat Singh,
Central University of Jharkhand, India
Bachha Babu,
Central University of Jammu, India

*CORRESPONDENCE
Bewunetu Zewude
✉ bewunetuzewude@gmail.com

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Health seeking behavior of street connected children in Addis Ababa, Ethiopia

Bewunetu Zewude[1]*, Getahun Siraw[2], Kibur Engdawork[3] and Getnet Tadele[3]

[1]Department of Sociology, College of Social Science and Humanities, Wolaita Sodo University, Sodo, Ethiopia, [2]Department of Sociology, College of Social Sciences and Humanities, Dilla University, Dilla, Ethiopia, [3]Department of Sociology, College of Social Science, Addis Ababa University, Addis Ababa, Ethiopia

Background: Street children are the most neglected segments of the society with limited access to healthcare services. The vulnerability of street children to various health risks has been found by previous studies but little is known about their perceived susceptibility, preventive behavior and illness responses. Hence, the purpose of this study was to identify the health seeking behavior of street children in Addis Ababa. The study focuses on perceived susceptibility to various health risks, sources of health risks, and behaviors pertaining to responding to perceived risks and experienced health problems among the most marginalized groups in Addis Ababa.

Methods: Using a mixed research approach, quantitative and qualitative data were collected through survey and interview methods from selected street children. SPSS and NVivo software were used to analyze the quantitative and qualitative data, respectively.

Results: Whereas the street children perceive to be susceptible for ill-health risks related with their living situations, responding to the perceived susceptibility mainly by maintaining personal hygiene and undertaking physical exercises have been identified. The study also revealed that street children were found to be vulnerable for the situations affecting their health and wellbeing mainly due to self-reported engagements in risky behaviors such as smoking cigarette (67.3%), sniffing glue or benzene (68.2%), sharing of personal materials having the potential of transmitting diseases from one person to another (25.5%), and unprotected sexual activities (14.1%). Experiences of visiting healthcare facilities in response to illness symptoms have also constituted an aspect of the health seeking behavior of the street children.

Conclusion: Awareness of the presence of health risks and perceived susceptibility to the risks promoted both preventive behavior and positive compliance in relation to illness response among children of the street in Addis Ababa.

KEYWORDS

street children, risk perception, prevention, illness response, susceptibility

Introduction

Health-seeking behavior refers to any action undertaken by individuals who perceive themselves to be susceptible to or have faced health problems for the purpose of finding an appropriate remedy and promoting good health status (Oberoi et al., 2016; Mushtaq et al., 2020). Cornally and McCarthy (2011) defined it as a problem-focused, planned behavior involving interpersonal interaction with a selected healthcare professional. Moreover, it is situated within the broader concept of health behavior that encompasses a range of activities undertaken to maintain good health, prevent negative health outcomes, and actions taken to restore a good state of health (Latunji and Akinyemi, 2018). Health-seeking behavior passes through a logical sequence of steps that begin with the perception and evaluation of symptoms and end with the utilization of different healthcare services (Mackian, 2004). It includes all the behaviors undertaken to maintain a healthy physical and mental state (primary prevention), to restore any deviation from normal health conditions (secondary prevention), and to reduce the impacts and progression of an illness (tertiary prevention) (Uche, 2017). According to Latunji and Akinyemi (2018), the state of the health-seeking behavior of members of a given society can be an important indicator of society's well-being and is linked to its overall socio-economic development. Above all, people's responses to symptoms of illness have significant implications for morbidity and progression of the illness. In other words, delaying or refusing to seek and contain a proper diagnosis and medical treatment are more likely to cause adverse negative health consequences (Afolabi et al., 2013; Adam and Aigbokhaode, 2018).

The nature of health-seeking behavior varies from person to person or between groups depending on different factors (Oberoi et al., 2016) which tends to result in varied levels of consumption of healthcare services between individuals in a group or across different groups in a society. According to Mackian (2004), the determinants of health-seeking behavior can broadly fall under geographical, social, cultural, economic, and organizational factors. Siddiqui (2014) identified factors such as the status of women, age, sex, household resources, costs of care, distance and physical access to healthcare services, perceived quality of healthcare services, and standards of drugs affecting health-seeking behavior. In addition, Basharat et al. (2019) stated that lack of awareness about risk factors, symptoms, and approach to treatment were the main reasons for delaying treatment. A study on the health-seeking behavior of slum dwellers in Dhaka City, Bangladesh (Jahan et al., 2015) found that limited access to healthcare is a serious constraint on the use of healthcare services. Likewise, Adane et al. (2017) concluded that increasing the proximity of health facilities, health education, and socio-development programs targeting illiterate mothers/caregivers and poor households may promote and increase health-seeking behavior in slum areas in Addis Ababa City.

Other studies have found factors such as the amount of social capital, level of access to health information, availability of providers, communication barriers, the need to keep one's health problem secret, availability of opportunities for specialized care, fear of side effects of drugs, level of education, type and severity of illness, costs of care in relation to time, travel and treatment, attitudes, beliefs and core values, life adaptation skills, psychological dispositions, social support, media, exposure to health information, gendered preference of care providers, religion, culture, marital status, income, occupation, work time of healthcare facilities, and the nature of the healthcare environment such as long waiting time, misbehavior of staffs, negligence of doctors, willingness to listen to disease history, commercial attitudes to prescribe pathological tests affecting health seeking behavior (Mackian, 2002; Afolabi et al., 2013; Webair and Bin-Gouth, 2013; Tegegne and Legese, 2014; Akeju et al., 2016; Rahman et al., 2016; Uche, 2017; Adam and Aigbokhaode, 2018; Latunji and Akinyemi, 2018; Basharat et al., 2019; Jalu et al., 2019; Khalil et al., 2019; Guta et al., 2021). According to Mackian (2002), health-seeking behavior is not just an isolated event; rather, it is the result of an evolving mix of social, personal, cultural, and experiential factors.

Being a street child involves vulnerability to multiple grounds of disadvantageous positions, mainly as far as health and well-being are concerned (Chowdhury et al., 2017; Tahmina et al., 2018; Said and Aldewachi, 2020; Abate et al., 2022). A review of the literature on the health conditions of street children in selected African countries (Cumber and Tsoka-Gwegweni, 2015) revealed that street children are vulnerable to poor health conditions, including violence, injuries, and HIV/AIDS, mainly because of factors such as homelessness, risky sexual behavior, and substance abuse. According to Ali and de Muynck (2005), street children are highly susceptible to adverse health outcomes such as physical injuries and respiratory and skin infections. Furthermore, a study conducted in Northern Ethiopia (Brhane et al., 2014) revealed that one-third of street children had started sexual intercourse, over 60% of them had more than one sexual partner, and 40.6% had sexual intercourse with commercial sex workers. Above all, Eshita (2018) concluded that street children are the most neglected part of society, with very negligible access to health care and lack of awareness of available health services.

Identifying the prevalence and extent of differences in health-seeking behavior across various social groups is crucial because of its implication on inequality in the access and utilization of healthcare facilities among members of diverse social groups. Besides the susceptibility of street children to various ill-health conditions, it is important that their health-seeking behavior be understood due to its policy implications for healthcare development and the reintegration of such marginalized social groups (Afolabi et al., 2013; Uche, 2017). Moreover, the health-seeking behavior of street youth in Ethiopia has not been adequately studied, and our knowledge in this case is mostly limited to the higher susceptibility to ill-health conditions among members of the social group (e.g., Tadele, 2009; Kapali, 2011; Brhane et al., 2014; Zewude, 2018; Abate et al., 2022). Therefore, the present study considered health-seeking behavior within the broader context of health behavior, including perceived susceptibility to health risks, preventive behavior against risks, patterns of illness responses, alternative care-seeking behavior, and health-related decision-making processes among street children in Addis Ababa, Ethiopia.

Materials and methods

Study area

The study was conducted in Addis Ababa, Ethiopia. Compared to other parts of the country, the issue of streetism has become a grave concern in Addis Ababa (Bekele, 2020). According to a scoping study of MOLSA (2018), Addis Ababa and DireDawa take the lion's share as far as the distribution of urban destitute living on street sides of Ethiopia is concerned. With more than 3,384,569 million dwellers according to the 2007 census and the 2022 projected population size of 5, 227,794 (with 4.44 growth rate), Addis Ababa is by far the largest city and is home to about a quarter of the country's urban population. Most of the development is concentrated in the city and it has always been experiencing large influx of people from rural areas and other smaller towns. The city is characterized by fast changing situations having a potential consequence of increasing the risk of involvement into street life for large number of vulnerable people living in the city, especially the urban poor (Veale et al., 1993). Conducting the study in Addis Ababa is necessary due to high prevalence of streetism (MOLSA, 2018; StreetInvest, 2020) and its consequences, such as high crime rates and decreasing environmental sanitation.

Research design

Conticini and Hulme (2007) suggest that the use of statistical data alone is less helpful for researches investigating children in street situations. "Every child has a unique story to tell. As important as it is to quantify this phenomenon, numbers are of little help in understanding the context in which they live, the desperation that leads them to run away from home, and the challenges they struggle with to survive on the streets" (Ferrara and Ferrara, 2005, p. 1). Accordingly, the study combined both qualitative and quantitative methods to identify the health seeking behavior of street children in Addis Ababa. We used a concurrent nested research design where methods and data were triangulated in addressing one or more research objectives (Barnes, 2019). Whereas survey was used to gather the quantitative data, interview method has been used to collect qualitative data from selected street children. According to Brierley (2017), a mixed methods design is useful to get a complete picture of the research question and a full understanding of what is being done.

Research methods and data sources

A cross-sectional survey was conducted in four sub-cities of the Addis Ababa City Administration in Ethiopia. The survey was pilot-tested with 20 street children to assess the adequacy of the instruments. The results of the pilot test showed that some questions were not clear for the street youth, which resulted in respondents requesting clarification. Accordingly, the researchers revised the instruments. After receiving feedback and making all the necessary corrections, the questionnaires proportional to the calculated sample size were duplicated. In addition, for the purpose of triangulating data, qualitative data were collected from research participants using in-depth interview method. Semi-structured questions were developed to guide the interview sessions.

Sampling and selection of research participants

The main methodological constraint encountered when studying street children is the impossibility of adopting sampling procedures to ensure that the relatively small group of interviewees represents the composition of the larger population of children in street situations (Conticini and Hulme, 2007). A one-stage cluster sampling technique was used to select the participants. Given the highly mobile nature of the study population, finding an appropriate population size concentrated in the study area was impossible, which makes obtaining sampling frames difficult. Therefore, research participants were randomly contacted to collect data through an interviewer-administered questionnaire. Accordingly, the major inclusion criteria were the age of respondents being within the category of 10–17, being children of the street who use the street both as a shelter and source of livelihood, and willingness to participate in the survey. The period of data collection coinciding with the rainy season in Ethiopia (end of May 2022 and June, 2022) the highly mobile nature of the study population reduced the predictability of their location, and the range of time suitable to interview the children being very limited, data collectors were able to contact 230 street children from which 220 cases were found to be completed and clean to be inserted in SPSS software. For the qualitative approach, a purposive sampling technique was used in which the researchers tried to maintain maximum variation in the characteristics of the chosen samples to include diverse perspectives and insights into the research. In addition, the sample size was the number of interviewees counted until the point at which a state of data saturation was attained in the sense that the researchers realized no new information was discovered, and enough data were collected to replicate the study (Fusch and Ness, 2015). Accordingly, 22 street children were interviewed in this study.

Instrument design

The questionnaire used to gather quantitative data for the present study was developed on the basis of Babitsch et al. (2012) and after an exhaustive review of previously published relevant research articles. The outcome (dependent) variable is the health-seeking behavior of respondents, measured in terms of both preventive health behavior and illness response behavior, whereas the independent variables include socio-demographic characteristics of the respondents, such as age, sex, education, religion, residential background, and the number of years spent on the street. The questionnaire mainly consisted of three sections: a section asking about the socio-demographic characteristics of respondents, the second section focusing on primary prevention behavior, and the third section related to respondents' illness response behavior. Accordingly, the first section seeking the socio-demographic characteristics of survey participants included questions such as age, sex, religion, educational status, residential background, and the number of years they stayed on the street. The second section consisted of questions regarding the respondents' primary preventive behavior. There were (1) "is there anything

TABLE 1 The socio-demographic characteristics of respondents.

Variables	Categories	Frequency (%)
Sex	Male	200 (90.9%)
	Female	20 (9.1%)
Educational status	Never attended school	26 (11.8%)
	Primary level (1–8)	184 (83.6%)
	Secondary level (9–12)	10 (4.5%)
Religious background	Orthodox Christian	110 (50%)
	Muslim	74 (33.6%)
	Protestant	30 (13.6%)
	Catholic	4 (1.8%)
	Adventist	1 (0.5%)
	Atheist	1 (0.5%)
Duration on the street	<1 year	48 (21.8%)
	1–3 years	95 (43.2%)
	4–6 years	64 (29.1%)
	7–9 years	13 (5.9%)
Residential background	Urban	134 (60.9%)
	Rural	86 (39.1%)
Total		220 (100%)

you do to protect yourself from ill-health conditions?" (2) "Have you ever had unprotected sexual intercourse/no condom use?" (3) "Do you maintain your personal hygiene (taking shower, changing cloths, etc)?", and (4) "Have you ever visited healthcare facilities (hospital/clinic/health center) for general health check-up?" among others. Finally, the third section of the questionnaire aimed to measure the illness response behavior of respondents and included questions such as (1) "Have you ever been sick since you joined street life?" (2) "If yes, have you ever visited healthcare facilities for diagnosis/treatment?", and (3) "What do you commonly do whenever you feel sick?", among other questions.

Method of data analysis

First, the data were checked for completeness. Only the questionnaires that were found to be correctly filled were inserted into SPSS software version 26. Data analysis was conducted using statistical techniques, including percentage and frequency distributions. Descriptive statistical techniques were used to analyze and present issues such as the socio-demographic characteristics of respondents, the situation of health risk perception, related preventive behavior, and patterns of illness responses among the respondents, among other things. For qualitative data, the audio records were first transcribed verbatim and then translated into English. The data were then coded using NVivo version 12 software followed by deep reading and identification of themes and sub-themes. Subsequently, the data were interpreted in relation to the specific research questions.

Data quality management

According to Costa (2022), "good data" are characterized mainly by accuracy, relevance, completeness, timeliness, and consistency. Because data quality management is a continuous process it was undertaken in three phases: before the field work, during data collection, and after the field during data entry and analysis. Before the field, all prescribed rules and principles were followed during questionnaire construction and the development of all other data gathering tools. Both face and criterion validity of the instruments were established, such as carefully selecting the variables/items after exhaustive review of the literature (Heale and Twycross, 2015). As much as possible, the process of recruiting data collectors considered previous exposure to street connected children or experience of undertaking relevant researches and implementation of community-based project works. In addition, sufficient training was given to data collectors with a strong supervision and field coordination made by the researcher. Pilot testing of the data collection instruments with relatively small number of street children has also been undertaken. Moreover, data were carefully entered into the software and stored on computer with a separate folder created for this purpose. Similar data quality assurance and controlling procedures were followed during data analysis and interpretation.

Ethical considerations

The characteristics of the study participants being under age and having low level of literacy makes it difficult for them to provide informed consent to participate in the study. Therefore, the researchers used research approaches that involve as minimum risk as possible to the safety and privacy of the children. According to Kaime-Atterhog (2012), allowing the street children to lead the research and having a long and sustained period of engagement in the field ensures that the interests of the children gets priority. Children were provided with adequate information, among other things, about what the research is all about, the level of potential risks involved as a result of participating in the research, the type of information required from them, and that the information they provide will be kept confidential. Maximum effort was also made to make sure that no child has been put into a risk as a result of participating in the study. In this regard, the fundamental principles of "do no harm" and "taking into account the best interest of the child" were kept throughout data collection and presentation of data. Above all, because consent is an ongoing process (Smart, 2018), children have been assured and reassured to withdraw from the research any time they feel discomfort, by telling them that such withdrawal does not involve any negative consequences to them.

Results

The socio-demographic characteristics of the participants are presented in Table 1. Accordingly, it is found that most (90.9%) of the respondents are males and the average age of the participants has been 15.27 (SD: 1.42). In addition, their

TABLE 2 Frequency distribution of perceived susceptibility and preventive behavior of respondents.

Variables/questions	Categories	Frequency (%)
Have you ever been concerned about being infected by a disease while living on the street?	Yes	157 (71.4%)
	No	63 (28.6%)
Have you ever had unprotected sexual intercourse/without the use of condom?	Yes	31 (14.1%)
	No	189 (85.9%)
Have you ever been tested for sexually transmitted diseases such as HIV/AIDS?	Yes	10 (4.5%)
	No	21 (9.5%)
Do you maintain your personal hygiene (taking shower, changing cloths, etc)?	Yes	199 (90.5%)
	No	21 (9.5%)
Do you smoke cigarette?	Yes	148 (67.3%)
	No	72 (32.7%)
Do you sniff glue/benzene?	Yes	150 (68.2%)
	No	70 (31.8%)
Do you share personal materials such as blade, needle, and teeth brush with your friends?	Yes	56 (25.5%)
	No	164 (74.5%)
Have you ever been using marijuana since you joined street life?	Yes	61 (27.7%)
	No	159 (72.3%)
Have you ever visited healthcare facilities for general health checkups?	Yes	54 (24.5%)
	No	166 (75.5%)
Total		220 (100%)

educational background revealed that the majority (83.6%) had attended only the primary level of education. Furthermore, while half (50%) of the respondents reported being Orthodox Christians in their religious faith, most (60.9%) replied that they had been raised in urban areas. Data regarding the period counted since joining street life revealed that most (43.2%) had stayed 1–3 years on the street.

Primary prevention behavior: perceived susceptibility and actions taken to prevent health risks

As shown in Table 2, most respondents (71.4%) perceived that they were susceptible to health risks as a result of their living conditions on the street. In addition, data have shown that street children are vulnerable to situations affecting their health and wellbeing, mainly due to self-reported engagement in risky behaviors. For instance, it was found that 67.3% of respondents smoked cigarettes, 68.2% had sniff glue or benzene, 25.5% shared personal materials with the potential to transmit diseases from one person to another, and 14.1% had unsafe sexual intercourse. Moreover, the results showed that three-quarters of street children had never visited health care centers. The absence of experience visiting healthcare facilities for the purpose of undergoing a general health check-up among most respondents (75.5%).

Respondents were asked whether there was something they did in response to the perceived or experienced health risks. According to the data presented in Figure 1, 73% of respondents replied that they do something to protect themselves from ill-health conditions, implying the existence of preventive health behaviors among street children in the study area. In addition, practices that positively contribute to the health and well-being of the respondents, such as experiences of maintaining personal hygiene (90.5%) with a relatively high interval of taking a shower, have also been reported, as shown in Table 2.

The percentage distributions of health beliefs and subsequent preventive behaviors of respondents presented in Table 3 reveal that stomach ache (45.2%), louse-borne diseases (38.2%), headache (36.9%), illnesses caused by exposure to harsh weather (36.3%), typhoid/typhus (22.3%), and cardiac infection (21%) were the health problems that respondents were most concerned about. In addition, maintaining personal hygiene (46.6%), doing physical exercise (44.1%), and prayer or spiritual activities (29.8%) were found to be the commonly used mechanisms used by respondents to protect themselves from ill-health conditions. On the other hand, for the respondents who disclosed that they do not do anything to protect themselves from health risks (27%, as shown in Figure 1), the most frequently reported reasons or barriers were financial problems (66.7%), their housing situation (23.3%), absence of health-related knowledge (16.7%), and absence of facilities (15%).

Illness response behavior of the respondents

Figure 2 shows that just over half of the street children reported visiting modern healthcare facilities whenever they felt

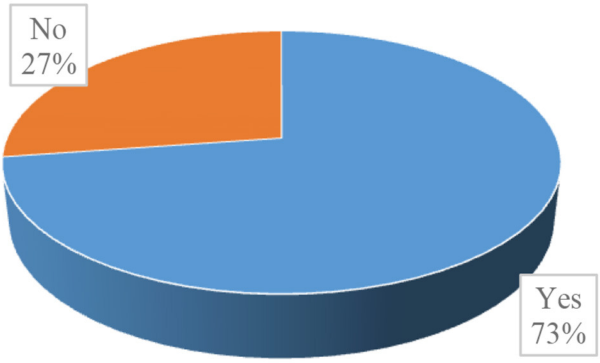

FIGURE 1
Is there anything you do to protect yourself from ill-health conditions?

sick, followed by self-care (25.9%), doing nothing (24.1%), and spiritual or religious treatment (20.9%).

As presented in Figure 3, the percentage distribution of responses regarding respondents' experiences of visiting healthcare facilities revealed that most (56%) respondents had ever visited healthcare facilities.

Among the respondents who reported that they had never visited healthcare facilities (23%), as shown in Figure 3, the most frequently mentioned reasons were financial problems (64.7%), the disease being less severe (29.4%), preference for self-care (7.8%), fear of pain during medical injection (3.9%), fear of long waiting hours in healthcare facilities (3.9%), and lack of awareness (3.9%), as shown in Table 4. Furthermore, respondents were asked about the conditions that enabled them to visit healthcare facilities, and most (48.2%) replied perceived severity of the disease, followed by feeling ill (27.7%), the presence of an adequate amount of money (27.3%), peer pressure (24.5%), and access to free healthcare services (23.2%).

Results from qualitative data: perceived susceptibility and responding to health risks

The study showed that street children perceive themselves to be highly susceptible to various health risks that affect their health and well-being. And one of the most frequently reported perceived health risks was "RF" which they believe is caused by the lack of personal hygiene.

> *I am more afraid of RF*[1] *because I have had previous experience with it. It is caused by a lack of personal hygiene and a sleeping area. RF is caused by having so many louses on your hair and clothes, especially if you don't wash it on a regular basis. Bed sheets we use to sleep on the ground may develop louse, especially if not washed on a regular basis. I was severely ill as a child as a result of this because I had no experience washing my body and clothes until I was older (XX7, male, 16 years old).*

Others have expressed their concerns about the possibility of contracting lung cancer and kidney infection as a result of smoking cigarettes:

> *Kidney disease and lung cancer. I'm especially concerned about lung cancer because a small wound on the lung can grow larger if you smoke cigarettes all the time. I am afraid of being exposed to cancer and becoming physically disabled as a result of having parts of my body cut to stop its spread (XX2, male, 15).*

For another child on the street, kidney infection is perceived to be caused by stressful situations and the absence of care.

> *It could be as a result of stress or from sleeping in cold weather. We also don't get up to urinate at night once we've fallen asleep because we usually sleep abnormally, possibly on top of others, and because we're afraid of the cold air condition. This may contribute to kidney problems (XX2, male, 15).*

Interviewees disclosed that they are highly vulnerable to various sexually transmitted infections, especially HIV/AIDS, because of their risky sexual practices. For instance, a male adolescent of the street disclosed that he often engages in unsafe sex with his female counterparts on the street and even suspects himself to be infected by HIV/AIDS.

> *Of all other diseases, I'm highly concerned about HIV AIDS because there are many females who live on the street like us. They come here, and we sometimes sleep together. Although we know the fact that some of them are already HIV positive, we boys living on the street don't use condoms. As a result, we are most likely to contract the virus from them.*

For most children on the street, susceptibility to ill-health conditions is believed to be associated with their living situation on the street:

> *Living on the streets is a disease by itself. One would be susceptible to communicable diseases such as typhus and typhoid while living here (XX4, male, 17 years old).*
>
> *I think I am very much susceptible to disease due to my street sleeping situation on the street. I sleep on the street without a blanket and hence, vulnerable to illness as a result of the cold weather. I also believe that having louse infestations on my clothes would put me at risk of developing other health issues. For example, I usually encounter shortage of breath after running a very short distance (XX10, male, 14 years old).*
>
> *For one thing, I beg money from strangers, eat hotel leftovers, buy and chew khat, buy and drink local whisky or "Areke," then get drunk and sleep on the ground, and so on. Because this is my daily routine, I am constantly exposed to various health problems (XX3, male, 18).*

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[1] RF stands for Relapsing Fever.

TABLE 3 Health beliefs and related preventive behavior of respondents.

Variables/items	Categories of responses	Responses		Percent of cases
		N	Percent	
The disease/ill-health conditions that respondents are most concerned about	HIV/AIDS	21	3.8%	13.4%
	Skin/dermal disease	20	3.6%	12.7%
	Other sexually transmitted infections	6	1.1%	3.8%
	Vector/louse borne diseases	60	10.9%	38.2%
	Heart Disease	33	6.0%	21.0%
	TB	13	2.4%	8.3%
	Typhoid/typhus	35	6.4%	22.3%
	Kidney failure	7	1.3%	4.5%
	Depression	25	4.5%	15.9%
	Stress	30	5.4%	19.1%
	Cancer	16	2.9%	10.2%
	Hepatitis	4	0.7%	2.5%
	Stomach-ache	71	12.9%	45.2%
	Headache	58	10.5%	36.9%
	Physical impairments	36	6.5%	22.9%
	Other accident-related injuries	19	3.4%	12.1%
	Illness caused by exposure to harsh weather	57	10.3%	36.3%
	Malaria	24	4.4%	15.3%
	Others	16	2.9%	10.2%
Total		551	100.0%	351.0%
Mechanisms of protecting oneself from ill-health conditions	Doing physical exercises	71	24.8%	44.1%
	Health check-ups	8	2.8%	5.0%
	Early reporting of symptoms	12	4.2%	7.5%
	Eating balanced diet	26	9.1%	16.1%
	Not using harmful drugs/substances	38	13.3%	23.6%
	Vaccination	7	2.4%	4.3%
	Prayer/other spiritual activities	48	16.8%	29.8%
	Maintaining personal hygiene	75	26.2%	46.6%
	Others	1	0.3%	0.6%
Total		286	100.0%	177.6%
Reasons for not doing something to protect one's health	Feelings of worthlessness	10	9.4%	16.7%
	Negligence due to running to meet survival needs	9	8.5%	15.0%
	Financial problems	40	37.7%	66.7%
	My housing situation	14	13.2%	23.3%
	Lack of health-related knowledge	10	9.4%	16.7%
	Absence of facilities	9	8.5%	15.0%
	Lack of access to healthcare services	6	5.7%	10.0%
	I feel that I should withstand challenges	1	0.9%	1.7%
	No reason	5	4.7%	8.3%
	Others	2	1.9%	3.3%
Total		106	100.0%	176.7%

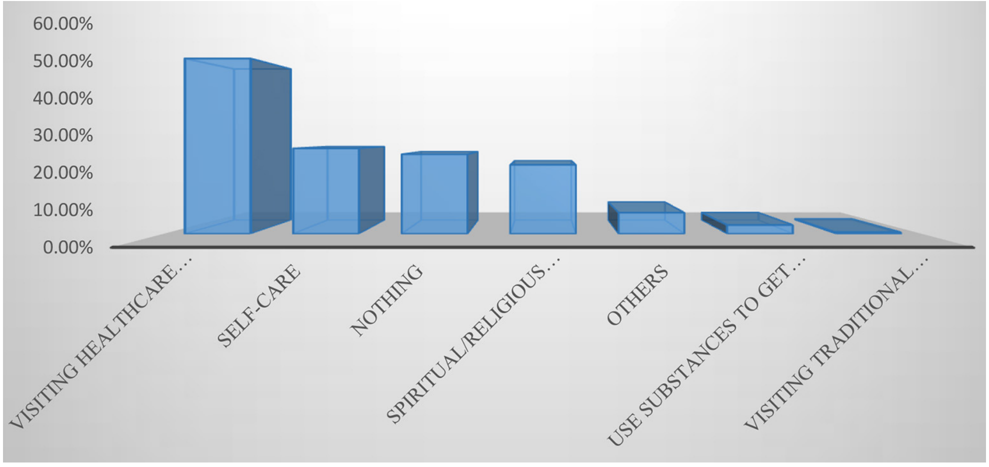

FIGURE 2
What do you commonly do whenever you feel sick?

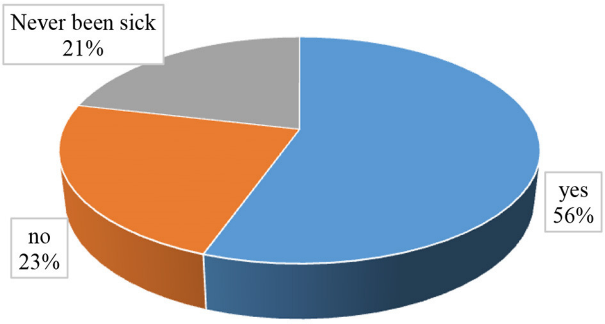

FIGURE 3
Have you ever visited healthcare facilities for diagnosis/treatment?

The harsh relationship between street children and the police in the city has been found to be another source of health risk for street children:

> *We are concerned that the police's brutality will cause us to accidentally fall while running, putting us in danger of physical injury or in danger of being involved in a car accident (XX9, male, 14 years old).*
>
> *The police, however, intimidate us all to leave the area. They dislike seeing us sitting and having fun together. They also came unexpectedly late at night while we were sleeping, beat us severely, and forced us to flee to other locations at night (XX3, 18, male).*

The study also indicated that perceived susceptibility to health risks is linked to the preventive health behavior of street children. As revealed by the participants, street children respond to perceived susceptibility using different mechanisms, where maintaining personal hygiene is a common practice:

> *If I don't maintain my personal hygiene, I'm sure I would have been exposed to various diseases, especially RF. This is because RF is caused by having so many louses on your hair and clothes, especially if you don't wash it on a regular basis. Once, I was severely ill as a result of it because I had no experience of washing my body and clothes (XX7, male, 16 years old).*
>
> *I now take various precautions to protect myself after being exposed to diseases. I, for example, take frequent showers, but we still get sick so easily (XX4, male, 17 years old).*

For some street children, the type of response to perceived or experienced health risks was based on experiential knowledge. A street child, for instance, disclosed that he tries to eat enough food, which he believes helps him cope with malaria:

> *I sometimes keep myself safe to avoid disease. I have a recurrent malaria infection, so I'm susceptible to becoming ill if I don't get enough food, and it forces me to be in cold weather at one time and hot weather at another. As a result, I take great care to avoid recurrence of this disease, particularly by eating enough food (XX9, male, 14 years old).*

Male street children who perceive that they are susceptible to risks of sexual violence, protecting themselves from potential perpetrators, especially strange street children, have been reported:

> *If we find anyone who wants to have a sexual relationship with us, we will kill him. If something like that were to happen, no one would stay in this area. There are no girls either. We all came from the same area, so we're all too familiar with one another. Other mature boys have sexual relationships with girls, but we never allow them to sleep with us (XX2, 15, male).*

Reports of reducing engagement in risky behaviors after realizing the negative consequences of such behaviors have also been reported.

TABLE 4 Reasons for not seeking healthcare and conditions of seeking treatment.

Questions	Categories of responses	Responses		Percent of cases
		N	Percent	
What was your reason for not been visiting healthcare facilities for diagnosis/treatment?	The disease was not that severe	15	21.7%	29.4%
	Financial problem	33	47.8%	64.7%
	Use substances to get temporary relief	1	1.4%	2.0%
	Fear of pain during injection	2	2.9%	3.9%
	Didn't know I should visit health facilities	2	2.9%	3.9%
	I prefer self-care	4	5.8%	7.8%
	I prefer traditional medicine	1	1.4%	2.0%
	I prefer spiritual healing	1	1.4%	2.0%
	Distance of health facilities	3	4.3%	5.9%
	Communication problems with health workers	1	1.4%	2.0%
	Fear of long waiting time in the health facilities	2	2.9%	3.9%
	I believe that I should withstand challenges	1	1.4%	2.0%
	Others	3	4.3%	5.9%
Total		69	100.0%	135.3%
If you get sick, under which of the following conditions do you visit healthcare facilities?	I will never visit healthcare facilities	3	0.9%	1.4%
	As soon as I feel ill	61	17.8%	27.7%
	If I perceive that the disease is severe/deadly	106	31.0%	48.2%
	When other alternative trials fail	4	1.2%	1.8%
	When friends/others insist me to do so	54	15.8%	24.5%
	When I have adequate money	60	17.5%	27.3%
	When I get free healthcare services	51	14.9%	23.2%
	Others	3	0.9%	1.4%
Total		342	100.0%	155.5%

> *I smoke a little amount of cigarette. Many of us here share a single cigarette. We used to smoke two or three times a day, but now I only smoke once a day to avoid health problems. If I smoked a lot of cigarettes, it would even give me a headache. In addition, I will not sleep in public places where people urinate to avoid illness, but I can't do anything about the chilly weather (XX1, 15, Male).*

The study also noted that research participants' preventive health behavior ranged from casual activities and efforts at the individual level to planned and organized activities of saving money and raising funds for emergency illness response. One street child reported:

> *There is an older guy among us who is in charge of coordinating activities of collecting money regularly to deal with any health risks that our members may face. We have money that we have collected from our group members to use during emergencies such as when diseases occur or when people want to travel to their families. I, for example, have 700 birr deposited for same purpose (male, 15 years old).*

In addition to preventive health behavior, we found that street children have a relatively high experience of healthcare-seeking behavior, which is expressed by responding to illness episodes. Whereas visits to healthcare facilities have been reported, purchasing drugs from nearby drug stores when feeling sick have also constituted aspects of health-seeking behavior:

> *. . . I became severely ill yesterday after eating half-spoiled leftover food from hotels, but I was able to handle it after visiting a health center for treatment. I received free treatment at Zewditu hospital but was asked to pay 200 birr for medicines, which I did (XX4, male, 17 years old).*
>
> *. . . I go to the pharmacy to get medicine for any minor health issue (XX1, 15, Male).*

> *...For example, one of my old friends was so addicted that one day he got drunk, hit his head against the wall inside the train line, and was severely beaten by police. He lay on the same ground for 6 days without food, developing a swarm of louses on his clothing while no one noticed. We took him to the hospital on the sixth day, but he died immediately due to RF and severe bleeding from his head (XX7, male, 16 years). ... There is also a child that I know who is currently undergoing treatment as a result of RF at a hospital that provides free medical care to us (XX7, male, 16 years).*

Experiences of visiting healthcare facilities have been found not only in response to illness episodes but also that healthcare seeking behavior among girls of the street have also been reported in cases of maternity care services:

> *...I faced no difficulties when I gave birth. It was after six months that I discovered my pregnancy status. I had regular pregnancy checkups until delivery. I was finally able to give birth at a health canter without any difficulties (XX6, female, 18 years).*

It was indicated that the availability of free healthcare services played a role in promoting healthcare-seeking behavior among street children.

> *...When a child becomes ill, we usually go to Yekatit 12 hospital and receive free treatment after waiting in line for a long time because no other health center treats us (XX3, male, 18).*
>
> *They go to Yekatit 12 hospital to receive free health care from a foreign woman who works there (XX6, 18, female).*

Discussion

The nature and extent of health-seeking behavior vary from one person to another or between groups, depending on different factors (Oberoi et al., 2016). A person's actions related to health behaviors promote good health and prevent health risks (Mushtaq et al., 2020). In this regard, studies (e.g., Eshita, 2018) show that street children are the most neglected part of society, with very limited access to health care and lack of awareness of available health services. According to Woan et al. (2013), street children's survival behaviors and exposure to poor shelters have resulted in morbidity, including infectious diseases, reproductive health, psychiatric diseases, and stunted growth. Although much has been said about the vulnerability of street children, little is known about their health-seeking behaviors. Hence, this study was undertaken to identify the health-seeking behavior of street children in Addis Ababa. To this end, both quantitative and qualitative data were collected from children on the street and analyzed to identify patterns in the data.

Perceived susceptibility refers to a person's perception that he or she may encounter the risks associated with [negative] health behavior, mostly embedded in the person's routine living experiences, which may expose him/her to a certain ill-health condition (Che et al., 2014). The results of the study indicated that most of the children and adolescents in the street perceive that they are susceptible to health risks, such as stomach ache, louse-borne diseases, headaches, illnesses caused by exposure to harsh weather, typhoid/typhus, and cardiac infection, as a result of the living conditions on the street. Disease risk perceptions are fundamental determinants of health behavior, and evidence regarding people's perceived susceptibility to a health threat is helpful for undertaking interventions that promote positive compliance (Harvey and Lawson, 2009; Ferrer and Klein, 2015). Accordingly, the majority of respondents had experience engaging in preventive health activities with the aim of protecting themselves from ill-health risks. Aspects of such preventive behavior include the experience of maintaining one's personal hygiene with a relatively high interval of taking a shower and performing physical exercises. According to Tarkang (2015), a person engages in preventive health behavior based on positive expectations that doing so would result in avoiding actual or perceived negative health conditions.

The other side of the finding about the health behavior of street children in the study area is their vulnerability to adverse health risks due to engaging in risky behaviors, such as smoking cigarettes, sniffing glue and benzene, unsafe sexual intercourse, and sharing personal materials with the potential to transmit diseases from one person to another. This finding is consistent with the results of a study conducted in Dhaka city (Eshita, 2018) which revealed that about half of street children engage in various risky behaviors such as smoking, unsafe sex, and abuse of drugs, which exposes them to physical and mental development problems. Furthermore, a study conducted in Northern Ethiopia (Brhane et al., 2014) revealed that one-third of street children had started sexual intercourse, over 60% of them had more than one sexual partner, and 40.6% had sexual intercourse with commercial sex workers. Moreover, the vulnerability of street children participating in this study was exacerbated by the absence of experience of visiting healthcare facilities for the purpose of undergoing general health check-ups among most of the respondents. Ali and de Muynck (2005) confirmed that street children are highly susceptible to adverse health outcomes such as physical injuries and respiratory and skin infections. Above all, Chowdhury et al. (2017) associated street children's exposure to various skin diseases and other communicable infections with their overall living conditions, such as overcrowded living situations, unhealthy sleeping areas, irregular baths, and fewer changes in clothes.

According to Adam and Aigbokhaode (2018), self-treatment is the most common type of illness response among people in developing countries, mainly because of the widely prevalent knowledge of traditional medical treatments and the use of alternative care services. In addition, Uche (2017) contended that people usually opt for the simplest form of treatment, which they deem more often than not, as the cheapest and most effective, and it is only when these simplest forms of treatment are adjudged as unsuccessful that the higher, more expensive, and conventional treatments are sought. In contrast, the results of the present study indicate that most respondents visited modern healthcare facilities whenever they felt sick, in addition to self-care practices and spiritual treatments. Moreover, this finding also differs from the results of a study conducted in Dhaka city by Eshita (2018) who concluded that street children often attempt self-medication, such as applying "masala" (spices) or "chuna" (quicklime) to wounds, drinking "soda" for gastro-intestinal problems, and taking over-the-counter drugs for all kinds of infections. Above all, Tegegne and Legese (2014) found that people who belong to the lowest social class in Addis Ababa, Ethiopia, do not visit professional care providers immediately after identifying disease symptoms and instead either ignore symptoms or seek other options. It is also indicated that, at the last stage, members of such social groups seek treatment from a trained allopathic.

For respondents who had never visited healthcare facilities, the most frequently mentioned reasons were financial problems, the disease being less severe, preference for self-care, fear of pain during medical injection, fear of long waiting hours in healthcare facilities, and lack of awareness. Similarly, Jalu et al. (2019) argued that low socio-demographic and economic status and poor exposure to health-related information were barriers to healthcare-seeking behavior. In addition, Eshita (2018) contended that the health-seeking behavior of street children is highly influenced by factors such as the availability of resources, knowledge of healthcare facilities, amount of waiting time to access healthcare services, travel distance to health centers, and faith in the healthcare provider. According to Akeju et al. (2016), high cost of medical care deters healthcare-seeking intentions. Moreover, similar to the results of the study, Andersen (1995) pointed out that enabling factors such as knowledge about how to access health services, income, health insurance, regular source of care, travel, and the extent and quality of social relationships affect individuals' healthcare-seeking behavior.

Kuuire et al. (2015) stated that although predisposing and enabling factors are necessary for healthcare utilization, they are not sufficient to lead to actual use, which is initiated by need that arises mainly as a result of the severity of illness. According to Oberoi et al. (2016), whether a person performs a particular health behavior is influenced by both the degree to which the disease is perceived by the person as threatening, and the extent to which a given health behavior is believed to be effective in terms of reducing negative health outcomes. Moreover, Andersen (1995) argued that people's healthcare-seeking behavior is determined by how they view their own general health and functional state, how they experience symptoms of illness, pain, and worries about their health, and whether or not they judge their problems to be of sufficient importance and magnitude to seek professional help. On the other hand, the results of binary logistic regression analysis between the outcome variable (respondents' tendency to visit healthcare facilities) and the independent variables (age, sex, education, residential background, religion, and duration on the street) have shown that respondents' healthcare-seeking behavior is significantly associated with the length of the period counted since they joined street life, while the other predictor variables were not significantly associated. This finding differs from most previous studies (e.g., Mackian, 2004; Siddiqui, 2014) in which the socio-demographic characteristics of respondents, such as age and sex, were significantly associated with healthcare-seeking behavior. It also differs from Andersen's (1995) predisposing factors that affect healthcare-seeking behavior, including sex, age, and educational status.

Conclusions

Better prospects of health-seeking behavior, manifested both in the actions taken to prevent health risks and in positive compliance with healthcare use, have been found among children and adolescents of the street in Addis Ababa. Whereas street children perceive themselves to be susceptible to ill-health risks related to their living situations, responding to the perceived susceptibility mainly by maintaining personal hygiene and undertaking physical exercises have been identified. In addition, the experience of visiting healthcare facilities in response to illness symptoms has also constituted an aspect of street children's health-seeking behavior. Furthermore, while perceived severity of the disease, having an adequate amount of money, and access to free healthcare services promoted intentions for healthcare visits, financial problems, perceived less severity of illnesses, and preference for self-care were identified as barriers to healthcare seeking. On the other hand, in addition to their living conditions that have the potential to put street children at risk of exposure to various health problems, their vulnerability has been exacerbated by involvement in risky behaviors, such as smoking cigarettes, sniffing glue and benzene, and unprotected sexual practices. Efforts to create an inclusive society where marginalized sections of the urban community require children and adolescents of the street to be reintegrated into mainstream society. One way of doing this might be to create better access to modern healthcare services and empowering street children to maintain their health and wellbeing. Hence, state and non-state actors are expected to play key roles in this regard.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

This study was approved by the Ethics Approval Committee of Dilla University. The research participants were first informed about the purpose of the research, including what role they expected from their side. Both verbal and written consent was obtained from all research participants. Additionally, a formal letter was obtained from the Department of Sociology at Addis Ababa University. This study was conducted in accordance with relevant guidelines.

Author contributions

BZ conceived the research idea, took the leading role in data analysis, and prepared the manuscript. GS, KE, and GT participated in initiating the research idea, actively participated in the development of the research proposal, preparation of the data gathering instruments, data collection, data analysis, and preparation of the manuscript. All authors have read, edited, and approved the final manuscript.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Abate, D., Eyeberu, A., Adare, D., Negash, B., Alemu, A., Beshir, T., et al. (2022). Health status of street children and reasons for being forced to live on the streets in Harar, Eastern Ethiopia. using mixed methods. *PLoS ONE* 17, e0265601. doi: 10.1371/journal.pone.0265601

Adam, V. Y., and Aigbokhaode, A. Q. (2018). Sociodemographic factors associated with the healthcare - seeking behavior of heads of households in a rural community in Southern Nigeria. *Sahel Med. J.* 21, 31–36. doi: 10.4103/1118-8561.232781

Adane, M., Mengistie, B., Mulat, W., Kloos, H., and Medhin, G. (2017). Utilization of health facilities and predictors of health-seeking behavior for under-five children with acute diarrhea in slums of Addis Ababa, Ethiopia : a community-based cross-sectional study. *J. Health Popul. Nutr.* 36, 1–12. doi: 10.1186/s41043-017-0085-1

Afolabi, M. O., Daropale, V. O., Irinoye, A. I., and Adegoke, A. A. (2013). Health-seeking behaviour and student perception of health care services in a university community in Nigeria. *Health* 5, 817–824. doi: 10.4236/health.2013.55108

Akeju, D. O., Oladapo, O. T., Vidler, M., Akinmade, A. A., Sawchuck, D., Qureshi, R., et al. (2016). Determinants of health care seeking behaviour during pregnancy in Ogun State, Nigeria. *Reprod. Health* 13, 68–97. doi: 10.1186/s12978-016-0139-7

Ali, M., and de Muynck, A. (2005). Illness incidence and health seeking behaviour among street children in Rawalpindi and Islamabad, Pakistan - a qualitative study. *Child Care Health Dev.* 31, 525–532. doi: 10.1111/j.1365-2214.2005.00545.x

Andersen, R. M. (1995). Revisiting the behavioral model and access to medical care: does it matter? *J. Health Soc. Behav.* 36, 1–10. doi: 10.2307/2137284

Babitsch, B., Gohl, D., and von Lengerke, T. (2012). Re-revisiting Andersen's behavioral model of health services use : a systematic review of studies from. *Psychosoc. Med.* 9, 1–15. doi: 10.3205/psm000089

Barnes, B. (2019). "Transformative mixed methods research in South Africa: Contributions to social justice," in *Transforming Research Methods in Social Sciences: Case Studies from South Africa*, eds S. Laher, A. Fynn, and S. Kramer (Johannesburg: Wits University Press), 303–316. doi: 10.18772/22019032750.24

Basharat, S., Shaikh, B. T., Rashid, H. U., and Rashid, M. (2019). Health seeking behaviour, delayed presentation and its impact among oral cancer patients in Pakistan: a retrospective qualitative study. *BMC Health Serv. Res.* 19, 715. doi: 10.1186/s12913-019-4521-3

Bekele, K. (2020). City gets street children rehabilitation center. *THE Reporter*. Available online at: https://www.thereporterethiopia.com/9666/ (accessed August 1, 2023).

Brhane, T., Assefa, B., and Birhan, N. (2014). Reproductive health behaviour of street youth and associated factors in Gondar city, Northwest Ethiopia. *Int. J. Med. Biomed. Res.* 3, 28–37. doi: 10.14194/ijmbr.3.1.6

Brierley, J. (2017). The role of a pragmatist paradigm when adopting mixed methods in behavioral accounting research. *Int. J. Behav. Account. Financ.* 6, 140–154. doi: 10.1504/IJBAF.2017.086432

Che, S., Barrett, E., Velez, M., Conn, S., Heinert, S., and Qiu, X. (2014). Using the health belief model to illustrate factors that influence risk assessment during pregnancy and implications for prenatal education about endocrine disruptors. *Policy Futures Educ.* 12, 961–974. doi: 10.2304/pfie.2014.12.7.961

Chowdhury, S., Chowdhury, A. S., Huq, K. A., Jahan, Y., Chowdhury, R., Ahmed, T., et al. (2017). Life style and risk behavior of street children in Bangladesh: a health perspective. *Health* 09, 577–591. doi: 10.4236/health.2017.94041

Conticini, A., and Hulme, D. (2007). Escaping violence, seeking freedom: why children in Bangladesh migrate to the street. *Dev. Change* 38, 201–227. doi: 10.1111/j.1467-7660.2007.00409.x

Cornally, N., and McCarthy, G. (2011). Help-seeking behavior: a concept analysis. *Int. J. Nurs. Pract.* 17, 280–288. doi: 10.1111/j.1440-172X.2011.01936.x

Costa, M. (2022). How to ensure data quality in field research. *Survey CTO*. Available online at: https://www.surveycto.com/blog/how-to-ensure-data-quality/ (accessed February 2, 2023).

Cumber, S., and Tsoka-Gwegweni, J. (2015). The health profile of street children in Africa: a literature review. *J. Public Health Afr.* 6, 566. doi: 10.4081/jphia.2015.566

Eshita, I. R. (2018). Health problems and health care seeking behavior of street children in Dhaka city. *MOJ Cell Sci. Rep.* 5, 9–13. doi: 10.15406/mojcsr.2018.05.00107

Ferrara, F., and Ferrara, V. (2005). *The Children's Prison: Street Children and India's Juvenile Justice System*. OHEnglish.pdf. Available online at: https://scholar.google.com/citations?view_op=view_citation&hl=en&user=1A0ZiBgAAAAJ&citation_for_view=1A0ZiBgAAAAJ:r0BpntZqJG4C (accessed February 2, 2023).

Ferrer, R., and Klein, W. M. (2015). Risk perceptions and health behavior. *Curr. Opin. Psychol.* 5, 85–89. doi: 10.1016/j.copsyc.2015.03.012

Fusch, P., and Ness, L. (2015). Are we there? Data saturation in qualitative research. *Qual. Rep.* 20, 1408–1416. doi: 10.46743/2160-3715/2015.2281

Guta, A., Amsalu, B., Weldamanuel, T., Sema, A., Abera, L., Demissie, B. S., et al. (2021). Utilization of modern contraceptives and associated factors among street women in Dire Dawa, Eastern Ethiopia: a mixed study. *Reprod. Health* 18, 212. doi: 10.1186/s12978-021-01263-z

Harvey, J., and Lawson, V. (2009). The importance of health belief models in determining self-care behavior in diabetes. *Diabet. Med.* 26, 5–13. doi: 10.1111/j.1464-5491.2008.02628.x

Heale, R., and Twycross, A. (2015). Validity and reliability in quantitative studies. *Evid. Based Nurs.* 18, 66–67. doi: 10.1136/eb-2015-102129

Jahan, N. A., Ishaq, S. R. H. N. S. F., and Rahman, M. Z. H. S. T. (2015). *Health Care Seeking Behavior of Slum-Dwellers in Dhaka City: Results of a Household Survey*. Report pre. Available online at: https://www.who.int/docs/default-source/searo/bangladesh/pdf-reports/year-2014-2015/health-care-seeking-behavior-of-slum-dwellers-in-dhaka-city---results-of-a-household-survey.pdf?sfvrsn=80237a60_2 (accessed February 2, 2023).

Jalu, M. T., Ahmed, A., Hashi, A., and Tekilu, A. (2019). Exploring barriers to reproductive, maternal, child and neonatal (RMNCH) health-seeking behaviors in Somali region, Ethiopia. *PLoS ONE* 14, e0212227. doi: 10.1371/journal.pone.0212227

Kaime-Atterhog, W. (2012). *From Children of the Garbage Bins to citizens: A Reflexive Ethnographic Study on the Care of "Street Children". Digital Comprehensive Summaries of Uppsala Dissertations from the Faculty of Medicine 790*. Available online at: https://www.diva-portal.org/smash/get/diva2,542215./FULLTEXT01.pdf (accessed February 2, 2023).

Kapali, R. (2011). *Health Seeking Behavior and Coping Strategies Used by Street Children of Evaluation Committee Table of Contents*. Academia. Available online at: https://www.academia.edu/3854232/HEALTH_SEEKING_BEHAVIOR_AND_COPING_STRATEGIES_USED_BY_STREET_CHILDREN_OFEVALUATION_COMMITTEETABLE_OF_CONTENTS (accessed July 26, 2023).

Khalil, M. M., Malik, E. M., Mohamed, N., Alnair, A., Ismail, I., Abu, M., et al. (2019). Factors affecting health seeking behaviors among mothers of under five children attending primary health care centers, Sudan. *Sci. J. Public Health* 7, 181–186. doi: 10.11648/j.sjph.20190706.11

Kuuire, V. Z., Bisung, E., Rishworth, A., Dixon, J., and Luginaah, I. (2015). Health-seeking behaviour during times of illness : a study among adults in a resource poor setting in Ghana. *J. Public Health* 38, 545–553. doi: 10.1093/pubmed/fdv176

Latunji, O., and Akinyemi, O. (2018). Factors influencing health-seeking behavior among civil servants in Ibadan, Nigeria. *Ann. Ib. Postgrad. Med.* 16, 52–60.

Mackian, S. (2002). *Health Systems Development Programme A Review of Health Seeking Behaviour : Problems and Prospects*. Health Systems Development Programme. Manchester: University of Manchester.

Mackian, S. (2004). Up the garden path and over the edge: where might health-seeking behaviour take us? *Health Policy Plann.* 19, 137–146. doi: 10.1093/heapol/czh017

MOLSA (2018). *Scoping Study of People with Special Needs (Urban Destitute) and Service Providers in 11 Cities of Ethiopia: Final Report. Federal Democratic Republic of Ethiopia, Ministry of Labor and Social Affairs (MOLSA)*. Urban Productive Safety Net Project (UPSNP) (IDA 57560, 151712. RFP No. UPSNP/C-021/17). Available online at: https://www.mowsa.gov.et/download-category/other-resources/ (accessed February 2, 2023).

Mushtaq, K., Hussain, M., Afzal, M., and Gilani, S. A. (2020). Factors affecting health seeking behavior and health services in Pakistan. *Natl. J. Health Sci.* 5, 30–34. doi: 10.21089/njhs.51.0030

Oberoi, S., Chaudhary, N., Patnaik, S., and Singh, A. (2016). Understanding health seeking behavior. *J. Family Med. Prim. Care* 5, 463–464. doi: 10.4103/2249-4863.192376

Rahman, M., Mabibur, R., Sultana, P., and Vincentas, G. (2016). Health seeking behavior and healthcare access to married women in bangladesh: encouraging and discouraging factors. *S. Asian J. Participative Dev.* 16, 5–13. Available online at: https://www.researchgate.net/publication/356960395_Health_Seeking_Behavior_and_Healthcare_Access_to_Married_Women_in_Bangladesh_Encouraging_and_Discouraging_Factors#fullTextFileContent

Said, N., and Aldewachi, A. (2020). *Exploring the Socioeconomic Conditions and Health Behavior of Street Children in Mosul, Isaq*. Available online at: https://www.researchgate.net/publication/343879867_Exploring_the_Socioeconomic_Conditions_and_health_behavior_of_Street_Children_in_Mosul_Iraq/stats (accessed February 2, 2023).

Siddiqui, M. S. (2014). Health seeking behavior of the people; knowledge, attitudes and practices (KAP) study of the people of urban slum areas of Karachi. *Prof. Med. J.* 18, 626–631. doi: 10.29309/TPMJ/2011.18.04.2651

Smart, J. (2018). *Ethical Considerations in Research and Evaluation with Children and Young People*. Available online at: https://aifs.gov.au/cfca/2018/03/08/ethical-considerations-research-and-evaluation-children-and-young-people (accessed February 2, 2023).

StreetInvest (2020). *Head Counting of Street Children in Addis Ababa and Adama (Nazreth), 2010/11*. Available online at: https://streetinvest.org/wp-content/uploads/2020/09/StreetInvest-Head-Count-Report-2010-11-Addis-Ababa-and-Adama_0.pdf (accessed February 2, 2023).

Tadele, G. (2009). 'Unrecognized victims': sexual abuse against male street children in Merkato area, Addis Ababa. *Ethiop. J. Health Dev.* 23, 175–182. doi: 10.4314/ejhd.v23i3.53238

Tahmina, A., Nasrin, H., Mamunur, R., Bedanta, R., and Anthony, L. (2018). Risk behaviors of street children in Dhaka city, Bangladesh: a cross-sectional study. *Open Access J. Microbiol. Biotechnol.* 3, 1–10. doi: 10.23880/OAJMB-16000130

Tarkang, E. E, and Zotor, F. B. (2015). Application of the health belief model (HBM) in HIV prevention: a literature review. *Cent. Afr. J. Public Health* 1, 1–8.

Tegegne, A., and Legese, M. (2014). The urban poor and health seeking behavior: global. *J. Hum. Soc. Sci. H Interdiscip.* 14, 1–14. Available online at: https://globaljournals.org/GJHSS_Volume14/2-The-Urban-Poor-and-Health.pdf (accessed February 2, 2023).

Uche, E. O. (2017). Factors affecting health seeking behaviour among rural dwellers in nigeria and its implication on. *Eur. J. Soc. Sci. Stud.* 2, 74–86. doi: 10.5281/zenodo.400695

Veale, A., Adefrisew, A., and Lalor, K. (1993). *Study on Street Children in Four Selected Towns of Ethiopia.* Addis Ababa: Ministry of Labor and Social Affairs, Ethiopia. UNICEF, Ethiopia, University College Cork, Ireland. Availabl online at: https://cora.ucc.ie/bitstream/handle/10468/2068/Study%20on%20Street%20Children.pdf?sequence=1andisAllowed=y (accessed February 2, 2023).

Webair, H. H., and Bin-Gouth, A. S. (2013). Factors affecting health seeking behavior for common childhood illnesses in Yemen. *Patient Prefer. Adher.* 2013, 1129–1138. doi: 10.2147/PPA.S51124

Woan, J., Lin, J., and Auerswald, C. (2013). The health status of street children and youth in low- and middle-income countries: a systematic review of the literature. *J. Adolesc. Health* 53, 314–321.e12. doi: 10.1016/j.jadohealth.2013.03.013

Zewude, B. (2018). Vulnerability to reproductive health risks among on-street women in Shashemene. *East Afr. J. Soc. Sci. Humanit.* 3, 57–68. doi: 10.20372/eajssh.v3i2.466

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EDITED BY
Magdalena Klimczuk-Kochańska,
University of Warsaw, Poland

REVIEWED BY
Meera Padhy,
University of Hyderabad, India
Min Qin,
University of Southampton, United Kingdom

*CORRESPONDENCE
Ashwin Tripathi
✉ ashwin.tripathi@iitgn.ac.in

†These authors have contributed equally to this work

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Leisure as social engagement: does it moderate the association between subjective wellbeing and depression in later life?

Ashwin Tripathi[1]*† and Tannistha Samanta[2]†

[1]Indian Institute of Technology Gandhinagar, Gandhinagar, India, [2]Flame University, Pune, Maharashtra, India

Objectives: To investigate the role of leisure (as social engagement) in moderating the association between subjective wellbeing and depressive symptoms among older Indians.

Methods: The sample included data from 39,538 older adults (aged 55–80) from the Longitudinal Aging Study in India (LASI, Wave-1), 2017–2018. Individual level questionnaire was used to examine the relationship among social engagement, subjective wellbeing, and depressive symptoms. Moderating effects of leisure activities were estimated through interaction analysis and linear multivariable modeling.

Results: Low participation in social engagement activities (or leisure) was associated with greater likelihood of depressive symptoms. Leisure activities positively and significantly moderated the subjective wellbeing among older adults with depressive symptoms. Results suggest a significant wealth gradient where affluent older Indians having a clear advantage in heightened levels of social engagement and subsequently lower likelihood of depressive symptoms. Additionally, being in an urban area, co-residence in a "joint" household and belonging to the dominant social groups in terms of caste and religious categories are associated with gains in wellbeing.

Discussion: The direct and indirect effects of social engagement suggest that depressive symptoms can be mitigated while enhancing overall wellbeing of older adults. This holds promise for social policy in redirecting efforts to develop age-friendly initiatives and social infrastructure that enhance the link between engagement and wellbeing.

KEYWORDS

leisure, social engagement, subjective wellbeing, depression, aging, LASI-Wave 1, India

Introduction

The human experience of aging has profound implications for economy, society and policy across the globe. Though sociodemographic trends of increasing life expectancy, declining fertility, changing living arrangements or pension and social security provisioning have been uneven across the world regions, but there is no denying that older adults now, regardless of their geographical location, spend more years in their post-retirement lives. Building on this backdrop, many scholars (Caputo and Simon, 2013; Agarwal et al., 2020) have shown concerns around rising needs for developing long-term care services, ensuring physical and mental wellbeing in later lives. Although the new generations of older adults are more healthy, active and engaged (Katz, 2000; World Health Organization, 2015), as captured by Laslett (1991) seminal concept of the "Third Age" where new forms of engagement and temporal autonomy (Gilleard and Higgs, 2002), that builds on the influential notion of "Successful Aging" (Kahn and Rowe, 1998), is crucial in understanding the continued participation of older people in economic and social activities. However, at the same time, scholars (Djernes, 2006; Goel et al., 2014) have noted the growing instances of geriatric depression among middle-age and older individuals. Psychometric disorders like these, further intensify the complications in gradual increase in physical illness and other risks of new disease and elevates mortality (Hossain et al., 2021). In fact, elderly depression can be considered as the outcome of physical and mental health and further entangled with socio-economic difficulties. Therefore, it becomes crucial to see if notions of successful aging (particularly, activity-based engagement) affect the mental wellbeing of the elderly. As such, there is now a well-established empirical link between "successful" or "productive" aging and overall wellbeing and improved quality of life (Baltes and Smith, 2003; Bowling, 2007). This becomes even more interesting in Asian contexts such as India, where the post-retirement lives are not always constructed around the ideals of "successful" aging; instead, a combination of patriarchal ideologies and economic realities compel different trajectories across gender, class and age groups (Dhal, 2017; Jecker, 2020).

There has been a growing interest in understanding the patterns of time-use among older persons since successful aging has been linked with how time is spent in activities that affect life satisfaction (see Gauthier and Smeeding, 2003, 2010). However, the empirical link between time-use for active and successful aging is not well documented (Kim, 2019; Wanka, 2019; Vilhelmson et al., 2022). Scholars (Sprod et al., 2015, 2017; Strazdins et al., 2016; Weir et al., 2018) have defined how people choose to use their time to engage in various activities of daily life as a prominent indicator of successful aging. This is further delimited by contextual complexities (Samanta, 2018; Lamb, 2020), where few scholars have (Lamb, 2014; Samanta, 2018) critiqued the western ideal of "successful aging" (with its emphasis on the individual self as a project) and argued for alternative cultural models of aging well built around ideals of harmony, self-acceptance and fate-determinism. Nonetheless, irrespective of the cultural context, mental health is an important determinant of successful aging and longevity (Fancourt and Tymoszuk, 2019) but is prone to decline with age due to numerous life events and circumstances experienced by older adults (such as bereavement-led lone living, impoverished social interactions, poor health, retirement) (Fancourt and Tymoszuk, 2019). In fact, to what extent and in what forms current generations of older adults engage in everyday activities remain unknown, especially in the developing world; and how active engagement could provide improved wellbeing remains unaddressed. That said, the role of social support/networks, living with spouse and socio-economic status has been recently explored using the recently released panel data on aging—Longitudinal Aging Survey in India (LASI) baseline survey (Wave 1, 2017–2018) (Hossain et al., 2021; Muhammad and Maurya, 2022; Muhammad and Rashid, 2022) to identify factors that can protect against the development of mental health issues like depression. But the link between social engagement (through leisure) and wellbeing remains underexplored (Adams et al., 2011; Chang et al., 2014). Given this lack, we examine how the everyday social engagement (aka, leisure) activities of older adults are utilized using the LASI dataset. Our exploration of these activities is based on the argument that people's everyday activity patterns—i.e., their time spent on daily activities and for different purpose have crucial implications for individual health and wellbeing (Havighurst, 1968; Weir et al., 2018; Bauman et al., 2019) and more specifically for individuals suffering from depression.

Put simply, the objective of this study was to investigate the role of social engagement through leisure practices in moderating the decreased subjective wellbeing experience among Indian older adults showing depressive symptoms. The study also seeks to understand the impact of socio-demographic features such as social class, urban residence, living arrangements and belonging to dominant social groups (caste and religious categories) on subjective wellbeing. Overall, with the growing aging population and mental health concerns—it is reasonable to examine pathways through which social policies and age-friendly initiatives can be re-directed to develop appropriate age-friendly societies in post-reform India.

Social-psychological wellbeing in later life: a review of existing scholarship

India is the second most populous country in the world with roughly 138 million[1] of 60+ persons (∼10.1%) in the total population (Arokiasamy et al., 2012). India added 34 million older persons from its last Census (2011) and this number is expected to increase by 56 million by the year 2031 (or 13.1% of the total population). While an alarmist narrative about "population explosion" (Hartmann, 2010) dominated demographic knowledge in the early decades of post-colonial India, this shifted quickly to aging being a "problem" given the changing social (modernization, urbanization, and changing family structures) and policy contexts. It is only recently that an attention to other dimensions of growing old, such as the role of social networks (Hirve et al., 2014; Himanshu et al., 2019), role of affective cultures (Brijnath, 2012; Devi et al., 2021); time-use patterns (Tripathi and Samanta, 2023b) and biometric parameters (Arokiasamy et al., 2012), allow innovative analysis of quality of life among older Indians (Mandi and Bansod, 2022).

One of the emerging public health concerns and a greater social challenge is the prevalence of depression among middle-aged to older people worldwide. India is no exception. For example, in a recent study, Muhammad and Maurya (2022) using LASI data reported that ∼35% of the Indian older population suffers from depression. WHO International[2] (2017) describes depression as a serious mood disorder that can affect the way individuals feel, act and think. It also holds ability to further intensify complications in treating physical illness and one's functionality (Pinquart and Sörensen, 2001; de Jong Gierveld and

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[1] https://www.mospi.gov.in/documents/213904/301563/Elderly%20in%20India%202021162798514 4626.pdf/a4647f03-bca1-1ae2-6c0f-9fc459dad64c

[2] Mental health of older adults (who.int) (https://www.who.int/news-room/fact-sheets/detail/mental-health-of-older-adults) (accessed March 10, 8:25 a.m.).

Hagestad, 2006). Although it is a common psychiatric disorder (Mirowsky and Ross, 2002; Butler, 2004) that can occur in childhood, adolescence, and in later life (Miech and Shanahan, 2000; Hammen, 2009) but impacts far greatly the older population. Chronic depression might also lead to loss of physical health, independence, employment and income, family and friends, house and safe environment (Van Baarsen et al., 2001). Older people across the world have found such event further escalating their health deterioration in case of inadequate coping strategies (Van Baarsen et al., 2001; Blazer, 2003; Drageset, 2004; Batistoni et al., 2007; Shahbazzadeghan et al., 2010; Drageset et al., 2011). Studies from India have consistently shown that those with poor self-rated health and functional limitations are at a significantly higher risk of depressive symptoms. Further, in contexts such as India where patriarchal ideologies restrict older women's access to mobility, re-partnering and economic security, widowhood has been shown to be associated with higher likelihood of late-life depression and cognitive impairment (Srivastava et al., 2021). Additionally, given the familial context of care and instrumental support in older ages, living alone (leading to an erosion of social capital) and residing in a rural area have been shown to be associated with higher proportion of depressive symptomology and feelings of loneliness among older Indians (Samanta, 2014; Muhammad and Meher, 2021).

At the same time, the growing global popularity of the successful aging paradigm, numerous studies have focused on interventions for promoting absence of mental and physical illnesses. Notwithstanding the critics of this paradigm, big cohort studies like *MacArthur Study of Successful Aging* (Berkman et al., 1993) and *Berlin Aging Study* (Baltes and Mayer, 2001) have explored the "what" of successful aging and determined a range of complex physical and cognitive abilities of older men and women functioning at high, medium and impaired ranges and further elaborated on the psychosocial and physiological conditions to distinguish among the old age groups. Thus, segregating the young-old from the old-old cohorts which are further influenced by the contemporary changes of consumerism and globalization. Escolar Chua and De Guzman (2014) experimental study on the effects of community-based third age learning program among older Filipino, showed that the treatment group showed higher life satisfaction, increased self-esteem and lower levels of depression. Similarly, numerous other studies have linked (social) engagement activities of older adults to positive health related outcomes (Aldridge and Lavender, 2000; Dench and Regan, 2000; Swindell, 2002; Elderhostel Inc., 2007; Formosa, 2010).

Third age, social engagement, and wellbeing: examining the pathways

Given the recent interest in gerontological scholarship on how late adulthood is lived, scholars have examined the link between Third Age lifestyles and overall wellbeing in later life. To be sure, Third Age is recognized as a (post-retirement) time for personal fulfillment and vitality among those who have acquired adequate savings and are hence able to make lifestyle-based consumerist choices. For example, research from Poland (Zadworna, 2020) showed that retirees who are engaged in Third Age related interventions (e.g., educational activities that promote lifelong learning) reported higher levels of self-rated health and life satisfaction than those who were not participating in such activities. Again, earlier studies have shown how Third Age activities such as volunteering and other forms of civic engagement serve as a vehicle through which social capital is reaped. This in turn promotes a heightened sense of self-worth and wellbeing among older adults (Hendricks and Cutler, 2004). Their active engagement in diverse forms of activities contributes toward their mental and physical alertness. There exists ample evidence for this positive correlation that can reduce the burden of health expenditures associated with population aging (Krawczynski and Olszewski, 2000; Cohen, 2005; Elderhostel Inc., 2007; Flood and Phillips, 2007; Nadasen, 2007; Hanna and Perlstein, 2008) and cognitively stimulating activities through sustained commitment to lifelong learning has led to increased life satisfaction and hence, successful (active/productive) aging (Escolar Chua and De Guzman's, 2014). Following Arai and Pedlar (2003), who argue toward emphasizing community, social capital and communal leisure practices to explore the social relevance of leisure, we explore the social engagement activities from LASI survey. As such, the activity theory (Havighurst, 1961; Longino et al., 1982) in gerontology which is often used as a shorthand for explaining increased wellbeing and reduced social isolation among older persons is built on the premise that (social) activity through satisfaction with outcomes, mental stimulation and personal routines improve self-efficacy. While health benefits of physical activity are well-established in gerontological tradition (Lancet, 2021), researchers have increasingly recognized the importance of social support pathways with friends, family kinship ties as promoting cognitive reappraisals making stressful situations less stressful (Lazarus and Folkman, 1984; cited in Adams et al., 2011). Building on this body of work, the current paper conceptualizes leisure as social engagement. The LASI survey offers a useful empirical site to examine the association between social engagement-based leisure activities and wellbeing in later life.

The activity-wellbeing link has been a key signifies for the Third Age lifestyle globally. In India, Third Agers are primarily urban, (upper) middle-class older adults—a growing cohort of "new-age elderly" (Samanta, 2018; Lamb, 2020)—who have been participants of outdoor leisure/travel, housing projects, fashion and lifestyle-based markets. This shift has ushered a post-retirement life among urban (upper) middle-class older Indians where leisure and experience can be "purchased without a loss of a productive and vital self" (Samanta, 2018, p. 95). Replacing the traditionally aspired dependence discourse of old age-commonly associated with aging in family-centric contexts-with leisure-based consumptive lifestyles, have motivated cultural anthropologists to remind us how the access and availability of free time varies across the social class (Samanta, 2018; Lamb, 2020). As such, this story about the politically influential middle to upper middle-class Indians with adequate residual spending power and cultural capital to engage in age-ambiguous consumer citizenry, is now well documented by academic commentators in India (Fernandes and Heller, 2006; Srivastava, 2007; Baviskar and Ray, 2020). In our previous work, we operationalize third age in the context through active participation in social engagement activities, as authors have noted that time-use is a valuable descriptor of people's lifestyle, as studying how people spend their time is critical for understanding the determinants and consequences of individuals' overall wellbeing and life satisfaction (Tripathi and Samanta, 2023a,b). On similar lines, Padhy et al. (2015) explores the positive relationship between leisure activities, wellbeing and life-satisfaction among young adults through leisure motivation. However, for a long time India has struggled to collect data on time-use variabilities of gender and generation (Hirway, 2021). Only recently, we have two nationally representative datasets—(i) LASI data which utilizes the stylized questions method in elucidating the time-use of older adults in their experimental module and (ii) the National Sample Survey Organization (NSSO) (2017–2018) that uses the time-diary approach in collecting time-use information. As we look into the completely unexplored area of older adults' time allocation pattern, we explore the LASI data to study the impact of social engagement activities with subjective wellbeing of the Indian elderlies. For this, we hypothesize the following below. Figure 1 shares the conceptual model for this study.

Hypothesis

H_1: Older adults with higher depressive symptoms are more likely to report lower levels of SWB, regardless of their socio-demographic characteristics.

H_2: Heightened levels of leisure (here, social engagement) are associated with advantageous socio-economic characteristics such as economic affluence, living with child(ren)/spouse and social affiliation with dominant castes and religious categories. As a corollary to this hypothesis, we argue that the leisure-socioeconomic nexus is a determinant of depressive symptoms and overall SWB.

Methods

Data and sample

LASI data set

This study utilized data from the nationally representative survey of the LASI Wave 1 (2017–2018), which investigates the health, economic, and social determinants and consequences of population aging in India. The representative sample included 72,250 individuals aged 45 years and above and their spouses across all states and union territories (UTs) of India except Sikkim. LASI adopts a multistage-stratified area probability cluster sampling design to select the eventual units of observation (a three-stage sampling design in rural areas and a four-stage sampling design in urban areas) (Detailed information on the sampling frame is available in https://www.iipsindia.ac.in/sites/default/files/LASI_India_Report_2020_compressed.pdf). The LASI survey provides scientific evidence on demographics, household economic status, chronic health conditions, symptom-based health conditions, functional and mental health, biomarkers, healthcare utilization, work and employment etc. Further, an individual survey schedule was administered to each consenting respondent aged 45 and above and their spouses (irrespective of age) in the sampled households. In addition, the LASI includes an individual module on biomarkers and direct health examination. The present study is based on the eligible respondents who are aged 55–80 years. The effective sample size for the present study was 39,538 older adults aged 55 and above, including 18,687 males and 20,851 females.

Measures

Depressive symptoms

In LASI, two internationally validated and comparable tools are used to assess depressive symptoms and episodes: the Center for Epidemiologic Studies Depression (CES-D) scale was used to identify the presence of depressive symptoms (Radloff, 1977) and the Composite International Diagnostic Interview—Short Form (CIDI-SF) scale, a structured interview scale, was used for diagnosing probable major depression (Kessler and Üstün, 2004). The CESD comprised of 10-item scale including questions (a) *How often did you have trouble concentrating*?, (b) *How often did you feel depressed?*, (c) *How often did you feel tired or low in energy?*, (d) *How often were you afraid of something?*, (e) *How often did you feel you were overall satisfied?*, (f) *How often did you feel alone?*, (g) *How often were you bothered by things that don't usually bother you?*, (h) *How often did you feel that everything you did was an effort?*, (i) *How often did you feel hopeful about the future?*, and (j) *How often did you feel happy?*. The Cronbach score for depressive symptoms was 0.79. Negatively framed questions were reversed scored ranging from (1) rarely or never (<1 day) to (4) Most or all the time (5–7 days). The scores were summed, with higher scores indicating higher levels of depressive symptoms (range 4–40). A depression dummy variable was created with scores <17 being coded as 0 and above 17 coded as 1. As the CESD scale for depression monitoring is globally acceptable and a score of more than 16 is considered to be depressed, we stick to the score 17 for creating our dummy variable (Muhammad et al., 2022).

Subjective wellbeing

In this paper, we use the LASI life satisfaction inventory that was assessed with a five-item scale that asks people how satisfied they are with their life (a) *In most ways my life is close to ideal*, (b) *the conditions of my life are excellent*, (c) *So far, I have got the important things I want in life*, (d) *If I could live my life again, I would change almost nothing*. In the questionnaire, the respondents were provided with seven response categories, ranging from (1) Strongly disagree to (7) Strongly Agree. A higher value indicating higher LS (continuous). This is a standard measure-defined as the self-assessed worth of an individual's life- used in other health surveys and reflects overall wellbeing of respondents in a reliable way (see Stephen et al., 2014 for a discussion on the age-related changes of multiple wellbeing measures).

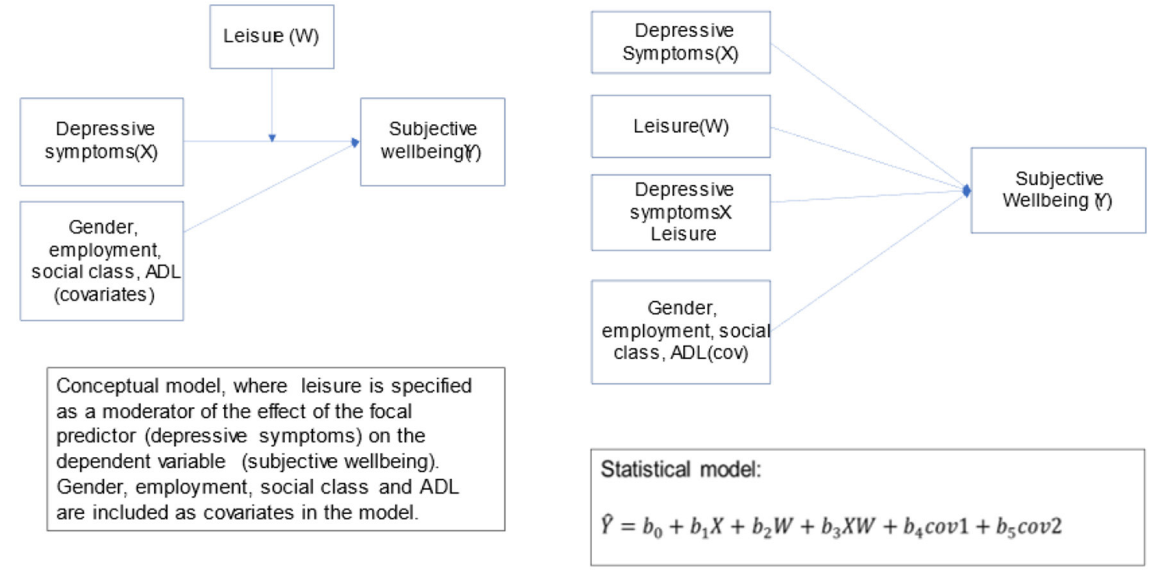

FIGURE 1
Conceptual model.

This was collected under the family and social network section of the LASI (2017–2018) questionnaire that also included questions related to discrimination (ill treatment) and psychosocial measures (life satisfaction, religiosity). We use psychosocial measures as a proxy for older adults' subjective wellbeing. The Cronbach score for subjective wellbeing is 0.89.

Leisure as social engagement

Defined as the extent to which an individual engages in social activities that are meaningful to them (Kumar et al., 2006), social activities were measured in LASI according to the reported frequency of participation in 11 social activities (Cronbach alpha 0.65). We use the social engagement as a proxy for their leisure. Examples include "[Attending] an educational or training course," and "[Going] to a sport, social, or other club". Frequency of participation in each activity was reported on a 7- point Likert scale ranging from 1 = "daily" to 7 = "never". This was recoded into binary categorical variable −1 = "yes" and 0 = "no". We created an additive summary index of the social activities' variables, where higher scores were indicative of higher social activities (range: 0–13). For analysis purposes, we created dummy binary variable (0 for no leisure activities and 1 for leisure activities ranging from 1 to 13).

Covariates

Other variables considered in analyses include age (years), gender, wealth index (proxy for social class) number of limitations of daily living (ADL; range: 0–3+), living arrangements, education and caste are utilized in analyzing the role of leisure on SWB among older adults with depressive symptoms.

Analysis

Sample distributions of demographic and health characteristics were compared across major depression diagnostic groups using t-tests and chi-square tests ($\alpha = 0.05$). This was followed by a Spearman's rank correlation analysis to identify potential sociodemographic, health, and behavioral predictors of depressive symptoms and subjective wellbeing. For instance, spearman correlation for depression and subjective wellbeing is −0.046, subjective wellbeing and leisure is 0.0784 and between leisure and depression is 0.032 (all at $p < 0.001$). Once we got the correlation coefficients, we identified potential variables across which the empirical model could be built. For the final analysis, we fit (two models) independent models for each measure of depression (CESD scale values), life satisfaction, and leisure. In each model, we estimated the total effect of depression on subjective wellbeing of older adults and the effect of social engagement via leisure/social engagement activities. The assumption of normality of the outcome/dependent variable was analyzed through skewness and kurtosis in the descriptive analysis. Similarly, homoscedasticity and absence of multicollinearity was confirmed through scatterplot and crosstabs, respectively. We first fit an unadjusted bivariate linear regression model estimating the association between depression and subjective wellbeing. We also added potential confounders to the model. These analyses were performed using Stata software (version 16).

Regression model

$$y_i = \beta_0 + \beta_1 x_i + \beta_1 z_i + \varepsilon_i \tag{1}$$

In the above Equation (1), y represents the predicted/outcome variable, i.e., subjective wellbeing of older adults age 55–80 years old. This is understood as the function of (i) depressive symptoms, depicted by x and (ii) social engagement activities shown by z. While β_0 represent the intercept, i.e., the constant value of subjective value when both x (depressive symptoms) and z (leisure) is equal to zero. At last, ε_i represents the residual/unexplained variation in the model that has not been taken into consideration. Below are more detailed equations to explain our theoretical models:

$$\mathrm{SWB_i}\ (y) = \beta_0 + \beta_1\,\mathrm{Depression_i} + \beta_2\,\mathrm{Leisure_i} + \varepsilon_i \qquad (2)$$

$$\begin{aligned}\mathrm{SWB_i}\ (y) &= \beta_0 + \beta_1\,\mathrm{Depression_i} + \beta_2\,\mathrm{Leisure_i}\\ &\quad + \beta_3\,(\mathrm{Depression} * \mathrm{Leisure})_i + \varepsilon_i \qquad (3)\end{aligned}$$

As per Equations (2) and (3), we now run these models in STATA-16 by also incorporating the covariates (discussed above) including gender, employment status, wealth index, living arrangements, education, caste, religion and ADL limitations in our sample to study the relationship.

Results

Descriptive statistics are detailed in Table 1. We considered older adults 55–80 years old. Age groups 55–60 and 61–65 comprise nearly 50% of our analytical sample. In both the age groups, we have more women respondent than men. The *t*-statistic test does show significant differences between both the genders across education, residence and wealth index. This is not presented in the tables but *t*-test was run in the background. Only 11% of our sample is aged 75 and above. This is expected as with age, the population size reduces and older adults with relatively better health have more chances of surviving. The data has been collected from urban and rural India but most female older adults show (∼67%) show no education. This statistic is better among the men, where only ∼35% men have had no access to education. Most of the study participant belonged to rural areas (66% men and 65% women). In terms of class structure, we operationalize social class using the wealth index that was collected as part of monthly per capita expenditure of older individuals. ADL limitations are quite common among older adults that includes concerns regarding struggles in doing everyday activities. Again, women show more limitations that men, where ∼50% of the women population have 1–3 limitations while only ∼32% of men show similar concerns. Intergenerational residence (living with spouse and is the most dominant form of living arrangement in the LASI sample (∼90% either living with their spouse/children). This is consistent with other studies that show the centrality of "joint family" as the defining characteristic of Indian households. Finally, we included variables characterizing social groupings in terms of caste (where "lower" caste groups include Scheduled Tribes, Scheduled Castes and Other Backward Castes, while the "forward" caste includes those in the "general" category). We know for a fact that Indian society remains highly stratified with status distinctions and hierarchies established through the routes of marriage, occupations, diet and lifestyle (see Desai, 2011; Natrajan and Jacob, 2018).

Table 2 shows the mean values and percentage of older adults for our three variables of interest. First, subjective wellbeing of older men and women does differ significantly and have a mean score of 24.22 for men and slightly lower for women at 23.70. Similarly, 46.9% men show depressive symptoms, while 49.6% women show similar effects. Again, more men engage in leisure activities (83.6%) while substantially lower women (79.3%) engage in leisure activities. We discuss the items included in each of our variables of interests in Table 2 in the methods section above.

In Table 3, represents nested, multivariate linear regression as also shown by Equation (2). We see for older adults who have depressive symptoms (continuous variable) show decreased subjective wellbeing ($\beta_1 = -0.186^{***}$). More specifically, if an older individual experience depressive symptom(s), the subjective wellbeing of individuals age 55–80 years old decrease by 18.6%. While for older adults who show no depressive symptoms, have a positive association with subjective well–being ($\beta_0 = 23.45^{***}$). With one unit increase in social engagement activities (as leisure) subjective wellbeing increases by ∼91%. Both the above stated results are statistically significant. Our theoretical motivation of older adults' social participation in improving overall/subjective wellbeing was further explored by interacting our two explanatory variables (depressive symptoms and social engagement activities). By interacting them (as shown in Equation 3), we see that individuals who show depressive symptoms but also engage in social activities, have positive impact on depressive symptoms ($\beta = 0.0522^{***}$). Thus, positively impacts their subjective wellbeing and is statistically significant as well.

We also see how this association varies across socio-demographic characteristics such as age, social class, living arrangements, caste and education. There is a clear age gradient in improved subjective wellbeing vis-à-vis leisure participation. For instance, as individuals age, their subjective wellbeing enhances, though the effect is not very neat. To complement this finding, we also see those individuals with activities of daily (ADL) limitations experience 49% less subjective wellbeing when compared to groups having no activities of daily limitations. Similarly, people living with spouse or children and with spouse and children (i.e., living in joint family structures) experience more subjective wellbeing than living alone or with others ($\beta = 2.4^{***}$). There also exists a strong caste component in the Indian context (check Appendix Table A1) where material and non-material gains (or otherwise) caste and social class belonging go hand in hand. For example, in Appendix Table A1, we see that older adults from unreserved caste experience 1.36% more subjective wellbeing compared to their reserved counterparts.

Discussion

The role of social engagement activities through leisure in enhancing the subjective wellbeing of older individuals with depressive symptoms

This paper examines the moderating role of social engagement activities among older individuals with depressive symptoms. This paper builds on the existing scholarship on Third Age that shows heightened levels of social engagement and leisure pursuits being associated with gains in overall later life wellbeing. We

TABLE 1 Socio-demographic characteristics of LASI (2017-18) sample.

Socio-demographic features	Total (N = 39,538)	Men (N = 18,687)	Women (N = 20,851)
Age group			
55–59	10,167 (25.71)	4,560 (24.40)	5,607 (26.89)
60–64	10,267 (25.97)	4,707 (25.19)	5,560 (26.67)
65–69	8,944 (22.62)	4,381 (23.44)	4,563 (21.88)
70–74	5,811 (14.70)	2,933 (15.70)	2,878 (13.80)
75–80	4,349 (11.00)	2,106 (11.27)	2,243 (10.76)
Education			
No education	20,235 (51.18)	6,419 (34.35)	13,816 (66.26)
Primary	9,689 (24.51)	5,549 (29.70)	4,140 (19.86)
Secondary	6,390 (16.16)	4,336 (23.20)	2,054 (9.85)
Higher	3,223 (8.15)	2,382 (12.75)	841 (4.03)
Residence			
Rural	26,006 (65.77)	12,407 (66.39)	13,599 (65.22)
Urban	13,532 (34.23)	6,280 (33.61)	7,252 (34.78)
Wealth index			
Poor	16,189 (40.95)	15,396 (38.94)	8,707 (41.76)
Middle	7,953 (20.11)	3,770 (20.17)	4,183 (20.06)
Affluent	15,396 (38.94)	7,435 (39.79)	7,961 (38.18)
Caste categories			
OBC	6,596 (16.97)	3,105 (16.87)	3,491 (17.06)
SC/ST	6,509 (16.74)	3,047 (16.55)	3,462 (16.92)
Upper caste (unreserved category)	14,865 (38.24)	7,116 (38.66)	7,749 (37.87)
Religion			
Hindu	28,503 (73.33)	13,544 (73.58)	14,959 (73.10)
Muslim	4,554 (11.72)	2,119 (11.51)	2,435 (11.90)
Christian	3,808 (9.80)	1,775 (9.64)	2,033 (9.93)
Others	2,007 (5.16)	970 (5.27)	1,037 (5.07)
ADL Limitations			
0	23,002 (58.18)	12,531 (67.06)	10,471 (50.22)
1	4,381 (11.08)	2,010 (10.76)	2,371 (11.37)
2	2,992 (7.57)	1,163 (6.22)	1,829 (8.77)
3+	9,163 (23.18)	2,983 (15.96)	6,180 (29.64)

Source: LASI Wave 1 (2017–18), Individual questionnaire, $n = 39,538$; weighted; (%s in parentheses).

mined the newly released Longitudinal Aging Study in India (LASI, 2017-18) data to show how social engagement activities, specifically leisure-based activities such as eating outside, playing, visiting friends and relatives and many more, to improve the subjective wellbeing of the older adults, even after controlling for their gender, age, social class, employment status and ADL limitations. As hypothesized, subjective wellbeing decreases with increased depressive symptoms. Previous studies, as described in our literature review, have emphasized this relationship between mental health issues and overall wellbeing of older individuals. As the social context of aging among the urban middle class in India is fast changing, we attempted to critique the alarmist narrative of social disengagement, dependence and debility that are commonly associated with later life. In fact, as suggested earlier, leisure-based activities and social engagement have remained outside the scope of gerontological scholarship in India. Some recent studies based on the baseline LASI data (which is currently cross-sectional in nature) focus on health inequalities depression and cognitive functioning,

TABLE 2 Descriptive statistics for variables of interest.

Variable	Men		Women		Pairwise *t*-test	
	N	Mean/(SE)	*N*	Mean/(SE)	*N*	Mean difference
Subjective wellbeing (SWB)	18,118	24.221	20,359	23.705	38,477	0.516***
		−0.053		−0.051		
Depression	18,111	17.692	20,363	18.032	38,474	−0.340***
		−0.038		−0.037		
Leisure	18,686	2.099	20,851	2.019	39,537	0.080***
		−0.003		−0.003		

Source: LASI Wave 1 (2017–18), Individual questionnaire; weighted. Statistical significance at $^{***}p < 0.01$.

TABLE 3 Multivariate linear regression estimates for depression and subjective wellbeing as moderated by leisure activities.

Variables	Subjective well being (independent)
Leisure	0.913***
	(0.307)
Depression	−0.186***
	(0.0333)
Depression * Leisure	0.0522***
	(0.0161)
Constant	23.45***
	(0.634)
Observations	38,418
R^2	0.015

Robust standard errors in parentheses.
$^{***}p < 0.01$.
$^{**}p < 0.05$.
$^{*}p < 0.1$.

elder abuse and depression (Muhammad et al., 2022), physical limitations and depressive symptoms (Hossain et al., 2021).

We hypothesized a negative association between depression and subjective wellbeing being moderated through social engagement as leisure (H_1). That is, engagement in leisure activities improves subjective wellbeing of individuals and more so among older adults with reported depressive symptoms. Our results reveal a positive influence of social engagement activities in mitigating the effects of depression among the Indian older adults and improving their subjective wellbeing (H_2) (as presented in Table 3). Our broader motivation for this paper lies at the emergence of Third Age (as a predictor for "successful aging") and how it relates to improved subjective wellbeing (Fancourt and Tymoszuk, 2019). In the process, we have shown that with older adults with no physical limitations experience improved wellbeing. Again, similar to other studies on older adult health outcomes (Gupta and Coffey, 2020; Vyas et al., 2022), we notice social group differentials in subjective wellbeing; specifically, being in the dominant caste (forward/none) and belonging to the affluent social class are associated with gains in subjective wellbeing. All in all, our analyses point to the Third Age lifestyle as an important predictor for aging successfully among urban middle-class older Indians.

Concluding remarks

Mental health is prone to decline with age because of life events (and thus increase in depressive symptoms) and circumstances commonly experienced by older adults. Many older individuals experience lone living, impoverished social interactions, poor health, retirement and worsening economic conditions (Barrientos et al., 2003). Many a times, it remains underdiagnosed and under treated that further leads to higher risk of dementia and other health shocks (Gupta and Coffey, 2020). Much research has been undertaken to identify factors that can protect again the development of depression, including social networks and social support, physical activity and cognitive stimulation. However, our study does not argue for preventive actions rather emphasizes the importance of social activities in mitigating the effects of depression on the subjective wellbeing of Indian older adults.

A similar study by Fancourt and Tymoszuk (2019) on their work on English Longitudinal Study of Aging (ELSA) argue that there has been growing research in demonstrating the effects of cultural engagement on depression. This includes studies of both active and receptive cultural engagement. Most of these studies, including ours have centered around the impact of cultural engagement on mitigating the effects of depression on the overall wellbeing of individuals. But we also argue that social engagement activities can also reduce the risk of depression in later years. This remains relevant, more so in the Indian context, as discussion around mental health among older individuals remain a tabooed topic. This could have led to non-response biases in the data among participants who experienced depressive episodes but did not report it.

One of the strengths of our study is the nationally representative older adults' baseline dataset which would incorporate subsequent waves of data collection in the coming years. Also, LASI uses well-validated measure of depression (CES-D scores) and has tested different thresholds (as the scale has been developed in this study through additive scores).

Limitations

Our study is however not without limitations. One of the empirical challenges we faced is the possibility of reverse causality of our interest variables. It is unclear if people who report high levels of subjective wellbeing (and lower likelihood of depression) are also the ones who engage in heightened levels of social activities. This raises the issue of reverse causality in the analysis of the relationship between subjective wellbeing, depression and leisure engagement activities. More specifically, this suggests that it is uncertain whether individuals who report higher levels of subjective wellbeing and lower likelihood of depression are the ones who actively engage in more social activities. We tried to partially mitigate the above problem by running our models with and without individuals with depression (results not reported in the paper) and we received similar results. Moreover, the LASI data does not provide data for individuals who are undergoing psychiatric treatment or medications (i.e., medically diagnosed cases of mental health issues). In addition to medically appropriate ethical data collection efforts, longitudinal/panel studies will help address questions of causality and selection bias thereby offering directions for effective and targeted interventions. Also, the findings also suggest the need to use qualitative assessment that explored the role of additional factors have on population's subjective wellbeing, thereby shaping public policy and form the foundation of intervention programs.

Implications

The paper highlights the importance of leisure activities in the lives of older adults. Through empirical evidence, we show that low participation in social engagement activities is associated with a higher likelihood of experiencing depressive symptoms. Therefore, we argue the importance of promoting and encouraging social engagement activities among older adults to enhance their overall subjective wellbeing. Interventions at policy level needs to consider aspects other than health in engaging older adults in their later lives. More specifically, create age-friendly initiatives and infrastructure that encourages engagement and improve mental health outcomes. Moreover, our findings also suggest a strong wealth gradient, where affluent older Indians experience heightened sense of social engagement. Therefore, policies need to address the inequities in accessing leisure, irrespective of their socio-economic status. Similarly, addressing the urban-rural differences in providing better access to social engagement opportunities, infrastructure and resources to contribute toward better wellbeing outcomes. Future research and interventions need to consider socio-cultural factors in planning initiatives, interventions and programs to provide more culturally sensitive and tailored needs in the context of older adults in India.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://www.iipsindia.ac.in/content/LASI-data.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

Adams, K. B., Leibbrandt, S., and Moon, H. (2011). A critical review of the literature on social and leisure activity and wellbeing in later life. *Ageing Soc.* 31, 683–712. doi: 10.1017/S0144686X10001091

Agarwal, A., Lubet, A., Mitgang, E., Mohanty, S., and Bloom, D. E. (2020). *Population aging in India: Facts, issues, and options*. Singapore: Springer, 289–311.

Aldridge, F., and Lavender, P. (2000). *The Impact of Learning on Health*. National Institute of Adult Continuing Education, 21 De Montfort Street, Leicester LE11 7GE, United Kingdom.

Arai, S., and Pedlar, A. (2003). *Moving Beyond Individualism in Leisure Theory: A Critical Analysis of Concepts of Community and Social Engagement*.

Arokiasamy, P., Bloom, D., Lee, J., Feeney, K., and Ozolins, M. (2012). "Longitudinal aging study in India: Vision, design, implementation, and preliminary findings," in *Aging in Asia: Findings From New and Emerging data initiative* (National Academies Press).

Baltes, P. B., and Mayer, K. U. (eds.) (2001). *The Berlin Aging Study: Aging From 70 to 100*. Cambridge: Cambridge University Press.

Baltes, P. B., and Smith, J. (2003). New frontiers in the future of aging: From successful aging of the young old to the dilemmas of the fourth age. *Gerontology* 49, 123–135. doi: 10.1159/000067946

Barrientos, A., Gorman, M., and Heslop, A. (2003). Old age poverty in developing countries: contributions and dependence in later life. *World Dev.* 31, 555–570. doi: 10.1016/S0305-750X(02)00211-5

Batistoni, S. S. T., Neri, A. L., and Cupertino, A. P. F. B. (2007). Validity of the center for epidemiological studies depression scale among Brazilian elderly. *Revista de saude publica* 41, 598–605. doi: 10.1590/S0034-89102007000400014

Bauman, A., Bittman, M., and Gershuny, J. (2019). A short history of time use research; implications for public health. *BMC Public Health* 19, 50. doi: 10.1186/s12889-019-6760-y

Baviskar, A., and Ray, R. (eds.) (2020). *Elite and Everyman: The Cultural Politics of the Indian Middle Classes*. Taylor and Francis.

Berkman, L. F., Seeman, T. E., Albert, M., Blazer, D., Kahn, R., Mohs, R., et al. (1993). High, usual and impaired functioning in community-dwelling older men and women: findings from the MacArthur Foundation Research Network on Successful Aging. *J. Clin. Epidemiol.* 46, 1129–1140. doi: 10.1016/0895-4356(93)90112-E

Blazer, D. G. (2003). Depression in late life: review and commentary. *J. Gerontol. Series Biol. Sci. Med. Sci.* 58, M249–M265. doi: 10.1093/gerona/58.3.M249

Bowling, A. (2007). Aspirations for older age in the 21st century: what is successful aging? *Int. J. Aging Hum. Dev.* 64, 263–297. doi: 10.2190/L0K1-87W4-9R01-7127

Brijnath, B. (2012). Why does institutionalised care not appeal to Indian families? Legislative and social answers from urban India. *Ageing Soc.* 32, 697–717. doi: 10.1017/S0144686X11000584

Butler, J. (2004). *Undoing Gender*. Psychology Press.

Caputo, J., and Simon, R. W. (2013). Physical limitation and emotional well-being: Gender and marital status variations. *J. Health Soc. Behav.* 54, 241–257. doi: 10.1177/0022146513484766

Chang, P. J., Wray, L., and Lin, Y. (2014). Social relationships, leisure activity, and health in older adults. *Health Psychol.* 33, 516. doi: 10.1037/hea0000051

Cohen, J. E. (2005). Human population grows up. *Sci. Am.* 293, 48–55. doi: 10.1038/scientificamerican0905-48

de Jong Gierveld, J., and Hagestad, G. O. (2006). Perspectives on the integration of older men and women. *Res. Aging* 28, 627–637. doi: 10.1177/0164027506291871

Dench, S., and Regan, J. (2000). *Learning in Later Life: Motivation and Impact.* Nottingham: DfEE.

Desai, S. (2011). *India's Social and Economic Transformation in the 21st Century*.

Devi, A., Hurd, L., and Samanta, T. (2021). Embodied aging: everyday body practices and later life identities among the South Asian Indian Gujarati diaspora in Canada. *Anthropol. Aging* 42, 86–104. doi: 10.5195/aa.2021.304

Dhal, G. K. (2017). *Middle class retirement in India: a qualitative study of active ageing, health, family relationships and quality of life* (doctoral dissertation). University of Surrey. Guildford, United Kingdom.

Djernes, J. K. (2006). Review article. Prevalence and predic-tors of depression in populations of elderly: a review. *Acta Psychiatr. Scand.* 113, 372–387. doi: 10.1111/j.1600-0447.2006.00770.x

Drageset, J. (2004). The importance of activities of daily living and social contact for loneliness: a survey among residents in nursing homes. *Scand. J. Caring Sci.* 18, 65–71. doi: 10.1111/j.0283-9318.2003.00251.x

Drageset, J., Kirkevold, M., and Espehaug, B. (2011). Loneliness and social support among nursing home residents without cognitive impairment: a questionnaire survey. *Int. J. Nurs. Stud.* 48, 611–619. doi: 10.1016/j.ijnurstu.2010.09.008

Elderhostel Inc. (2007). *Mental Stimulation and Lifelong Learning Activities in the 55+ Population*. Boston, MA: Author.

Escolar Chua, R. L., and De Guzman, A. B. (2014). Effects of third age learning programs on the life satisfaction, self-esteem, and depression level among a select group of community dwelling Filipino elderly. *Educ. Gerontol.* 40, 77–90. doi: 10.1080/03601277.2012.701157

Fancourt, D., and Tymoszuk, U. (2019). Cultural engagement and incident depression in older adults: evidence from the English Longitudinal Study of Ageing. *Br. J. Psychiatry* 214, 225–229. doi: 10.1192/bjp.2018.267

Fernandes, L., and Heller, P. (2006). Hegemonic aspirations: New middle class politics and India's democracy in comparative perspective. *Crit. Asian Std.* 38, 495–522.

Flood, M., and Phillips, K. D. (2007). Creativity in older adults: a plethora of possibilities. *Issues Mental Health Nurs.* 28, 389–411. doi: 10.1080/016128407012 52956

Formosa, M. (2010). Universities of the third age: a rationale for transformative education in later life. *J. Transform. Educ.* 8, 197–219. doi: 10.1177/1541344611419857

Gauthier, A. H., and Smeeding, T. M. (2003). Time use at older ages: cross-national differences. *Res. Aging* 25, 247–274. doi: 10.1177/0164027503025003003

Gauthier, A. H., and Smeeding, T. M. (2010). "Historical trends in the patterns of time use of older adults," in *Aging in Advanced Industrial States*, eds S. Tuljapurkar, S. Ogawa, and A. H. Gauthier (Heidelberg: Springer), 289–310.

Gilleard, C., and Higgs, P. (2002). The third age: class, cohort or generation? *Ageing Soc.* 22, 369–382. doi: 10.1017/S0144686X0200870X

Goel, P. K., Muzammil, K., Kumar, S., Singh, J. V., and Raghav, S. K. (2014). Socio-demographic correlates of depression among elderly slum dwellers of North India. *Nepal J. Epidemiol.* 4, 316–322. doi: 10.3126/nje.v4i1.10133

Gupta, A., and Coffey, D. (2020). Caste, religion, and mental health in India. *Popul. Res. Policy Rev.* 39, 1119–1141. doi: 10.1007/s11113-020-09585-9

Hammen, C. (2009). Adolescent depression: stressful interpersonal contexts and risk for recurrence. *Curr. Direct. Psychol. Sci.* 18, 200–204. doi: 10.1111/j.1467-8721.2009.01636.x

Hanna, G., and Perlstein, S. (2008). Creativity matters: arts and aging in America. *Monograph* 1–15.

Hartmann, B. (2010). Rethinking the role of population in human security. *Global Environ. Change Hum. Secur.* 193–215. doi: 10.7551/mitpress/8210.003.0016

Havighurst, R. J. (1961). Successful aging. *Gerontologist*. 1, 8–13. doi: 10.1093/geront/1.1.8

Havighurst, R. J. (1968). Personality and patterns of aging. *Gerontologist* 8, 20–23. doi: 10.1093/geront/8.1_Part_2.20

Hendricks, J., and Cutler, S. J. (2004). Volunteerism and socioemotional selectivity in later life. *J. Gerontol. Series Psychol. Sci. Soc. Sci.* 59, S251–S257. doi: 10.1093/geronb/59.5.S251

Himanshu, H., Arokiasamy, P., and Talukdar, B. (2019). Illustrative effects of social capital on health and quality of life among older adult in India: results from WHO-SAGE India. *Arch. Gerontol. Geriatr.* 82, 15–21. doi: 10.1016/j.archger.2019.01.005

Hirve, S., Oud, J. H., Sambhudas, S., Juvekar, S., Blomstedt, Y., Tollman, S., et al. (2014). Unpacking self-rated health and quality of life in older adults and elderly in India: a structural equation modelling approach. *Soc. Indic. Res.* 117, 105–119. doi: 10.1007/s11205-013-0334-7

Hirway, I. (2021). Conducting time-use surveys employing rigorous methods to produce quality data. *Indian J. Lab. Econ.* 64, 883–898. doi: 10.1007/s41027-021-00351-9

Hossain, B., Yadav, P. K., Nagargoje, V. P., and Vinod Joseph, K. J. (2021). Association between physical limitations and depressive symptoms among Indian elderly: marital status as a moderator. *BMC Psychiatry* 21, 11. doi: 10.1186/s12888-021-03587-3

Jecker, N. S. (2020). *Ending Midlife Bias: New Values for Old Age*. Oxford: Oxford University Press.

Kahn, R. L., and Rowe, J. W. (1998). Dr. Rowe and Dr. Kahn reply. *Gerontologist* 38, 151–151. doi: 10.1093/geront/38.2.151a

Katz, S. (2000). Busy bodies: Activity, aging, and the management of everyday life. *J. Aging Stud.* 14, 135–152. doi: 10.1016/S0890-4065(00)80008-0

Kessler, R. C., and Üstün, T. B. (2004). The world mental health (WMH) survey initiative version of the world health organization (WHO) composite international diagnostic interview (CIDI). *Int. J. Method. Psychol. Res.* 13, 93–121.

Kim, J.H. (2019). Productive aging of Korean older people based on time use. *Soc. Sci. Med.* 229, 6–13. doi: 10.1016/j.socscimed.2018.04.020

Krawczynski, M., and Olszewski, H. (2000). Psychological well-being associated with a physical activity programme for persons over 60 years old. *Psychol. Sport Exerc.* 1, 57–63. doi: 10.1016/S1469-0292(00)00004-2

Kumar, R., Jorm, A. F., Parslow, R. A., and Sachdev, P. S. (2006). Depression in mild cognitive impairment in a community sample of individuals 60–64 years old. *Int. Psychogeriatr.* 18, 471–480.

Lamb, S. (2014). Permanent personhood or meaningful decline? Toward a critical anthropology of successful aging. *J. Aging Stud.* 29, 41–52. doi: 10.1016/j.jaging.2013.12.006

Lamb, S. (2020). On vulnerability, resilience, and age: Older Americans reflect on the pandemic. *Anthropol. Aging* 41, 177–186.

Lancet, T. (2021). India's COVID-19 emergency. *Lancet (London, England).* 397, 1683. doi: 10.1016/S0140-6736(21)01052-7

Laslett, P. (1991). *A Fresh Map of Life: The Emergence of the Third Age*. Cambridge, MA: Harvard University Press.

Lazarus, R. S., and Folkman, S. (1984). *Stress, Appraisal, and Coping*. Springer Publishing Company.

Longino, C. F. Jr., and Kart, C. S. (1982). Explicating activity theory: a formal replication. *J. Gerontol.* 37, 713–722. doi: 10.1093/geronj/37.6.713

Mandi, R., and Bansod, D. W. (2022). *Association between Social Network, Social Support, and Life Satisfaction Among Elderly in India: Evidence from LASI Survey.*

Miech, R. A., and Shanahan, M. J. (2000). Socioeconomic status and depression over the life course. *J. Health Soc. Behav.* 162–176. doi: 10.2307/2676303

Mirowsky, J., and Ross, C. E. (2002). Depression, parenthood, and age at first birth. *Soc. Sci. Med.* 54, 1281–1298. doi: 10.1016/S0277-9536(01)00096-X

Muhammad, T., and Maurya, P. (2022). Social support moderates the association of functional difficulty with major depression among community-dwelling older adults: evidence from LASI, 2017–18. *BMC Psychiatr.* 22, 1–13.

Muhammad, T., and Meher, T. (2021). Association of late-life depression with cognitive impairment: evidence from a cross-sectional study among older adults in India. *BMC Geriatr.* 21, 364. doi: 10.1186/s12877-021-02314-7

Muhammad, T., and Rashid, M. (2022). Prevalence and correlates of pain and associated depression among community-dwelling older adults: Cross-sectional findings from LASI, 2017–2018. *Depress. Anxiety* 39, 163–174.

Muhammad, T., Skariah, A. E., Kumar, M., and Srivastava, S. (2022). Socioeconomic and health-related inequalities in major depressive symptoms among older adults: a Wagstaff's decomposition analysis of data from the LASI baseline survey, 2017–2018. *BMJ Open* 12, e054730. doi: 10.1136/bmjopen-2021-054730

Nadasen, K. (2007). 'We are too busy being active and enjoying ourselves to feel the aches and pains': perceived health benefits of line dancing for older women. *Qual. Ageing Older Adults.* 8, 4–14. doi: 10.1108/14717794200700016

Natrajan, B., and Jacob, S. (2018). 'Provincialising' vegetarianism putting Indian food habits in their place. *Econ. Polit. Weekly* 53, 54–64.

Padhy, M., Valli, S. K., Pienyu, R., Padiri, R. A., and Chelli, K. (2015). Leisure motivation and well-being among adolescents and young adults. *Psychol. Stud.* 60, 314–320. doi: 10.1007/s12646-015-0327-5

Pinquart, M., and Sörensen, S. (2001). Gender differences in self-concept and psychological well-being in old age: a meta-analysis. *J. Gerontol. Series Psychol. Sci. Soc. Sci.* 56, P195–P213. doi: 10.1093/geronb/56.4.P195

Radloff, L. S. (1977). The CES-D scale: A self-report depression scale for research in the general population. *Appl. Psychol. Measure.* 1, 385–401.

Samanta, T. (2014). *Household Context, Social Capital and Wellbeing of Older Adults in India (No. 2). BKPAI Working Paper Series II.*

Samanta, T. (2018). The 'Good Life': third age, Brand Modi and the cultural demise of old age in urban India. *Anthropol. Aging* 39, 94–104. doi: 10.5195/aa.2018.208

Shahbazzadeghan, B., Farmanbar, R., Ghanbari, A., and Roshan, Z. (2010). The study of the effects of the regular exercise program on the self-esteem of the elderly in the old people home of rasht. *Eur. J. Soc. Sci.* 13, 271–277.

Sprod, J., Olds, T., Brown, W., Burton, N., van Uffelen, J., Ferrar, K., and Maher, C. (2017). Changes in use of time across retirement: a longitudinal study. *Maturitas* 100, 70–76. doi: 10.1016/j.maturitas.2017.02.018

Sprod, J. A., Ferrar, K., Olds, T., and Maher, C. (2015). Changes in sedentary behaviours across the retirement transition: a systematic review. *Age Ageing* 44, 918–925. doi: 10.1093/ageing/afv140

Srivastava, S. (2007). *Passionate Modernity, Sexuality, Consumption, and Class in India.* New Delhi: Routledge.

Srivastava, S., Debnath, P., Shri, N., and Muhammad, T. (2021). The association of widowhood and living alone with depression among older adults in India. *Sci. Rep.* 11, 21641. doi: 10.1038/s41598-021-01238-x

Stephen, J., James, N., Bram, V., and Tarani, C. (2014). *Aging and Subjective Well-being in Later Life*, 1079–5014.

Strazdins, L., Welsh, J., Korda, R., Broom, D., and Paolucci, F. (2016). Not all hours are equal: could time be a social determinant of health? *Sociol. Health Illness* 38, 21–42. doi: 10.1111/1467-9566.12300

Swindell, R. (2002). U3A online: a virtual university of the third age for isolated older people. *Int. J. Lifelong Educ.* 21, 414–429. doi: 10.1080/02601370210156727

Tripathi, A., and Samanta, T. (2023a). Leisure as self-care in the times of the pandemic: Insights from a time-use diary study in India. *Leis. Stud.* 42, 633–643. doi: 10.1080/02614367.2022.2121415

Tripathi, A., and Samanta, T. (2023b). "I Don't want to have the time when I do nothing": aging and reconfigured leisure practices during the pandemic. *Ageing Int.* 1–22. doi: 10.1007/s12126-023-09519-8

Van Baarsen, B., Snijders, T. A., Smit, J. H., and Van Duijn, M. A. (2001). Lonely but not alone: emotional isolation and social isolation as two distinct dimensions of loneliness in older people. *Educ. Psychol. Measur.* 61, 119–135. doi: 10.1177/00131640121971103

Vilhelmson, B., Thulin, E., and Elldér, E. (2022). Is ageing becoming more active? Exploring cohort-wise changes in everyday time use among the older population in Sweden. *Eur. J. Ageing* 19, 447–461. doi: 10.1007/s10433-021-00647-1

Vyas, S., Hathi, P., and Gupta, A. (2022). Social disadvantage, economic inequality, and life expectancy in nine Indian states. *Proc. Natl. Acad. Sci.* 119, e2109226119. doi: 10.1073/pnas.2109226119

Wanka, A (2019). No time to waste. How the social practices of temporal organization change in the transition from work to retirement. *Time Soc.* 494–517 doi: 10.1177/0961463X19890985

Weir, D. R., Waite, L. J., Wong, R., and Freedman, V. A. (2018). "New measures and new designs in demography of aging research," in *Future Directions for the Demography of Aging*, eds M. D. Hayward and M. K. Majmundar (Washington DC: The National Academic Press), 371–396.

World Health Organization (2015). *World Report on Ageing and Health.* Geneva: Author.

Zadworna, M. (2020). Healthy aging and the University of the Third Age–Health behavior and subjective health outcomes in older adults. *Arch. Gerontol. Geriatr.* 90, 104126. doi: 10.1016/j.archger.2020.104126

Appendix

TABLE A1 Nested multivariate linear regression analysis for subjective wellbeing, leisure, and socio-demographic variables, predicting depressive symptoms ($N = 38{,}386$, LASI 2017–18).

Variables	SWB (Co-efficient/ SE)	SWB (Co-efficient/ SE)
Leisure	0.857***	0.394
	(0.308)	(0.307)
Depression	−0.187***	−0.149***
	(0.0333)	(0.0332)
Leisure * Depression	0.0535***	0.0450***
	(0.0161)	(0.0160)
Age 60–64 (Ref: 55–59)	0.0599	0.184*
	(0.101)	(0.102)
Age 65–69	0.163	0.492***
	(0.105)	(0.108)
Age 70–74	0.0235	0.516***
	(0.120)	(0.126)
Age 75–80	0.133	0.779***
	(0.133)	(0.142)
Gender (= Female)	−0.332***	0.138*
	(0.0736)	(0.0828)
1 ADL Limitations (Ref: No ADL Limitations)		−0.548***
		(0.119)
2 ADL Limitations		−0.911***
		(0.141)
3 ADL Limitations		−1.676***
		(0.0961)
Living with Spouse (Ref: Living alone)		263* * *
		(0.195)
Living with Spouse and Children		2.920***
		(0.186)
Living with Children and others		2.285***
		(0.191)
Living with others only		1.111***
		(0.246)
Working (Ref: Unemployed/retired)		−0.185**
		(0.0841)
Middle class (Ref: Poor)		0.425***
		(0.0996)
Affluent class		0.761***
		(0.0852)
Muslim (Ref: Hindu)		−0.603***
		(0.118)
Christian		0.496***
		(0.132)
Others		0.965***
		(0.168)
OBC (Ref: SC/ST – Lower caste)		0.577***
		(0.0916)
Other (Unreserved/Upper Caste)		1.369***
		(0.103)
Constant	23.65***	20.87***
	(0.640)	(0.672)
Observations	38,418	37,765
R-squared	0.016	0.042

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Andrzej Klimczuk,
Warsaw School of Economics, Poland

REVIEWED BY
Soo-Dam Kim,
Korea Institute of Oriental Medicine (KIOM),
Republic of Korea
Enshe Jiang,
Henan University, China

*CORRESPONDENCE
Virginia Sun
✉ vsun@coh.org

†These authors have contributed equally to this work

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Social determinants of health and lung cancer surgery: a qualitative study

Dede K. Teteh[1,2†], Betty Ferrell[2], Oluwatimilehin Okunowo[3], Aidea Downie[4], Loretta Erhunmwunsee[5], Susanne B. Montgomery[6], Dan Raz[5], Rick Kittles[7], Jae Y. Kim[5†] and Virginia Sun[2,5*†]

[1]Department of Health Sciences, Crean College of Health and Behavioral Sciences, Chapman University, Orange, CA, United States, [2]Division of Nursing Research and Education, Department of Population Sciences, City of Hope Comprehensive Cancer Center, Duarte, CA, United States, [3]Division of Biostatistics, Department of Computational and Quantitative Medicine, Beckman Research Institute of City of Hope, Duarte, CA, United States, [4]School of Public Health, Brown University, Providence, RI, United States, [5]Department of Surgery, City of Hope Comprehensive Cancer Center, Duarte, CA, United States, [6]School of Behavioral Health, Loma Linda University, Loma Linda, CA, United States, [7]Department of Community Health and Preventive Medicine, Morehouse School of Medicine, Atlanta, GA, United States

Introduction: Social determinants of health (SDOH) are non-clinical factors that may affect the outcomes of cancer patients. The purpose of this study was to describe the influence of SDOH factors on quality of life (QOL)-related outcomes for lung cancer surgery patients.

Methods: Thirteen patients enrolled in a randomized trial of a dyadic self-management intervention were invited and agreed to participate in semi-structured key informant interviews at study completion (3 months post-discharge). A conventional content analysis approach was used to identify codes and themes that were derived from the interviews. Independent investigators coded the qualitative data, which were subsequently confirmed by a second group of independent investigators. Themes were finalized, and discrepancies were reviewed and resolved.

Results: Six themes, each with several subthemes, emerged. Overall, most participants were knowledgeable about the concept of SDOH and perceived that provider awareness of SDOH information was important for the delivery of comprehensive care in surgery. Some participants described financial challenges during treatment that were exacerbated by their cancer diagnosis and resulted in stress and poor QOL. The perceived impact of education varied and included its importance in navigating the healthcare system, decision-making on health behaviors, and more economic mobility opportunities. Some participants experienced barriers to accessing healthcare due to insurance coverage, travel burden, and the fear of losing quality insurance coverage due to retirement. Neighborhood and built environment factors such as safety, air quality, access to green space, and other environmental factors were perceived as important to QOL. Social support through families/friends and spiritual/religious communities was perceived as important to postoperative recovery.

Discussion: Among lung cancer surgery patients, SDOH factors can impact QOL and the patient's survivorship journey. Importantly, SDOH should be assessed routinely to identify patients with unmet needs across the five domains. SDOH-driven interventions are needed to address these unmet needs and to improve the QOL and quality of care for lung cancer surgery patients.

KEYWORDS

cancer, community support, lung cancer surgery, patients, oncology, quality of life, social determinants of health, structural determinants of health

Introduction

Social determinants of health (SDOH) are factors that contribute to the conditions by which people live, work, age, play, and worship that determine their quality of life (QOL) and mortality (1, 2). SDOH are organized into five broad domains: economic stability, education access and quality, neighborhood and built environment, healthcare access and quality, and social and community context (3). While understudied in oncology research, SDOH factors impact the QOL of patients and their family caregivers (4).

Lung cancer is the leading cause of cancer deaths. Survival is low due to late diagnosis. Despite the proven effectiveness of screening for early detection, access is not equitably distributed (5). Patients also experience several detrimental health outcomes throughout their survivorship journeys that are compounded by SDOH factors (4). Non-clinical factors such as race/ethnicity, insurance status, education, neighborhood features, and income have been associated with perioperative complications and survival following surgery (6). Patients with private insurance are less likely to have postoperative complications (7) and disparities in postoperative mortality for non-white patients (8) from low median-income communities and lower educational attainment persist (7).

Additionally, patients commonly experience mental health challenges, such as worry about transportation, treatment cost, symptoms and side effects, lack of social support, anxiety about function decline, and impact on work (9, 10). As patients experience a decreased QOL due to the disease and treatment process (11, 12) (e.g., surgery and chemotherapy), social support (13, 14) and spiritual/religious wellness resources (15, 16) have been shown to improve outcomes. The importance of addressing psychosocial support access for patients is critical during their survivorship journey (17–20). Sex assigned at birth, age, and other sociodemographic factors have influenced supportive care needs (17). For instance, female status, poor emotional functioning, and younger age have been associated with increased use of psychosocial support services (19). With respect to QOL, prior research has also noted the importance of the provision of palliative care and end-of-life care support (21–23), including practices such as symptom management, education, and coping mechanisms for patients and family caregivers.

Furthermore, levels of economic stability can impact a patient's lung cancer diagnosis (24–26), treatment access (27), and QOL (28, 29). Educational attainment may also inform delays in treatment referrals (30) and healthcare access for lung cancer patients (31). Finally, there remain significant challenges in neighborhood and built environment conditions, including occupational and residential exposures related to diagnosis and access to care (32–35). Neighborhood-level characteristics have been used to identify high-risk lung cancer behavioral patterns in Maryland (36). The negative effects of lower socioeconomic status on treatment and survival have also been determined with the effects of segregation and economic deprivation determining receipt of lung cancer surgery in Georgia (37). Thus, an individual's geographical residence may determine their treatment and survival (36–38). However, the current literature on the impact of SDOH on lung cancer patient outcomes is limited and focused primarily on healthcare access and quality, economic stability, and social and community context domains (4). Research on lung cancer surgery patients is also lacking narratives from this population and warrants additional inquiry (6). Thus, to better understand potential barriers to QOL for lung cancer surgery patients, we explored SDOH-related outcomes across the five established SDOH domains.

Materials and methods

Intervention, sample, and setting

This study is a part of a randomized trial of a multimedia self-management intervention for lung cancer surgery patients and family caregivers from a National Cancer Institute designated comprehensive cancer center in Southern California.

Procedures

Participants enrolled in the parent study were eligible for the qualitative study at 3 months post-discharge and following completion of the parent study. During informed consent of the parent study (before surgery), participants were able to select whether they were willing to be contacted for participation in the qualitative study. The parent study followed participants for up to 3 months post-discharge from surgery. Thus, many participants were in the post-treatment survivorship trajectory or completing additional adjuvant treatments based on the stage of the disease. A nurse interventionist and research assistant from the parent study invited participants who agreed to be contacted for the qualitative study. Patient eligibility criteria included: (a) diagnosis of lung cancer as determined by surgeons; (b) underwent curative intent surgery for lung cancer treatment; (c) a family caregiver (FCG) enrolled in the parent study; (d) age 21 years or older; and (e) able to read, speak, or understand English.

The lead author (DT) conducted the semi-structured key informant interviews (Appendix A) with a co-facilitator (*VS*). The interview guide was developed in collaboration with co-authors and pilot-tested with patients in the same data collection pool. Questions were developed in three-phases. To introduce the concept of SDOH to participants, Phase 1 included a review of the "A Tale of two Zip Codes" (Two Zip Codes) video (39) followed by three awareness questions. The Two Zip Codes video was developed by the California Endowment to detail the SDOH impact on life expectancy in the United States in the context of racial and economic discrimination. The video highlights these SDOH factors on health by comparing two individuals from affluent and disadvantaged communities. Phase 2 included questions on QOL and survivorship by SDOH domains, and

Phase 3 questions were developed to solicit how SDOH information can be incorporated into patients' survivorship care planning. Interview questions were developed based on previous research findings (4) and subject matter expert recommendations from our research team. The interview guide was revised and refined based on pilot test implementation.

Each interview lasted approximately 60 min and was conducted *via* Microsoft Teams to minimize travel burden for participants. Instructions on how to operate Teams were provided *via* email, and an outlook calendar invite was sent to participants before each interview. A nurse interventionist and research assistant also reminded patients *via* telephone and/or email and reviewed Teams' instructions with patients before their scheduled interviews.

Demographic and SDOH information was obtained at the baseline of the parent study using the Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences (PRAPARE) (40). This 21-item instrument measures SDOH domains for patients related to environment, economic stability, and social and emotional health factors. PRAPARE is a standardized patient and social risk assessment tool informed by research on SDOH and aligns with national initiatives (e.g., the Department of Health and Human Services' Healthy People), federal reporting requirements, and the International Classification of Diseases-10 clinical coding system. Participants provided consent for this study during the parent study onboarding procedures. An institutional review board approved the study protocol and procedures.

Data analysis

The conventional content analysis approach was used to identify themes from patients' experiences (41). Codes and subsequent themes were derived from participants' interviews and relevant research, or theory was used to interpret meaning from data. Our research team published a systematic literature review on the impact of SDOH on FCG as well as lung cancer patients which informed our interpretation of the data for this study (4). We used the US Department of Health and Human Services' SDOH framework which includes five broad domains: economic stability, education access and quality, neighborhood and built environment, healthcare access and quality, and social and community context. The process included four independent coders (DT, VS, JK, and BF) followed by four independent reviewers (DT, VS, JK, and AB) who developed the initial content themes. Two reviewers (DT and VS) reviewed and finalized the themes. Coding and/or theme disagreements were discussed, refined, and resolved. Descriptive statistics were used to summarize patients' demographic characteristics. For continuous variables, median and interquartile range were reported; sample size and proportion were reported for categorical variables.

Results

A total of 106 participants of the parent study agreed to be contacted to participate in the qualitative study. Out of this total, we interviewed 13 lung cancer surgery patients for the study and were able to reach saturation with the sample size. Participants were primarily non-Hispanic (85%) and white or Caucasian (69%) with catholic religious affiliation (39%). Most patients (as shown in Table 1) spoke with their social support network five or more times a week (46%). Participants' stress levels varied before surgery ranging from "very much" (15%) to "a little bit" (31%). English was the primary language spoken by respondents, and most individuals (85%) completed more than a high school education. Patients were either insured through Medicare (46%) or private insurance (54%) and had adequate access to healthcare services. In addition, respondents did not have any housing insecurities, transportation issues, or neighborhood safety challenges. While some patients were unemployed (17%) or retired (33%), most were working full-time (50%) and reported an annual household income greater than $100,000 (39%). Two patients were discharged from the Armed Forces and very few respondents lacked access to food, clothing, utilities, childcare, or a phone in the past year. One respondent did indicate a lack of access to "all utilities" and another participant did not provide additional information about utility needs.

Theme 1: knowledge about SDOH factors, quality of life outcomes, and potential health impacts

Patients were knowledgeable about the concept of SDOH before watching the "Tale of two Zip Codes" video illustration. The video as a result reinforced concepts about the impacts of social and environmental factors on QOL (five subthemes). The discussion of socioeconomic privilege, access to parks, nutrition, healthcare access, and race/ethnicity were highlighted as determinants of positive health outcomes (see Table 2). There was also consensus on the usefulness of providers knowing SDOH factors to tailor the survivorship care plan of surgery patients (two subthemes). SDOH was seen as an implementation of a whole-person care plan that exemplified the attributes of a caring provider. Some considered the need for knowledge about resource availability before and after treatment, healthcare access related to affordability of co-payments and insurance, and a better understanding of the patient's worldview to tailor health solutions. Patients did not recall discussing the impact of SDOH on their health outcomes with their providers before surgery. Patients also stated that while the information may have been useful, the priority of the provider was to treat their disease.

Theme 2: economic stability challenges and financial toxicity-related concerns

Several patients experienced economic challenges during their treatment resulting in detrimental financial toxicity-related QOL concerns as described in two primary themes (as shown in Table 3). One patient returned to work to have access to health insurance and paid time off during treatment. Another patient's worries about continuing treatment after the expiration of her Consolidated Omnibus Budget Reconciliation Act (COBRA) insurance benefits were a source of chronic stress. For others, financial insecurity stressors had always been persistent but were now exasperated by a cancer diagnosis, which was the case for a single mom with worries of not having sufficient savings for retirement. Fortunately, some patients

TABLE 1 Lung cancer surgery patients' demographic characteristics by social determinants of health (SDOH) domains ($N = 13$).

SDOH domain	Characteristics	n (%)
Social and community context	**Age** in years, Median (Q1–Q3)	67 (61–67)
	Sex assigned at birth	
	Female	7 (53.8)
	Male	6 (46.2)
	Ethnicity	
	Hispanic	1 (7.7)
	Non-Hispanic	11 (84.6)
	Choose not to answer	1 (7.7)
	Race	
	Asian	1 (7.7)
	Black/African American	1 (7.7)
	White or Caucasian	9 (69.2)
	Other[a]	1 (7.7)
	Choose not to answer	1 (7.7)
	Religious affiliation	
	Protestant[b]	2 (15.4)
	Catholic	5 (38.5)
	Jewish	1 (7.7)
	Other	3 (23.1)
	No religious affiliation	2 (15.4)
	Household size	
	Less than two	7 (53.8)
	Two	2 (15.4)
	More than two	4 (30.8)
	Social support communication	
	1 or 2 times a week	5 (38.5)
	3 to 5 times a week	1 (7.7)
	5 or more times a week	6 (46.2)
	Choose not to answer	1 (7.7)
	Stress levels	
	Not at all	2 (15.4)
	A little bit	4 (30.8)
	Somewhat	2 (15.4)
	Quite a bit	3 (23.1)
	Very much	2 (15.4)
	Imprisonment in the past year	
	Yes	0 (0.0)
	No	13 (100.0)
	Refugee status	
	Yes	0 (0.0)
	No	13 (100.0)
	Domestic violence	
	Yes	0 (0.0)
	No	12 (92.3)
	No partner in the past year	1 (7.7)

(Continued)

TABLE 1 (Continued)

SDOH domain	Characteristics	n (%)
Education access and quality	**Language**	
	English	13 (100.0)
	Other than English	0 (0.0)
	Choose not to answer	0 (0.0)
	Education	
	< High school degree	0 (0.0)
	High school diploma or GED	2 (15.4)
	More than high school	11 (84.6)
	Choose not to answer	0 (0.0)
Healthcare access and quality	**Main insurance**	
	Medicaid/CHIP Medicaid	0 (0.0)
	Medicare	6 (46.2)
	Private Insurance	7 (53.8)
	Other Public Insurance	0 (0.0)
	Lack of access to medicine or healthcare	
	Yes	2 (15.4)
	No	11 (84.6)
Neighborhood and built environment	**Housing Situation**	
	I have housing	13 (100.0)
	I do not have housing	0 (0.0)
	Choose not to answer	0 (0.0)
	Worry about losing housing (n = 12)	
	Yes	0 (0.0)
	No	12 (100.0)
	Choose not to answer	0 (0.0)
	Transportation access consequences	
	Medical appointments or medications	0 (0.0)
	Non-medical meetings, etc.	0 (0.0)
	No	13 (100.0)
	Choose not to answer	0 (0.0)
	Physical and emotional safety	
	Yes	12 (92.3)
	No	0 (0.0)
	Unsure	1 (7.7)
Economic stability	**Employment status**	
	Unemployed	2 (16.7)
	Full-time	6 (50.0)
	Unemployed but not seeking	4 (33.3)
	Annual household income	
	$15,000 to $30,000	1 (7.7)
	$50,001 to $75,000	4 (30.8)
	$75,001 to $100,000	3 (23.1)
	Greater than $100,000	5 (38.5)

(Continued)

TABLE 1 (Continued)

SDOH domain	Characteristics	n (%)
	Migrant farm worker	
	Yes	0 (0.0)
	No	12 (92.3)
	Choose not to answer	1 (7.7)
	Discharged from armed forces (n = 12)	
	Yes	2 (16.7)
	No	10 (83.3)
	Lack of access to food	
	Yes	2 (15.4)
	No	11 (84.6)
	Lack of access to clothing	
	Yes	2 (15.4)
	No	11 (84.6)
	Lack of access to utilities	
	Yes	2 (15.4)
	No	11 (84.6)
	Lack of access to childcare (n = 11)	
	Yes	2 (18.2)
	No	9 (81.8)
	Lack of access to phone	
	Yes	2 (15.4)
	No	11 (84.6)

[a]Other response denoted as “Hispanic”. [b]Protestant religious affiliation included Baptist, Methodist, Lutheran, Episcopalian, Evangelical, etc.

did not have economic stability concerns despite high deductibles, and out-of-pocket healthcare costs associated with their treatments.

Theme 3: impact and importance of education access on QOL

Four subthemes described the variable experiences of education on QOL for patients. They included the importance of education for healthcare navigation, lifestyle decision-making strategies for health behavior change, the connection among education, economic mobility opportunities, and better health outcomes, as well as no impact of education on QOL (as shown in Table 4). The benefits of matriculating through an academic degree program were described by participants to include the ability to conduct personal research, comprehension of medical terms or increased health literacy, and decision-making strategies related to the types of questions to ask providers to navigate the healthcare system. There were also benefits for some that propelled lifestyle decision-making strategies or modifications of unhealthy behavior patterns. However, as described by a few participants, the knowledge of a topic does not always result in avoidance of actions such as smoking that have known detrimental health consequences. In addition, participants also briefly discussed the connection between education and economic mobility opportunities that could lead to better health and improved QOL. However, most participants did not agree with the statement “*people with higher levels of education live healthier and longer lives.*” Their understanding of education extended beyond the mere attainment of an academic degree. Several patients attributed their health literacy to their lived experiences, which in turn resulted in their improved ability to navigate their survivorship journeys and better overall health. They also noted that having a positive and/or inquisitive mindset and professional background (e.g., real estate and claims adjuster) had a positive impact on health outcomes.

Theme 4: access to quality healthcare including insurance status, lack of follow-up after surgery, and COVID-19 challenges

Seven subthemes described participants’ experiences with access and receipt of quality healthcare (see Table 5 for details). Overall, access to healthcare was not a major problem for participants. Positive aspects of healthcare access were common, with overall satisfaction with the quality of care. Proactive postoperative follow-up by the healthcare team on postoperative symptoms and overall wellbeing was viewed as quality care. A quality care environment that promoted clinical excellence, safety, and compassion was important for participants.

Others shared examples of challenges in accessing healthcare that were associated with insurance coverage. Despite having insurance coverage, access to quality healthcare was not guaranteed for many participants. Fears and anxiety around insurance coverage as

TABLE 2 Knowledge about social determinants of health impact on lung cancer surgery patients.

Themes	Example quotes
Knowledge about SDOH factors and quality of life outcomes:	
Socioeconomic privilege	"Well, I guess it's kind of in a way, states the obvious. If you are from a higher socioeconomic background, you probably have better health outcomes, in general, then somebody in a poor neighborhood."
Availability and accessibility of parks, walkability	"Well, I've worked in human resources for years, so I know how it works. So, I understand it very well. Small communities that are in the poor range versus the other ones. You can see that in well, we live in Southern California and South County has beautiful parks and you know accessible to walking and riding your bike where the metropolitan older cities do not. They're trying. They're getting better, but they do not."
Determinants of health outcomes	"Yes, actually, I do not think I heard it put that way, but I have heard that where you live matters, and it contributes to your health outcome. Well, I know that I've had access to healthcare, and I know a lot of people do not, and I think that I feel that that's probably related to economics. And I do know that genes do make a difference and also a young life, and they did not really talk about that too much. Or I guess that's my understanding. I know that I feel that since I had lung cancer that may be living in LA is more polluted than, say, Denver. And so that could contribute to my health outcome. I guess that's about it."
Race/ethnicity related factors	"Well, I'm African American, so even if I had not heard it, I knew it. Yeah, absolutely. What resonated [with] me [inaudible] these kinds of discussion, that kind of information is so important for making not just this country, but the whole world, that it's almost like so many people are even unaware of being involved in these kinds of discussions. Well, the community that we live in is a combination of both."
Healthcare access and quality	"How do these people do it when you are sick and I'm sitting there in the lobby of [a hospital], watching these other major cancer patients and their journey and what they have to go through. And if you do not have health care? You're and you are basically totally messed up because how are you going to [inaudible] even feel that you are getting the right quality of service. If you feel that you do not have any insurance. And if I did not have health care? I do not. I would have to sell my house to pay for my medical bills."
Effectiveness of including SDOH in survivorship care plan:	
Impact of SDOH on QOL should be discussed before surgery	"So other people, I think it would have done them better, more beneficial. Because people aren't optimistic there. They always think the other foots [is going to] drop and everything [is going to] be bad. So, I think if they would have known or they would have given you more information before the surgery, I think that would have helped. I do not know from my experience that they do offer. I mean, if they do talk about it, my physician never did. So, I think that it would be wise for them to have, to offer that information. Sorry, some people want it. Some people need it. And some people do not. But I think it should be talked about Prior to surgery."
	"I think so. Because you they got to know. Do you have the insurance? Do you have the resources? Can you afford the copayments? Yes, I think that would be good for the treatment team to know. If someone needs additional resources, do they have the support behind them? Are they able to take care of themselves? Because some people get really sick and cannot get out of bed and others, like I was pretty much okay [and] was just tired."
	"Oh yeah, no, I think, yeah, I do. I do. Because you know, I have been in sales for you know, 20–30 years or whatever and you know, knowing who your customer is exactly and what their kind of worldview might look like and the way they are looking at things certainly helps me tailor solutions for them that will fit. So yeah, I would think that this is helpful for caregivers and medical professionals, I would think."
	"Yes. Well, I think if your providers are aware of your [inaudible], and if they care, right? So that's a big part of it is whether you have a good provider that is a caring provider and wants to see you as a person, wants to treat the whole you then great. But sometimes I think a lot of times we are just another patient that walks in the door and you got 15 min and then I gotta get you out of here."
Priority of providers was surgery	"So, it's a hard question because the team did what they had to do and answered all my questions. Everybody's not going to be the same [inaudible]. [It] depends on them and say, look, this is your condition, this is where [what we are] going to do. And they kept asking me, do you have any other questions? Do you have any other questions? But if you do not, ask them, you cannot [receive an] answer."
	"I'm sure yes, I have no problem with that. It may have been helpful, but I do not know that it would have made a big difference, but I would not have a problem with them knowing about it beforehand. I do not know. I do not know. Things could have been changed. The surgeries were what they were and pretty much had to follow its course, so I do not think it would have made any a big difference."

TABLE 3 Economic stability challenges and financial toxicity related concerns of lung cancer surgery patients.

Themes	Example quotes
Health insurance access and financial insecurity	"My cobra is going to end in August, so I'm looking to see how should [I] manage that. Because this chemo supposed to be 3 years, [and] chemo is pretty expensive per month. So, I have to wait, does not make sense back then, to even start it because I may not be able to finish it. So, there's a lot of stressors. One day at a time… Well, the thing is I read something about the financial department [on] one piece of paper. Says well, you have to qualify financially, you have to have this income that income, but see, that's not what I'm looking for. I'm looking for someone to guide me so that it will allow me, to be able to continue what I have now. So that I can have [hospital name] be able to do a specialty drug, and not have a high out of pocket expense for every doctor's visit. You know, there's a lot of things to think about. I mean, this is just one, one part of [my] life that I have to worry about, I have other aspects of my life that I have to worry about as well with my parents passing away. You know, so I have to get that squared away. So that's a lot of my shoulders right now, you know."
No economic challenges or concerns despite the high cost of healthcare	"I mean, it costs a lot of their money, but I mean. I'll be paying for it for many, many years, but it is what it is. Yeah, sure. I mean, but I have high deductibles, I'm self-employed. So, I do not have a great coverage. I've got okay coverage and I think so far out of pocket, I have a $8,200 out of pocket expenses. Unfortunately, I had surgery in December. Which was $8,200 out of pocket. And then I started treatment in March, which is $8,200 out of pocket. So, you know, we are talking, you know, [over $10,000] just right off the top. Yup, that's a big chunk of change that I did not have sitting there. But again, it is what it is and I'm blessed to be able to pay my bills. You know, there's a lot of people out there that cannot even afford to pay [their] bills or get the treatments or whatever. I've never known hunger and I certainly was not pushed to hunger by the treatments."
	"I always have financial [security] at the back of my mind, you know, being a single mom and put one kid through flight school and other one through bachelor's degree, there was just a lot. And so now it's time to start saving, but I already should have been retired, right? So, in my mind, there's [an] economic [insecurity] as far as financial stability, I do not feel like I have a lot of it, but I'm working towards it. Other than that, I had no insecurities."
	"My boss had laid me off. But financially, I mean, we are okay. I've probably made like somewhere around 80,000 a year for what a while. I'm on Social Security. I'm not working. My wife works. She works at [a hospital]. We do not own our home. You know, we did own a home [inaudible]. I was working too much to find another one [home], so we rent. But we have a nice house. The townhouse, I got a good landlord, and then we do not have any particular stress that way. Not living high on the hog or anything, you know, and I do [have to] watch my spending. But I think we are set up okay, we are we can keep going until my wife and I die without having to worry about [money]."

participants faced retirement age were prominent. Negative experiences with the healthcare system included a lack of follow-up after surgery and initial delays in diagnosis. Due to COVID-19, participants described delays with initial diagnosis due to the inability to see specialists and have biopsies. The authors described the impact of the COVID-19 pandemic on care delivery and QOL for this population in a previous publication (42). Additionally, travel burdens to obtain cancer care and for family/friends to visit were primarily financial, with high gas costs. For participants, long trips after chemotherapy were challenging due to post-infusion toxicities.

Finally, descriptions of survivorship journey challenges were mainly focused on symptoms, recovery, and care coordination. Participants described challenges with dyspnea, prolonged coughing, pain, constipation, and weight loss. They described recovery and healing as a slow process, and frustrations with their inability to participate in activities that they used to enjoy and return to work. On the survivorship journey, participants were still "processing their diagnosis" and "grieving" the reality of being diagnosed. Challenges related to care coordination included not knowing which clinician was responsible for different aspects of their care.

Theme 5: neighborhood and built environment disparities and health impact variability

The overarching theme that emerged from the patient interviews was a common understanding of significant disparities in the neighborhood and the built environment, even among those participants who were not negatively affected by these factors. Four sub-themes centered around safety, air quality, access to parks and green space, and other environmental causes of cancer (Table 6).

Although most participants felt that they lived in relatively safe areas, they acknowledged the stark disparities between safe neighborhoods and unsafe neighborhoods. Some participants noted that safe neighborhoods were sometimes geographically very close to unsafe neighborhoods. All the participants in the study lived in Southern California, so it was unsurprising that air quality was a common issue. Several participants felt that poor air quality contributes to developing lung cancer, particularly among never smokers. Other participants commented that certain parts of Southern California have better air quality—communities close to the beach and some less densely populated areas. Participants noted very tangible air pollution, which they could sense from traffic or recent wildfires. Generally, participants felt more affluent areas have better air quality.

Participants also commonly expressed they had adequate access to parks or other green spaces in the form of hiking trails. Some patients noted that local parks were not well maintained. Others commented that although they had parks in their neighborhood, they seldom used them. Finally, participants raised the issue of other environmental exposures to carcinogens. One participant wondered whether living near a gas station may have affected her health. Others questioned whether prior experiences of living near factories or other industrial complexes may have caused their cancers.

TABLE 4 Education quality and access impact on quality of life for lung cancer surgery patients.

Themes	Example quotes
Importance of education for healthcare navigation	"You learn your basics, but nowadays I think education plays a big part of everybody's lives, and I just think if they know more about healthcare and where they are going, I think it's great. I because of my dad going through cancer, every time a doctor would ask me a question, I was there Googling it. OK, what does that mean? …So, you become an advocate of your own parents. Now with mine, obviously, when they told me I had a mass, I am Googling what is a mass mean…So, I think if you have the right education, and you know how to ask the right questions. I've learned that the more questions you ask, the better you are gonna be with yourself."
	"Yeah, if you have education then you know, just through memory, muscle memory… People who go to college, they know how to take notes. They know how to do research because you have to do research paper, right? So yeah, that's what we have to do is we have to research what cancer is the type of cancer you have? What's good for this particular type of cancer? So yeah, comes into hand, comes handy to have higher education."
	"[I] have a bachelors in chemical engineering and I did postgraduate work in business. Yeah, I think so, because I am technically trained and I could read some of the medical reports and I could ask, you know, good questions of the doctor. What does this mean and what does that mean? So, I'm not flying blind. Like, maybe most patients would be."
	"I see doctors a lot more often now. Before I barely went to the doctor. I had to be really sick before I would go. You know I'm learning a lot about it, you know, when they mentioned something new, I read up on it."
Lifestyle decision-making strategies for health behavior change	"Oh yeah, I agree. Well, if you are educated, that means you probably read, you are aware of developments you learn over time which behavior to avoid, which behaviors do [you] accentuate for healthy living. You know, I've been a jogger, I walk, and I do not overindulge. Never had drugs in my life. That kind of goes along with that, I think."
	"Yes. Well, you know, I'm not personal in this area by any stretch of the imagination. But you know, I tried to be for a number of years now, you know, we have tried to be as healthy as you can and find out as much as we can about the things that do affect our health. You know outside of our own body and so, I'm always looking for information that can make you know they can keep me more knowledgeable about what's the best things to do. The best way to live. They keep me as healthy as possible."
	"Because I, you know, I'm college educated. And you know, I think I've lived a pretty good life and I've tried to do reasonably healthy things, you know, since I've learned how important that is. The only thing I can think of is the fact that I did smoke all those years and I'm assuming that even though some people get cancer, that mine was a well, you know what mine was. So, I'm assuming that my [actions] has something to do with that because Cancer is so prevalent among…, so much more prevalent among people who smoke than those who do not."
Connection between education, economic mobility opportunities and better health outcomes	"Oh, I think that yes, I would agree with that in a general sense. I think that stress plays a big part, so sometimes that can counteract that. But because somebody's educated, can probably kinda think for themselves on how to get their needs met. That's what I'm thinking, and I guess that's all I have to say on that… We'll make more money also, someone who's more [educated] make more money and then therefore they can maybe have better health care that way. I have a graduate degree, but I went back to school later on, so I got my bachelor's degree and master's degree. I graduated in 2015. So, before that I just had some Community College education."
	"I think it's true because people [who] are more educated, usually have better jobs, have more money. But then it's not true with my case because I dropped out at 9th grade. And then in my 30s, I would get my GED. But then this what I'm working as a claims adjuster. I just kind of fell into it, but I'm making about 90,000 a year. I probably would be in the different field, maybe making more money or it could have affected it. You know, I could have been educated and got into a different field and made more money. I would have the resources to eat better, exercise, be active. I think it's a little different because you can have those degrees nowadays and not be able to find a job. So, you gotta be careful on what you are educated [in] and if there's employment in that area. Oh, if they are taught how to research, you know and study up on their diagnosis and treatment and people that usually go to school, you know, higher education, they are from wealthier families. So, they are upbringing is different than you know, I was raised by a single mother who basically made minimum wage, so there wasn't much money in the family growing up."
No impact of education on quality of life	"My education, I mean, I never finished high school. I've been to, I do not know how many colleges and stuff like that, but you know, I did not even finish high school. But it did not seem to stop me for anything. I do not know. I do not think it affected anything. I think it's more of a mindset, you know. It's kind of this, you know, I do not have any fear of it."
	"Well, not necessarily a degree, but the person, if they are well read and study on their own. The information is available, so they have got an inquiring mind, access to the internet. It's not strictly related to a degree. If you have a degree, you are more likely to access those tools. But anyone, even without a high school diploma, if they are inquiring and curious, the information should be out there."
	"I do not know, I do not think, I mean I've got a master's degree. I got a business and MBA, but I do not know. I mean, I guess you know, I'm 56 years old, so I [went] to school at a time where they still put projectors [inaudible]. So maybe it helped me, you know. But I do not know if they had a direct, I do not know that I can directly draw a line between like what happened here [and my education level]. You know what I mean? My wife, though however, I should say this, my wife is a speech pathologist. So you know, and obviously she's not a doctor, not an MD, not you know, but you know works in the healthcare field, works with doctors, understands how to read clinical studies, knows the insurance game you know and all that sort of stuff so that and offer education and having her as a resource to me, now that was a big help."
	"I think I agree for the most part because that's with an assumption, that the assumption is that higher educated people are gonna try to get more information. And as it pertains to health, you know that means that, that person most likely is going to try to get more information than a person who is not educated right? Yeah, but I'm not sure that has anything to do with my education, to be honest, which I think that's just the kind of person that I am. Yeah, I've been a curious person in my whole life."

TABLE 5 Access to quality healthcare included insurance status, lack of follow-up after surgery, and COVID-19 challenges.

Themes	Example quotes
Access to healthcare:	
Challenges with access	"For me, the health care HMO system is horrible. I was so frustrated and pissed off. I mean, I was getting pretty aggressive, but I mean not like, you know, hurt somebody or something like that, but I definitely wasn't backing down or accepting anything any of the doctors. I mean, I do not have the greatest review of doctors at this point in my life. You know, they also tell me such so much bullshit. It's unbelievable. But so, I changed to PPO, and I did this so I can get into City of Hope also."
	"I have PPO HMO and I pay. A lot to have that which is kind of sad that people do not have that flexibility, do that. So I know that I was treated extremely well. I see myself and I go. What if you do not have this kind of health care?"
	"And I scary because I'm almost. I'm almost at the retirement age and this is what comes through my mind. Ohh my gosh, how am I gonna keep up this this insurance? You know, because as you get older, things happen. And how have you thought about how you are going to keep up with your insurance after you retire?"
Positive aspects of healthcare access	"I have come to rely on my health care providers and to follow direction. I think within the last certainly 10 years I've had a shift where before that I thought I'm in charge of myself and if I need to go to see the doctor, I'm gonna listen to what they say. But I'm gonna decide for myself. I'm a lot more willing just to okay, I just have to trust this person. They know more than I do. You know, it's no one's ever 100% right. But I might as well follow their direction and I can let go of that responsibility. Right. I do not, you know. And actually, that's been a little freeing."
	"I know that after my surgery they certainly were concerned with my comfort and how I was doing, you know. I'll say mentally, just kind of generally they were very inquisitive and kind and wanting to make sure I was handling things well. And even when I was home and I did start to have pain, some nerve pain, that was really great how I they were so much available for me to call in, talk to the nurse, they connected with my doctor's office."
	"They had a little stuffed bear with a shirt that was called [inaudible]. And so of course I used him to cough. But I was really glad he was in the room. I wasn't able to have either my daughter or my boyfriend comes in because they had both been exposed to somebody who had COVID, so I was there alone. I have my little bear and I love that. You know, the simplest little thing."
Palliative care access and knowledge	"I'm aware of it, but I did not think it was pertinent to me I guess, I think of it as people in Hospice or whatever, so it's probably a broader term than that [knowledge about palliative care services, and no one mentioned the service]. With the things they were doing ongoing and I was wasn't aware of. That would have fallen into that category. Mainly in the symptoms, I think particularly the cough. There's something I would actually probably use some help on and the shortness of breath the more concerned long term is this what I'm gonna be dealing with or will it get better over time?"
	"I guess that was aware they existed, but I'm concerned like I think I've done pretty well. I have, you know, it's palliative care sounds like the last hope or resistance or so. No, I've had no need for those, thankfully."
Description of survivorship journey challenges:	
Symptoms	"When I got out, I mean, you know, it's hard to breathe…. Well, my little weird sensations, little pains or numbness or whatever it is are in the front…. And you know, my whole thing was at that time was the cough. You know, I was coughing constantly… the coughing was driving me nuts. I was like around the clock…. You know, sleep is just it's hard to get it to sleep…. Being constipated is a real frustrating experience and then does that to you."
	"I think I was really hard on myself. I just did not like the uncomfortable of not being able to breathe right sometimes. I kept I had a panic attack once, and I just thought ohh my gosh, I cannot breathe. I cannot breathe and I had to tone myself down and put myself in a space of. Just a. Of a different realm. Thinking about being in the beach like your background is and just calming myself down so I could breathe again normally. The pain was a little uncomfortable only in my sense, and then, you know, you are a woman. So, you wanna look your best. And the idea that I could not wear a bra for a while was kind of comfortable. So I had to wear all this stuff on top of it. So. But then it just got better. I just realized you are your worst enemy."
Recovery	"You know, I still wanna get stronger. I still want to gain some weight. I mean, I'm not giving up there. I went out with normal life, so I can golf or do whatever I feel like doing. I'm still real weak and I have not got all my strength back. But you know, I'm getting a lot stronger and that's a slow process. That's the other part. Healing is a slow process."
	"I went back to work three days after surgery, and I can only put in 4 h a day. Now I'm putting in 11 h a day. But I'm able to."
	"Well, I'm still getting used to it. I'm 56 I'm a nonsmoker. I've been really healthy. My whole life I've invested a lot in my health and having this happen to me was you know, like a six-month slow-motion airplane crash. So, I feel like. I feel like my life is potentially shortened. I feel much more unsure about the future then I used to be. That could be a reason God gave us to me. I do not know. I'm not very good at present. What else can I say? It sucks. I do not like it at all. I mean, I'm not happy with it at all. I'm still, probably going through all the stages of grief, you know, in regard to it, and I really do not know how I'm supposed to manage the intensity and level of work that I've done in the past professionally and do all the things that I'm doing now to try to keep me from getting cancer again in the future, so I have no clue. I really do not know how that's going to work out."
	"As much as I think I'm strong, I do not have a lot of leeway left for other things, I think, that I had before."
	"But you know, I have to do the screenings cause I guess there's still a 50% chance that it could come back. So that bothers me a little bit. That's essentially the extent I think I'm still processing the fact that I've gotten this diagnosis."

(Continued)

TABLE 5 (Continued)

Themes	Example quotes
Care Coordination	"Before I did not have that much knowledge so that that part. Like I think I needed a flow chart. I needed to know what each doctor was there for me. Because you can say one word and say hey, so what is that doctor do really for me? So that's just me though, because I did not. Just because this doctor had a title, I did not know what he was supposed to do for me like, why am I seeing you? Ohh Okay, it's because of this Okay. Well, a surgeon? Yeah, that's pretty obvious. I know what a surgeon does. But I did not know what a Pulmonary doctor was. But yeah, I just I guess maybe if you are in shock. You're still receiving the information."
Negative experience with healthcare system:	
Lack of follow-up after surgery	"The only thing that had me very, very upset was I had surgery on a Monday. They took 15% of my lung out. I was just discharged on a Wednesday. And not one soul, not one soul called me at all the next day, the second day, the whole weekend. There was one girl. She's on the research team. She's the only one that called on the following Tuesday. That's it. Not a nurse. Not the doctor's office. Nobody. And I was kind of a little I'm gonna tell you I was ticked off…"
Delays in care	"But for 10 years I told him I cannot breathe. I cannot breathe. I cannot breathe. And he kept telling me, I do not know what to tell you. I do not know what to tell you. I do not know what to tell you. I've done X rays of your lungs are fine, but really, I had COPD that wasn't being treated for 10 whole years... So I went from nothing wrong with you, to you have already died practically…And I truly believe if they had caught it sooner at least started treating it sooner. It would not be to the degree that it is."
Positive experiences with healthcare system:	
Healthcare team	"They knew where they were [doing]. They never lost sight and they just followed me through it."
	"You do the whole thing by yourself, so they become your family. And yeah, they just make you. You're just so grateful for all these people that are working. You know, through the holidays, it does not matter what the weather is like, it just and everybody. I never met anybody there that did not love, love their job."
Care environment	"You're with the right people. There are people that support you as people that are going through what you are going through. The whole environment was just made you feel like you are in a world class place and that you are safe. Or at least you are in the best place you could be…"
	"I do not have enough good things to say about that because one of the things that's really important is that I can go there in the morning and I can have my scans and see him a couple hours later and walk out of there knowing that my skin was clear. That's huge. As opposed to getting a scan done here in [hospital name] and then make an appointment…"
Burden of traveling long distance to obtain care:	
Challenges with family and friends visiting after surgery	"Yeah, cause none of my friends could come up visit me because it's 50 miles away. When I was in the hospital for three days. Cause gas. It's not because of you guys. It's not because of the distances cause of how much it costs anymore right now."
Challenges with treatment	"I mean, it's possible if there's no traffic to get there in 45 min. That's also possible for it to take an hour and a half. Hello, it's a hassle, you know. Especially now with gas, I mean gas is so expensive. It's like oh no. You know that's good. Take a big chunk out to drive there."
	"…where I got my treatment is 2 1/2 h from here. And Lancaster, where I got my chemo treatments, is about an hour and a half. It was not convenient, but we do have a Cancer Center here. They do not have a thoracic surgeon and they do not do lung cancer here. When you leave chemo, you do not usually feel very good and then just spend a couple hours in the car, usually is not great."
	"So, if my surgery was on Monday, I had to go up on Friday to get my COVID test. And then Monday I came in for surgery. Not that I would not have done it. It's just I'm thinking you have offices down the road. Why cannot it just go there? But you cannot? Not yet."
	"…42 miles. I would like to walk next door if I could, you know. Yeah. But you know what? I if I have a choice between great care Versus going next door, I would take great care every time if I have to. I have, you know, we have gone out of state for things. No. You know, really in Southern California and, you know, things can be a way away. And so, you know, we used to drive and then I'm sure everyone wants to be able to do what's the most convenient thing to do, you know…"
Delays in lung cancer diagnosis due to COVID-19	"First of all, there was COVID last August, September, October COVID was very, very high. I he could not find a pulmonary specialist that could take me. That was number one because they were dealing with COVID patients in the hospitals. They were had no availability to get me in…"
	"…nobody is doing biopsies, nobody. I mean nobody…And so at this point I am so upset. I figure I'm going to die any hour. I mean, I did not know how sick I was, I did not know anything really…"

Theme 6: social, interpersonal, coping, and community context perspectives

Participants provided perspectives about their emotional, relational, and coping strategies for dealing with the challenges of their survivorship journeys including access to familial, social, spiritual, and religious support systems. As shown in Table 7, two main themes and four subthemes describe the experiences of patients. Overall, patients stressed the importance of having a positive outlook, with one patient noting that a person could be their own worst enemy in this process. Particularly, some patients discussed the stigma and self-blame of being former smokers, the consequences of their past actions that led to their diagnosis, and the burden on their families which weighed heavily on them.

TABLE 6 Neighborhood and built environment disparities and health impact variability for lung cancer surgery patients.

Themes	Example quotes
Safety	"I live in a town now that is fairly mixed where you can be in a very wealthy kind of enclave and then go a few blocks and be in a very poor couple of blocks... on my street, I feel very safe... but about a half a mile away, there's been shootings and whatnot."
Green space availability	"I'm about 2 1/2 miles from a popular hiking trail... I can bike there and it's a beautiful stream with trees."
Air quality	"Air pollution because I never smoked. And so of course we do not know the exact cause, but I suspect maybe just pollution in general." "I live in Southern California and Southern California is noted for having bad air quality, for example. But I would have paid attention to the area that I live... It would have made me aware of things so that I could make sure that the choices that I made would be more beneficial for me and my family from a health point."
Other environmental exposures	"I was exposed over the years to certain environmental effects by being in large factories."

TABLE 7 Social, interpersonal, coping, and community context perspectives of lung cancer surgery patients.

Themes	Example quotes
Coping with diagnosis, treatment, and self-blame:	
Stigma and self-blame	"Well, I'm Angry with myself a lot. Because I smoked all my life, and it could have been avoided. You know, it's just one of those things. And I have a lot of anger and guilt that I put my family through this and things like that."
	"I smoked up until I found out. And had for a long time and at that point I quit, and people say, well, how did you quit, and I go dude, when you see these people that are trying to save your life. And you really keep smoking. That just like does not even make sense. You're just going to keep killing yourself. Well, all these people are trying to save you. And not ask for a thing back."
Emotional impact of diagnosis	"I can say that you know, like, you know, I guess I was very unprepared for the emotional impact of cancer. And I do not really blame that on anybody, right. I do not blame that. And I cannot say that what I went through is like, whatever. I do not know what everybody else wanted. But I certainly was really thrown off by that."
Familial, social and spiritual support:	
Social support	"You know, there were days that I did not want to walk. I just wanted to lay down and just…I just did not wanna do that and they would come around and goes. Come on, let us go do it [go for a walk]. Let us go do it. Half a block. Two blocks. Come on. Come on. So that helped. That really helped. So, I have an amazing support."
Spiritual and religious support	"So, for sure you know, I come from a very Christian background, and I believe in the power of prayer. And I had, I was online. If I was on a lot of prayer chains and prayer lists and I know that has always [played] a role in particular, [my] own attitude. I believe that it can be the difference, honestly. Between how you handle something. I do not know. I think it just gives you a bit of confidence and a bit of peace that you are not ever…you know, I never felt alone. I never felt that I did not have someone to turn to. You know, I never felt like I was abandoned in any way. And I think that as a Christian that has a lot to do with that. That I never felt alone. Yep. I know, I know, a lot of people would not consider those exactly like a mutually friendly, but I do not know…right, right. Thank you, Jesus, for the Xanax."
	"I think it's more spirituality. My mother was a big reader of *Kahlil Gibran* who's a prophet, and so we kind of read his books and we really enjoy him, and I wasn't brought up really religious. I did bring my son up Catholic so and I do pray, and I am Christian and so I think all of its…I think all of that combined…"
Isolation during COVID-19 pandemic	"I think I probably could have done more. I could have talked to more of my close friends. COVID has kind of impacted me socially that way. I was so used to, I have a handful of good friends that we would go out to lunch, dropped breakfast, or go for a walk. And my friends typically were pretty COVID isolation, and I felt if I was outdoors, I was pretty comfortable getting together. But my friends were not necessarily so and so I'm not super good at talking on the phone. And so, I let that social network gets a too far away. I did connect once I got the diagnosis, I knew it was important for me to touch in and tell people what was going on, and I did that and there were a few phone calls but probably not as much of my friend network support, and that's on me as much as on them."

Patients used varying coping strategies to navigate their diagnosis and treatment journeys. Most patients were unprepared to deal with the emotional and physical ramifications of their diagnosis and treatments which impacted their ability to breathe, work, and socialize, resulting in decreasing their activity levels and minimizing their caregiving responsibilities for other family members. Several patients initially withdrew from their familial and social relationships but eventually found solace in allowing the care and presence of their social network to provide support. Many noted that their familial and social relationships were supportive and encouraged activities beneficial to their recovery that they would not have otherwise been motivated to complete. Participants who were dually patients and caregivers experienced stressors related to caring for children with special healthcare needs and other family members during their recovery. Others discussed feeling isolated or disconnected from relationships in part due to the COVID-19 pandemic.

In addition, spiritual and religious support was used by patients as a tool for connection, and a way to cope with their mortality using traditional and non-traditional religious formats. Patients' actions ranged from lighting a candle before prayer, asking God for forgiveness, blessing of good health, going to church on Sunday in person or *via* Zoom, returning to the practices of Catholicism to receive their last rites, and reading poetic essays from *The Prophet* by Kahlil Gibran about love, life, religion, and death.

Discussion

Lung cancer surgery patients experience an array of detrimental factors related to their survivorship journeys that are compounded by SDOH conditions. Despite most participants having health insurance, they experienced several challenges related to financial toxicity, access to quality healthcare, neighborhood and built environment accessibility and exposures, as well as social and interpersonal barriers due to their diagnosis and treatment. They were knowledgeable about the impact of SDOH on their QOL, and the potential effectiveness of including discussions of SDOH in their survivorship care plan. Patients, however, understood that the primary directive of their healthcare team was to treat their disease.

Financial toxicity is one of the most common concerns for patients with cancer including lung cancer (43). Similar to previous studies (44, 45), some of our participants experienced distress related to medical insurance status, out-of-pocket costs, and treatment expenses that negatively affected their QOL. Fortunately, most patients did not have economic stability challenges or financial toxicity concerns. According to Hazell et al., protective factors against financial toxicity for lung cancer patients include older age, white race, employment status, having Medicare insurance, and an annual household income of more than $100,000 (44). Patients in our study were from privileged socioeconomic backgrounds with annual household incomes greater than $100,000 and white, with Medicare or private insurance. For example, one patient spent over $10,000 out of pocket during the initiation of their lung cancer treatment, and another patient was on social security and receiving spousal financial support with no economic stability concerns. Although we lacked representation from minoritized and under-resourced communities who carry a great burden of the disease, it is critical to examine SDOH disparities (46, 47) including financial toxicity concerns and their impact on under-resourced and minoritized lung cancer surgery patients in future studies. Doing so, using mixed methods with the use of validated screening tools such as PRAPARE (40) or the comprehensive score for financial toxicity (48), may better our understanding of the impact of financial toxicity on QOL and survival.

Educational attainment is associated with economic mobility opportunities which influences other SDOH factors such as income, healthcare access, food and housing security, transportation, and neighborhood residence (1, 2). Participants in our study did not discuss challenges related to food, clothing, and utilities. English was the primary language, and most patients had more than a high school education. Education is associated with survival rates of patients with lung cancer (49, 50). Patients of higher education have better survival rates and earlier diagnosis of disease than patients from lower educational attainment (e.g., grade school education). Additionally, the definition of education for patients and its impact on their QOL extended beyond a formal academic degree. An individual's lived experience provides similar health literacy skills as completing an academic degree. This speaks to the potential limitations of solely relying on questions such as "what is the highest level of school that you have finished?" (40) to determine the impact of education on QOL. While the literature on the positive association between education and longevity is clear (51), determinants of educational attainment for lung cancer surgery outcomes are developing. It is important to include parallel educational experiences in addition to academic degree attainment when determining the impact of these variables on QOL.

Furthermore, SDOH disparities in healthcare impact the quality of lung cancer surgical care, management, and survival of lung cancer patients (52, 53). These healthcare disparities are associated with less use of surgery, more frequent use of more invasive surgical approaches, and lower postoperative survival rates (52). Minoritized groups including Black, Hispanic, American Indian, and Alaskan Native Americans are less likely to receive surgery for early-stage lung cancers even when adjusting for socioeconomic variables (52). As discussed by Bonner and Wakeam (6), there is a "*de facto* segregation" of lung cancer surgical care where non-white individuals on Medicaid or uninsured are more likely to receive treatment at low-volume hospitals where the quality of care maybe compromised, which consequently may impact the short- and long-term survival and overall QOL of these patients. With an underrepresented sample of these groups in our sample, we lack the data to adequately determine the burden of SDOH factors on healthcare access and quality. However, the burden of access was present in our study from the context of future worries about receiving care due to insurance status (e.g., ending of COBRA). Additionally, as the literature on SDOH disparities in lung cancer surgical care continues to expand, future research designs could benefit from including variations in outcome measures including volume, specific clinical complications, long-term survival, and mortality (6). The evaluation of these outcomes in conjunction with increased inclusion of socioeconomic information may inform disparities-focused interventions that improve access and surgical care delivery for patients.

Participants also acknowledged the relationship between their neighborhood and built environment and health outcomes. Safety, green space, and air quality were determinants of better QOL for participants. Patients also questioned the carcinogenetic effects of environmental pollutants due to proximity to factories, gas stations, and other industrial complexes. Pizzo et al. found significant associations between environmental pollution from a sewage and industrial plant in Italy and increased lung cancer risk for individuals living within 1.5 km (54). Patients residing in lower socioeconomic neighborhoods in Southern California with higher levels of airborne pollutants (e.g., $PM_{2.5}$ exposure) have an increased probability of having a *TP53*-mutated lung cancer diagnosis which is associated with poor survival rates (55). Similar findings were shown by Yu and colleagues, with an association between air pollution from the combustion of coal and aggressive tumor biology for Chinese residents (56). In concert with social factors, future research designs should incorporate biological and environmental assessments of patients to better understand the burden of SDOH on QOL.

Moreover, social and community factors can determine patients' QOL throughout their survivorship journey (4). Factors related to their psychosocial wellbeing, community engagement, and social support availability contribute to their health (1). Participants in our study received social support from their family and friends as well as through their spiritual activities and religious networks. Social support is an important factor for improving QOL for lung cancer patients (57). Particularly, the availability of social support for lung cancer patients is important for symptom management and better psychological and physical QOL (58, 59). For instance, early implementation of an interdisciplinary social support care model had long-term QOL improvements related to psychological distress 12 months after lung cancer surgery (60).

Additionally, the largest religious affiliation of participants from the study was Catholic (38.5%), and few had no religious affiliation. We did not quantitatively assess the spiritual wellbeing of patients but explored their understanding of their religion or spiritual support through interviews. It is important to note descriptions for these terms as their assessments are not synonymous and some patients provided distinctions between their spiritual practices that did not include religious doctrines. Spirituality can be described as the belief in a greater energy or force beyond oneself and the actualization of that belief in connection with self, others, nature, and the sacred (4). Religion includes traditions, rituals, and social practices combined with the belief in an unseen world and a deity which is often represented through doctrines (61). Religion can be an expression of one's spirituality and is not always dependent on a religious affiliation.

Nevertheless, spiritual support positively impacts perceptions of disease (62) and can be protective against emotional distress for lung cancer survivors (63). Spiritual wellbeing of these studies was assessed using the Functional Assessment of Chronic Illness Therapy (FACIT-Sp-12) which includes measurements of meaning and peace, and the role of faith in illness (64) to understand the protective factors against emotional distress of patients. A religious and spiritual support intervention delivered by chaplains also has demonstrated similar salutary effects on lung and gastrointestinal cancer patients' QOL (65). Religious support for the intervention was used to measure religious involvement which included three dimensions of religiosity: organizational religious activity, non-organization religious activity, and intrinsic religiosity (66). Spiritual wellbeing was also measured using the FACIT-Sp-12 tool. The critical importance of social support including spiritual and religious support is well-established (57). However, the integration or formal assessments of these support systems for lung cancer surgery patients is not well-known for patients throughout their survivorship journeys. While our patients discussed the importance of these systems for their QOL, their needs were not assessed before their surgery. This begs the question, how do we integrate these SDOH assessments into healthcare practice and provide support when needs are identified? This question is out of the scope of the current study, but an important next step is answering this question for future interventions for this population. Additionally, we recommend that SDOH assessments be considered a fifth vital sign (67) for lung cancer surgery patients and embedded into the standard of care practice and workflow.

Study limitations

The findings should be considered in the context of several strengths and limitations. This study used a mixed methods approach to access barriers to QOL of lung cancer surgery patients from an NCI-designated comprehensive cancer center in Southern California. The use of PRAPARE in conjunction with qualitative questions across the five broad SDOH domains provided an informative narrative on SDOH disparities for this population. The use of a multimedia tool "A tale of two Zip Codes" supported the discussion with participants on SDOH. The use of Microsoft Teams is a notable strength as the burden of travel was minimized and allowed the research team to pilot the teleconferencing technology for qualitative data collection. The main limitation of this study is the lack of representation from under-resourced and minoritized communities. However, the sociodemographic background of participants mirrors the catchment area of the cancer center. We also did not address perspectives from family caregivers or clinicians in this study, but these perspectives will be evaluated in future studies as both groups were involved with our data collection efforts.

Conclusion

Lung cancer surgery patients experience several barriers during their survivorship journeys combined with SDOH influences that impact their QOL. Notably, some patients experienced financial toxicity but reported that they received quality healthcare and social support throughout their diagnosis and treatment. Considerations for neighborhood safety and green space were discussed to have salutary impacts on health in addition to explorations about exposures to environmental pollutants due to proximity to industrial complexes. Education was described beyond the attainment of an academic degree and the inclusion of individual lived experiences to support the survivorship journey. SDOH remains an important consideration for QOL and survivorship, but the inclusion of these assessments and the implementation of solutions once needs are identified remain a challenge as the primary objective of the healthcare team is to treat the disease.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Beckman Research Institute, City of Hope. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

DT: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Validation, Visualization, Writing – original draft, Writing – review & editing. BF: Formal analysis, Writing – review & editing. OO: Formal analysis, Writing – original draft, Writing – review & editing. AD: Formal analysis, Writing – original draft. LE: Methodology, Writing – review & editing. SM: Methodology, Writing – review & editing. DR: Writing – review & editing. RK: Writing – review & editing. JK: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing. VS: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Visualization, Writing – original draft, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

The author(s) declared that they were an editorial board member of Frontiers, at the time of submission. This had no impact on the peer review process and the final decision.

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References

1. Asare M, Flannery M, Kamen C. Social determinants of health: a framework for studying cancer health disparities and minority participation in research. *Oncol Nurs Forum*. (2017) 44:20. doi: 10.1188/17.ONF.20-23

2. Braveman P, Gottlieb L. The social determinants of health: it's time to consider the causes of the causes. *Public Health Rep*. (2014) 129:19–31. doi: 10.1177/00333549141291S206

3. U.S. Department of Health and Human Services. Social determinants of health. (n.d.). Available from: https://health.gov/healthypeople/objectives-and-data/browse-objectives#social-determinants-of-health.

4. Teteh DK, Love M, Ericson M, Chan M, Phillips T, Toor A, et al. Social determinants of health among family caregiver centered outcomes in lung cancer: a systematic review. *J Thorac Dis*. (2023) 15:2824–35. doi: 10.21037/jtd-22-1613

5. Sosa E, D'Souza G, Akhtar A, Sur M, Love K, Duffels J, et al. Racial and socioeconomic disparities in lung cancer screening in the United States: a systematic review. *CA Cancer J Clin*. (2021) 71:299–314. doi: 10.3322/caac.21671

6. Bonner SN, Wakeam E. The volume-outcome relationship in lung cancer surgery: the impact of the social determinants of health care delivery. *J Thorac Cardiovasc Surg*. (2022) 163:1933–7. doi: 10.1016/j.jtcvs.2021.02.104

7. Melvan JN, Sancheti MS, Gillespie T, Nickleach DC, Liu Y, Higgins K, et al. Nonclinical factors associated with 30-day mortality after lung Cancer resection: an analysis of 215,000 patients using the National Cancer Data Base. *J Am Coll Surg*. (2015) 221:550–63. doi: 10.1016/j.jamcollsurg.2015.03.056

8. Lam MB, Raphael K, Mehtsun WT, Phelan J, Orav EJ, Jha AK, et al. Changes in racial disparities in mortality after Cancer surgery in the US, 2007-2016. *JAMA Netw Open*. (2020) 3:e2027415. doi: 10.1001/jamanetworkopen.2020.27415

9. Martin MY, Fouad MN, Oster RA, Schrag D, Urmie J, Sanders S, et al. What do cancer patients worry about when making decisions about treatment? Variation across racial/ethnic groups. *Support Care Cancer*. (2014) 22:233–44. doi: 10.1007/s00520-013-1958-5

10. Lyons KS, Miller LM, McCarthy MJ. The roles of dyadic appraisal and coping in couples with lung Cancer. *J Fam Nurs*. (2016) 22:493–514. doi: 10.1177/1074840716675976

11. Kyte K, Ekstedt M, Rustoen T, Oksholm T. Longing to get back on track: Patients' experiences and supportive care needs after lung cancer surgery. *J. Clin. Nurs.* (2019) 28:1546–54. doi: 10.1111/jocn.14751

12. Hung HY, Wu LM, Chen KP. Determinants of quality of life in lung Cancer patients. *J Nurs Scholarsh*. (2018) 50:257–64. doi: 10.1111/jnu.12376

13. Dogan N, Tan M. Quality of life and social support in patients with lung Cancer. *Int J Caring Sci*. (2019) 12:263–9.

14. Madani H, Pourmemari M, Moghimi M, Rashvand F. Hopelessness, perceived social support and their relationship in Iranian patients with Cancer. *Asia Pac J Oncol Nurs*. (2018) 5:314–9. doi: 10.4103/apjon.apjon_5_18

15. Skalla KA, Ferrell B. Challenges in assessing spiritual distress in survivors of Cancer. *Clin J Oncol Nurs*. (2015) 19:99–104. doi: 10.1188/15.CJON.99-104

16. Chang NW, Lin KC, Hsu WH, Lee SC, Chan JY, Wang KY. The effect of gender on health-related quality of life and related factors in post-lobectomy lung-cancer patients. *Eur J Oncol Nurs*. (2015) 19:292–300. doi: 10.1016/j.ejon.2014.10.015

17. Rose P, Quail H, McPhelim J, Simpson M. Experiences and outcomes of lung cancer patients using electronic assessments. *Cancer Nurs. Pract.* (2017) 16:26–30. doi: 10.7748/cnp.2017.e1434

18. Lee CS, Lyons KS. Patterns, relevance, and predictors of dyadic mental health over time in lung cancer. *Psycho-Oncology*. (2019) 28:1721–7. doi: 10.1002/pon.5153

19. Eichler M, Hechtner M, Wehler B, Buhl R, Stratmann J, Sebastian M, et al. Use of psychosocial services by lung cancer survivors in Germany: results of a German multicenter study (LARIS). *Strahlenther Onkol*. (2019) 195:1018–27. doi: 10.1007/s00066-019-01490-1

20. Shi Y, Gu F, Hou Ll H. Self-reported depression among patients with non-small cell lung cancer. Thoracic. *Cancer*. (2015) 6:334–7. doi: 10.1111/1759-7714.12179

21. Ermers DJM, KJH Bussel, Perry M, Engels Y, Schers HJ, van van Bussel KJH. Advance care planning for patients with cancer in the palliative phase in Dutch general practices. *Fam Pract* (2019) 36, 587–593. doi: 10.1093/fampra/cmy124

22. Falchook AD, Dusetzina SB, Tian F, Basak R, Selvam N, Chen RC. Aggressive end-of-life care for metastatic cancer patients younger than age 65 years. *JNCI*. (2017) 109:1–6. doi: 10.1093/jnci/djx028

23. Temel JS, Greer JA, El-Jawahri A, Pirl WF, Park ER, Jackson VA, et al. Effects of early integrated palliative Care in Patients with Lung and GI Cancer: a randomized clinical trial. *J Clin Oncol*. (2017) 35:834–41. doi: 10.1200/JCO.2016.70.5046

24. Hovanec J, Siemiatycki J, Conway DI, Olsson A, Stücker I, Guida F, et al. Lung cancer and socioeconomic status in a pooled analysis of case-control studies. *PLoS One*. (2018) 13:e0192999. doi: 10.1371/journal.pone.0192999.

25. Nicolau B, Madathil SA, Castonguay G, Rousseau MC, Parent ME, Siemiatycki J. Shared social mechanisms underlying the risk of nine cancers: a life course study. *Int J Cancer*. (2019) 144:59–67. doi: 10.1002/ijc.31719

26. Behrens T, Groß I, Siemiatycki J, Conway DI, Olsson A, Stücker I, et al. Occupational prestige, social mobility and the association with lung cancer in men. *BMC Cancer*. (2016) 16:395. doi: 10.1186/s12885-016-2432-9

27. Zhou LF, Zhang MX, Kong LQ, Lyman GH, Wang K, Lu W, et al. Costs, trends, and related factors in treating lung Cancer patients in 67 hospitals in Guangxi. *China Cancer Invest*. (2017) 35:345–57. doi: 10.1080/07357907.2017.1296156

28. Adorno G, Wallace C. Preparation for the end of life and life completion during late-stage lung cancer: an exploratory analysis. *Palliat Support Care*. (2017) 15:554–64. doi: 10.1017/S1478951516001012

29. Barbaret C, Delgado-Guay MO, Sanchez S, Brosse C, Ruer M, Rhondali W, et al. Inequalities in financial distress, symptoms, and quality of life among patients with advanced Cancer in France and the U.S. *Oncologist*. (2019) 24:1121–7. doi: 10.1634/theoncologist.2018-0353

30. Verma R, Pathmanathan S, Otty ZA, Binder J, Vangaveti VN, Buttner P, et al. Delays in lung cancer management pathways between rural and urban patients in North Queensland: a mixed methods study. *Intern Med J*. (2018) 48:1228–33. doi: 10.1111/imj.13934

31. Billmeier SE, Ayanian JZ, He Y, Jaklitsch MT, Rogers SO. Predictors of nursing home admission, severe functional impairment, or death one year after surgery for non-small cell lung cancer. *Ann Surg*. (2013) 257:555–63. doi: 10.1097/SLA.0b013e31828353af

32. Torres-Durán M, Ruano-Ravina A, Kelsey KT, Parente-Lamelas I, Provencio M, Leiro-Fernández V, et al. Small cell lung cancer in never-smokers. *Eur Respir J*. (2016) 47:947–53. doi: 10.1183/13993003.01524-2015

33. Torres-Durán M, Ruano-Ravina A, Parente-Lamelas I, Leiro-Fernández V, Abal-Arca J, Montero-Martínez C, et al. Lung cancer in never-smokers: a case-control study in a radon-prone area (Galicia, Spain). *Eur Respir J*. (2014) 44:994–1001. doi: 10.1183/09031936.00017114

34. Rodríguez-Martínez Á, Ruano-Ravina A, Torres-Durán M, Vidal-García I, Leiro-Fernández V, Hernández-Hernández J, et al. Small cell lung cance. Methodology and preliminary results of the SMALL CELL study. *Arch Bronconeumol*. (2017) 53:675–81. doi: 10.1016/j.arbres.2017.04.016

35. Torres-Durán M, Ruano-Ravina A, Parente-Lamelas I, Leiro-Fernández V, Abal-Arca J, Montero-Martínez C, et al. Residential radon and lung cancer characteristics in never smokers. *Int J Radiat Biol*. (2015) 91:605–10. doi: 10.3109/09553002.2015.1047985

36. Klassen AC, Hsieh S, Pankiewicz A, Kabbe A, Hayes J, Curriero F. The association of neighborhood-level social class and tobacco consumption with adverse lung cancer characteristics in Maryland. *Tob Induc Dis*. (2019) 17:06. doi: 10.18332/tid/100525

37. Johnson AM, Johnson A, Hines RB, Bayakly R. The effects of residential segregation and neighborhood characteristics on surgery and survival in patients with early-stage non-small cell lung Cancer. *Cancer Epidemiol Biomark Prev*. (2016) 25:750–8. doi: 10.1158/1055-9965.Epi-15-1126

38. Erhunmwunsee L, Wing SE, Zou X, Coogan P, Palmer JR, Lennie WF. Neighborhood disadvantage and lung cancer risk in a national cohort of never smoking black women. *Lung Cancer*. (2022) 173:21–7. doi: 10.1016/j.lungcan.2022.08.022

39. The California Endowment. A Tale of Two Zip Codes. (2016). Available from: https://www.youtube.com/watch?v=Eu7d0BMRt0o (Accessed July 11, 2023)

40. The National Association of Community Health Centers. Protocol for Responding to and Assessing Patients' Assets, Risks, and Experiences. (n.d.). Available at: http://www.nachc.org/research-and-data/prapare/

41. Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. (2005) 15:1277–88. doi: 10.1177/1049732305276687

42. Teteh DK, Barajas J, Ferrell B, Zhou Z, Erhunmwunsee L, Raz DJ, et al. The impact of the COVID-19 pandemic on care delivery and quality of life in lung cancer surgery. *J Surg Oncol*. (2022) 126:407–16. doi: 10.1002/jso.26902

43. Fu L, Zhuang M, Luo C, Zhu R, Wu B, Xu W, et al. Financial toxicity in patients with lung cancer: a scoping review protocol. *BMJ Open*. (2022) 12:e057801. doi: 10.1136/bmjopen-2021-057801

44. Hazell SZ, Fu W, Hu C, Voong KR, Lee B, Peterson V, et al. Financial toxicity in lung cancer: an assessment of magnitude, perception, and impact on quality of life. *Ann Oncol*. (2020) 31:96–102. doi: 10.1016/j.annonc.2019.10.006

45. Friedes C, Hazell SZ, Fu W, Hu C, Voong RK, Lee B, et al. Longitudinal trends of financial toxicity in patients with lung Cancer: a prospective cohort study. *JCO Oncol. Pract*. (2021) 17:e1094–109. doi: 10.1200/op.20.00721

46. Mitchell E, Alese OB, Yates C, Rivers BM, Blackstock W, Newman L, et al. Cancer healthcare disparities among African Americans in the United States. *J Natl Med Assoc*. (2022) 114:236–50. doi: 10.1016/j.jnma.2022.01.004

47. Ashing KT, Jones V, Bedell F, Phillips T, Erhunmwunsee L. Calling attention to the role of race-driven societal determinants of health on aggressive tumor biology: a focus on black Americans. *JCO Oncol Pract*. (2022) 18:15–22. doi: 10.1200/op.21.00297

48. Boulanger M, Mitchell C, Zhong J, Hsu M. Financial toxicity in lung cancer. *Front Oncol*. (2022) 12:1004102. doi: 10.3389/fonc.2022.1004102

49. Zhou K, Shi H, Chen R, Cochuyt JJ, Hodge DO, Manochakian R, et al. Association of Race, socioeconomic factors, and treatment characteristics with overall survival in patients with limited-stage small cell lung Cancer. *JAMA Netw Open*. (2021) 4:e2032276–6. doi: 10.1001/jamanetworkopen.2020.32276

50. Herndon JE, Kornblith AB, Holland JC, Paskett ED. Patient education level as a predictor of survival in lung cancer clinical trials. *J Clin Oncol*. (2008) 26:4116–23. doi: 10.1200/jco.2008.16.7460

51. Roy B, Kiefe CI, Jacobs DR, Goff DC, Lloyd-Jones D, Shikany JM, et al. Education, race/ethnicity, and causes of premature mortality among middle-aged adults in 4 US urban communities: results from CARDIA, 1985–2017. *Am J Public Health*. (2020) 110:530–6. doi: 10.2105/ajph.2019.305506

52. Namburi N, Timsina L, Ninad N, Ceppa D, Birdas T. The impact of social determinants of health on management of stage I non-small cell lung cancer. *Am J Surg*. (2022) 223:1063–6. doi: 10.1016/j.amjsurg.2021.10.022

53. Farjah F, Grau-Sepulveda MV, Gaissert H, Block M, Grogan E, Brown LM, et al. Volume pledge is not associated with better short-term outcomes after lung cancer resection. *J Clin Oncol*. (2020) 38:3518–27. doi: 10.1200/jco.20.00329

54. Pizzo AM, Chellini E, Costantini AS. Lung cancer risk and residence in the neighborhood of a sewage plant in Italy. A case-control study. *Tumori*. (2011) 97:9–13. doi: 10.1177/030089161109700102

55. Erhunmwunsee L, Wing SE, Shen J, Hu H, Sosa E, Lopez LN, et al. The association between polluted neighborhoods and TP53-mutated non-small cell lung Cancer. *Cancer Epidemiol Biomark Prev*. (2021) 30:1498–505. doi: 10.1158/1055-9965.Epi-20-1555

56. Yu XJ, Yang MJ, Zhou B, Wang GZ, Huang YC, Wu LC, et al. Characterization of somatic mutations in air pollution-related lung Cancer. *EBioMedicine*. (2015) 2:583–90. doi: 10.1016/j.ebiom.2015.04.003

57. Hofman A, Zajdel N, Klekowski J, Chabowski M. Improving social support to increase QoL in lung Cancer patients. *Cancer Manag Res*. (2021) 13:2319–27. doi: 10.2147/cmar.S278087

58. Gu W, Xu YM, Zhong BL. Health-related quality of life in Chinese inpatients with lung cancer treated in large general hospitals: across-sectional study. *BMJ Open*. (2018) 8:e019873. doi: 10.1136/bmjopen-2017-019873

59. Huang ZP, Cheng HL, Loh SY, Cheng KKF. Functional status, supportive care needs, and health-related quality of life in advanced lung Cancer patients aged 50 and older. *Asia Pac J Oncol Nurs*. (2020) 7:151–60. doi: 10.4103/apjon.apjon_50_19

60. Raz DJ, Sun V, Kim JY, Williams AC, Koczywas M, Cristea M, et al. Long-term effect of an interdisciplinary supportive care intervention for lung cancer survivors after surgical procedures. *Ann Thorac Surg*. (2016) 101:495–503. doi: 10.1016/j.athoracsur.2015.07.031

61. McKim DK. *The Westminster dictionary of theological terms: Revised and expanded*. Germantown, TN: Westminster John Knox Press (2014) ISBN: 0664238351.

62. Kahraman BN, Pehlivan S. The effect of spiritual well-being on illness perception of lung cancer patients. *Support Care Cancer*. (2023) 31:107. doi: 10.1007/s00520-022-07527-z

63. Gudenkauf LM, Clark MM, Novotny PJ, Piderman KM, Ehlers SL, Patten CA, et al. Spirituality and emotional distress among lung cancer survivors. *Clin Lung Cancer*. (2019) 20:e661–6. doi: 10.1016/j.cllc.2019.06.015

64. Peterman AH, Fitchett G, Brady MJ, Hernandez L, Cella D. Measuring spiritual well-being in people with cancer: the functional assessment of chronic illness therapy—spiritual well-being scale (FACIT-Sp). *Ann Behav Med*. (2002) 24:49–58. doi: 10.1207/S15324796ABM2401_06

65. Perez SEV, Maiko S, Burke ES, Slaven JE, Johns SA, Smith OJ, et al. Spiritual care assessment and intervention (SCAI) for adult outpatients with advanced cancer and caregivers: a pilot trial to assess feasibility, acceptability, and preliminary effects. *Am. J. Hospice Palliative Med*. (2022) 39:895–906. doi: 10.1177/10499091211042860

66. Koenig HG, Büssing A. The Duke University religion index (DUREL): a five-item measure for use in epidemological studies. *Religions*. (2010) 1:78–85. doi: 10.3390/rel1010078

67. Pardo C, McLaren R Jr, Minkoff H. Social determinants of health: the fifth vital sign. *Am J Perinatol*. (2022). doi: 10.1055/a-1787-7307

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Magdalena Klimczuk-Kochańska,
University of Warsaw, Poland

REVIEWED BY
Jorge Cunha,
University of Minho, Portugal
Palmira Immordino,
University of Palermo, Italy

*CORRESPONDENCE
Per Kåks
✉ per.kaks@uu.se

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Implementing a social innovation for community-based peer support for immigrant mothers in Sweden: a mixed-methods process evaluation

Per Kåks[1]*, Linnea Stansert Katzen[1], Mats Målqvist[1],
Anna Bergström[1] and Sibylle Herzig van Wees[1,2]

[1]SWEDESD, Department of Women's and Children's Health, Uppsala University, Uppsala, Sweden,
[2]Department of Global Public Health, Karolinska Institute, Stockholm, Sweden

Introduction: A South African social innovation based on peer support for mothers was contextualized in southern Sweden. The objective of the project was to support expectant women and mothers of young children in immigrant communities to access public services that would benefit maternal and child health. This study aimed to assess how the intervention was implemented, what the contextual barriers and facilitators were, and how the implementation was perceived by those who delivered and received it.

Methods: The study used mixed methods with a convergent parallel design and followed the Medical Research Council guidance on process evaluations of complex interventions. Semi-structured interviews ($n = 19$) were conducted with peer supporters, client mothers, and key stakeholders involved in the intervention. The qualitative data were analyzed using content analysis. Quantitative data on peer supporters' activities were collected during contacts with client mothers and were presented descriptively.

Results: The five peer supporters had 1,294 contacts with client mothers, of which 507 were first-time contacts. The reach was perceived as wide, and the dose of the intervention was tailored to individual needs. Barriers to implementation included community mistrust of social services, norms on gender roles and parenting, and funding challenges. The implementation was facilitated by the organization's reputation, network, experience, and third-sector affiliation. Peer supporters tended to prioritize linking clients to other services over the educational components of the intervention, sometimes doing more than what was originally planned. Implementation strategies used included building trust, using multiple outreach venues, using internal support structures, and providing practical assistance as an entry point to comprehensive psychosocial support. The personal connection between peer supporters and clients was highly valued, and the building of relationships enabled them to address sensitive topics. Peer supporters sometimes experienced a blurred line between professional and personal roles.

Conclusions: Peer supporters used a variety of strategies to navigate identified barriers and facilitators. Trust was central both as a contextual factor and a strategy for implementation. It is valuable to maintain a balance between flexibility and adherence to the function of peer supporters. Further research is needed to evaluate the effects of the intervention.

KEYWORDS

social innovation, peer support, process evaluation, mixed-methods, parents, children, maternal and child health

Introduction and aim

In recent decades, Sweden has seen an increasing socioeconomic divide (1). With immigrant families having a higher risk of being on the lower side of the socioeconomic spectrum, this has resulted in inequities in health. One example of this is that infant mortality rates are twice as high for children born to mothers who have immigrated than for those born to Swedish-born mothers (2). Such disparities reflect a complex set of social and health-related factors that can impact the wellbeing of immigrant parents and their children. This includes interactions with the welfare system, such as how different resources and services are used.

Immigrant populations in high-income countries often face multiple challenges in accessing public services. Previous research has indicated that migrants in Europe may find it difficult both to get an overview of what services are available and how they can be accessed (3, 4). When accessing health services, factors such as language difficulties and discrimination can be barriers to their effective use (5). As a consequence, immigrants are less likely than the native population to use preventive services and more likely to use emergency services (5). From a provider's perspective, the key challenges in providing care to immigrant populations in high-income countries have previously been summarized as lack of communication, continuity, and confidence (6).

Qualitative research in Sweden has highlighted how newly arrived immigrant parents struggle to adjust to a new type of social life and a sense of uncertainty surrounding housing, residence permits and income (7, 8). Similar studies have also identified a need for information on what culturally appropriate parenting entails and what support is available from the authorities (9, 10). While parental support groups are offered to all parents in Sweden through the child health services, they are not utilized by immigrant and low-income parents to the same degree as the majority population (11). A report on migration and health in southern Sweden has highlighted lack of trust in institutions as a barrier to welfare consumption, as it is more prevalent among those who have migrated to Sweden than the general population (12). This can sometimes take the form of mistrust of social services, with parents avoiding communicating their support needs due to a fear of being separated from their children on social grounds (9).

Ensuring that the social and health needs of parents who have immigrated to Sweden are met requires new approaches to address how public services are accessed and used. Social innovation has emerged as a conceptual framework to describe the innovative efforts of both civil society, the public sector and parts of the private sector to develop and implement new, efficient solutions to complex societal challenges (13). At the core of the concept is a priority for social rather than commercial benefits. The European Commission has defined social innovation as "new ideas that address social needs, create social relationships and new collaborations" (13), which emphasize the interactive and cooperative aspect of development and implementation. The innovative component can consist of new ways of filling in social gaps by improving access to existing welfare services, and not just the development of new welfare services *per se* (14). Peer support programs are a form of social innovation that has been used to improve health outcomes and integration among marginalized groups (15). The concept is based on the idea that social challenges are best understood from the inside and that those who have successfully navigated such challenges can use their experiences to support others (16).

A variety of social innovations based on peer support targeting marginalized parents have been tested in low-, middle- and high-income countries (15, 17). One such innovation is the Mentor Mother model developed by the Philani Maternal, Child Health and Nutrition Trust in Cape Town, South Africa (18). The Mentor Mother model involves health-focused parenting support provided by women who themselves come from the area where they work as Mentor Mothers. This support is delivered as home visits, provided both in the form of educational interventions and through linking families to clinic-based healthcare and other services when needed. The model is summarized in five principles:

1. A careful recruitment process. The recruitment of Mentor Mothers follows the principle of positive deviance, aiming to identify women who have managed to raise healthy children despite challenging circumstances. This background enables them to act as role models in their work. All mentor mothers work in the area where they live.
2. Appropriate training. The Mentor Mothers initially receive a 6-week course on maternal and child health, motivational interviewing and other intervention strategies. In addition, they also receive continuous training on a monthly basis.
3. Home-based, action-oriented health intervention. The families' homes are used as a platform to discuss the health and wellbeing of children and mothers, focusing on nutrition, HIV, tuberculosis, pregnancy, mental health, personal finances, and more. The Mentor Mother shares her knowledge and skills to help families find their own solutions to the problems they face, rather than solving the problems for them. Visits are made weekly to monthly.
4. In-the-field supervision and support. Each Mentor Mother is regularly supported by coordinators in the field. Time

is set aside for debriefing on difficult cases and feedback on performance.

5. Monitoring and performance feedback. Field activities and client health outcomes are tracked over time to enable evaluation of performance and effectiveness. The data also makes it possible to identify particularly vulnerable families.

In 2021, the model was contextualized and implemented as a peer support intervention for immigrant mothers and pregnant women in Malmö in southern Sweden (19). This resulted in a change of focus to social determinants of health, prioritizing linking to other services and new ways of recruiting and maintaining contact with the heterogeneous target group. By evaluating the implementation of this program, we hope to inform both its further development and the development of similar social innovations targeting the health and wellbeing of marginalized communities. We also seek to contribute to the literature on the transfer of social innovations between contexts by illustrating how continuous adaptation and learning can take place within a civil society-led intervention. This study thus aims to contribute to the literature on peer support by increasing the understanding of internal and external factors that influence the possibility of using peer support as a means of promoting health and social inclusion in a high-income context characterized by social divides. The need for such efforts is pressing given the increasing disparities among the Swedish population, which poses unique challenges for the provision of welfare services and public sector interactions with marginalized groups.

Aim

This article aims to assess how the peer supporters enacted their roles, what adaptations of the social innovation have been made during the course of implementation, how the implementation has been perceived by those who deliver and receive it, and what barriers and facilitators were identified during the implementation process.

Methods

Setting

This study was conducted within the organization *Yallatrappan*, a social enterprise based in a socioeconomically disadvantaged area in Malmö. The enterprise focuses on providing platforms for work integration for immigrant women. Since 2021, they also run the peer support program for pregnant immigrant women and mothers of children up to 5 years old. The steering group for the program consists of representatives from Yallatrappan, the Church of Sweden and Uppsala University. It also has a recent addition of representatives from housing companies interested in increasing livelihoods and knowledge of rights and obligations among their tenants.

Malmö is Sweden's third largest city with a population of 357,000, of which 36% are born in a foreign country (20). The city has a high unemployment rate of 12.6% of the population aged 16–64 years, compared to the national average of 6.7% (21). The city is also characterized by a high degree of residential and social segregation, resulting in disparities in health between neighborhoods (22).

The peer support intervention

The peer support program employs five women from the area, all of whom have themselves immigrated and successfully integrated into Swedish society. Each peer supporter works 30 h a week. They all have previous experience of working with women and children. The peer supporters are selected to cover the most common language groups among immigrants in the area. In their daily work, they conduct outreach to make contact with pregnant women or mothers of children up to 5 years old (subsequently referred to as *client mothers*). They map the client mothers' individual needs regarding contact with public services such as authorities, healthcare or civil society organizations, in order to support the client mothers in these contacts. They also work informatively by educating client mothers about Swedish public and civil society services, as well as on topics related to parenting and maternal and child health. The content of the intervention is largely user-driven and the peer supporters' work is tailored to the individual client mothers' needs.

To guide the implementation of the peer support intervention, a logic model was constructed together with stakeholders comprising the steering group during the first half of 2021. This model described the intended inputs, activities, outputs, outcomes and long-term impact of the intervention, as well as assumed causal mechanisms underpinning the logic model.

As stated in Figure 1, the inputs specified in the model included financing for peer supporters and a coordinator as well as implementation strategies such as partnerships, training, supervision and quality monitoring. The activities included identifying socially vulnerable immigrant mothers and pregnant women in need of assistance in navigating Swedish society and parenting and health practices, and mapping the needs of these women. Subsequently, the peer supporters focus on linking them to public services and civil society organizations based on individual needs. They also support mothers by providing information on how these services operated, and providing information on matters relating to parenting, early childhood education and maternal and child health in the Swedish context. The outputs were defined to correspond to the activities in terms of information received on health, parenting and services, and linking to services and civil society organizations. The outcomes for the intervention were specified to include increased knowledge of Swedish society, citizen rights, parenting and health, and increased use of relevant educational, social and health services, and civil society organizations. The overarching impact was described as empowering of the target group, to contribute to a society where everyone has the possibility to lead a good life.

By clearly describing the components of the logic model, the stakeholders of the peer support project gained a common understanding of what the project was aiming for and how this would be achieved. Furthermore, by defining the activities and outputs, the logic model also enabled an evaluation of the fidelity to these and the identification of possible adaptations within this process evaluation.

Study design

The study was designed as a mixed-methods process evaluation conducted between January and December 2022. Process evaluations can be used to shed light on the pathways linking the intervention intended to be implemented to the outcomes produced, and has been described as a vital part of community-based interventions (23). The use of both quantitative and qualitative data can offer both opportunities for exploring the findings of one data type using another method, and for determining how different types of data converge or diverge. This study followed a convergent parallel design where qualitative and quantitative data were collected and analyzed simultaneously and integrated at the point of analysis to allow for triangulation (24).

The United Kingdom Medical Research Council (MRC) guidance on process evaluation of complex interventions was used to guide the study (Figure 2) (25). The guidance provides a framework specifying a structured methodology for evaluating key domains that affect the possibility for an intervention to achieve its desired outcomes. These domains include:

- *Context:* external or internal factors affecting the intervention or its implementation,
- *Implementation:* fidelity to the activities specified in the logic model, dose, reach, adaptation and the implementation process, and
- *Mechanisms of impact:* mediating pathways, participant interactions with the intervention and unintended pathways and consequences.

In other words, the MRC framework can be used to investigate what was delivered within the intervention, how it was delivered, the circumstances that have shaped the intervention and its delivery and how the intervention produced change. Understanding these aspects of the implementation process can provide information about how the intervention—and other similar interventions—might be further adapted, improved, scaled, and replicated.

Data collection

To evaluate the implementation domains of the MRC framework, quantitative data were collected continuously over 12 months, with data collection starting when the intervention had been on-going for 1 year. The data were recorded by peer

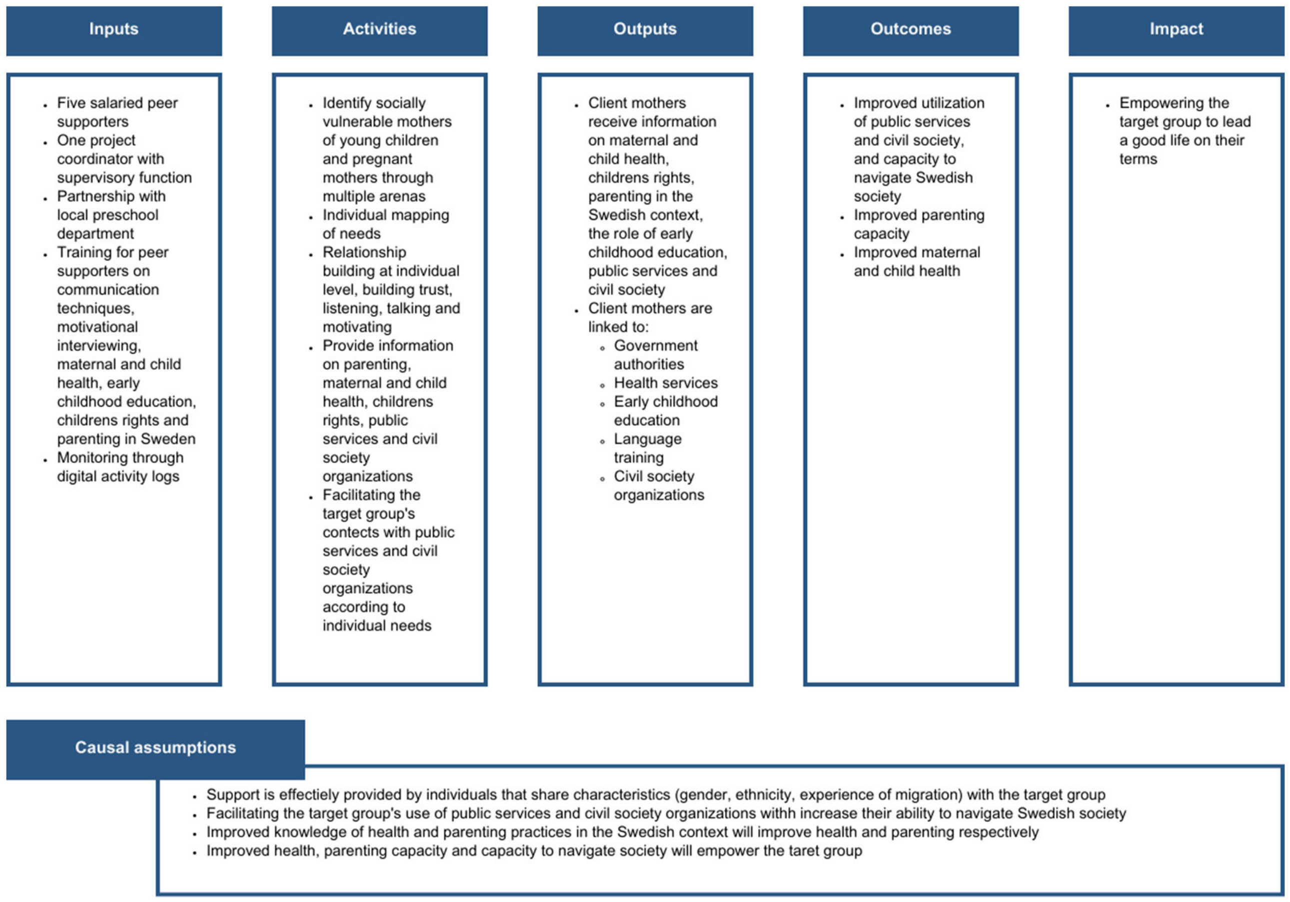

FIGURE 1
Logic model of the peer support intervention.

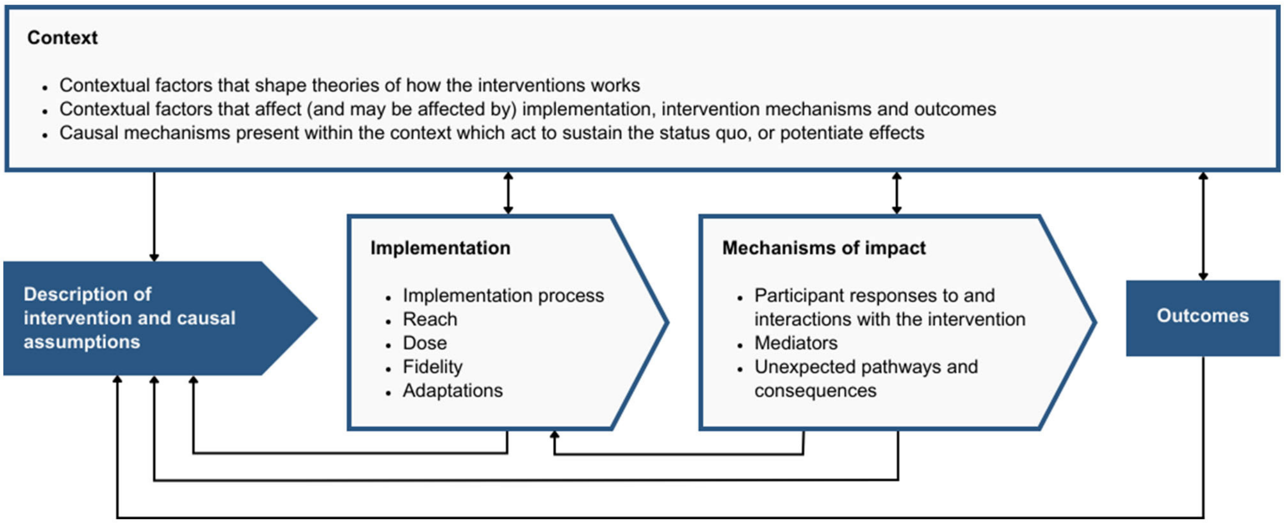

FIGURE 2
Domains of the MRC framework.

supporters after each meeting with a client mother, using digital activity logs collected through the software Kobo Toolbox on electronic tablets (26). The data collection forms were constructed in consultation with peer supporters to be comprehensible and feasible to use. The collected data included what information client mothers received during meetings, what type of practical support they received, date and location for meetings, and if it was a physical meeting or through telephone. No data on topics of discussion (i.e., health, parenting, etc.) with client mothers were collected, as this was found to be too complicated to record accurately. To ensure that the implementing civil society organization complied with European Union General Data Protection Regulation (GDPR), no personal data were registered for the client mothers. This also ensured that data collection did not interfere with the intervention logic based on building trust among vulnerable populations. Consequently, it was not possible to follow individuals over time in the log data.

When 6 months of quantitative data collection had passed, qualitative data were gathered from a range of stakeholders involved in the project to explore their experiences of the implementation of the intervention. All five peer supporters employed within the intervention were interviewed in-person on their experiences of delivering the intervention. Digital video interviews were held with all six steering group members (excluding the authors), focusing on the organizational aspects of the implementation process. Eight in-person interviews were also held with client mothers who had received the intervention, to assess how they perceived their need for peer support and how they had received it. They were recruited on the basis that they belonged to two of the main language groups that the peer supporters worked with, Somali and Arabic. The client mothers were recruited by the peer supporters and were interviewed by public health students in their mother tongue. The interview guides used during all interviews were developed to include questions covering the domains of the MRC framework (Supplementary material 1). All nineteen interviewees were female. All interviews were audio recorded and transcribed verbatim, and the interviews held in client mothers' first languages were translated to English or Swedish. Notes on preliminary themes were taken continuously during the process of collecting and transcribing the material.

Data analysis

The activity log data were compiled and visualized in Tableau 2022.1.0 software (27). The activity log data were divided in terms of if it was the first, second or third or more meeting between peer supporter and client mother. This enabled analyzing how activities changed when they had met several times.

The interview transcripts were imported into NVivo 14 software for data management and analysis (28). The data were analyzed using both deductive and inductive content analysis (29). All transcripts were first coded deductively for manifest content by the first author, using the MRC framework domains as pre-set themes. The data within each sub-domain were then coded again by the first and second author, using an inductive approach to generate codes. The codes were condensed into categories. Repeated reading and re-reading was undertaken to clarify differences, and discrepancies in coding were discussed to generate consensus. The categories were then agreed upon by the first, second, and last author. The generated categories were subsequently discussed within the whole research group before the analysis was finalized.

Methodological considerations and reflexivity

This study combined the use of qualitative and quantitative data. The advantage of a mixed-methods type of study design is that the research questions can be examined from different angles to increase the validity of the results. The integration of two types of data can be done in different ways. We chose to integrate the data at the point of analysis. An alternative approach could have been to let the quantitative data guide the collection of qualitative data, e.g., by informing the development of interview guides. This could have allowed for a more in-depth exploration of questions raised by the quantitative data, but might also have limited the collection of qualitative data by putting a larger emphasis on exploring quantitative results. It would also have delayed the collection of qualitative data. As the project was in continuous development it was important to capture both qualitative and quantitative data in a synchronous manner.

The interviews with the steering group members and peer supporters were conducted by the first author, who is a white male doctor. The first author had come to know these participants on previous occasions. However, it is possible that the power dynamics of the interview situation influenced what the participants, especially the peer supporters, were comfortable expressing. The interviews may also have been influenced by the fact that it was in the participants' interest to emphasize the positive aspects of the project. However, during the interviews, challenges were repeatedly highlighted and participants were able to problematize aspects of the intervention that had not gone as planned.

The interviews with client mothers were held by two female students fluent in the mothers' respective first languages. No other individuals were present during these interviews, to minimize power discrepancy and promote a free and relaxed interview situation. The client mothers were recruited to the study by the peer supporters. This may have contributed to a social desirability bias, influencing what they said during the interviews and their willingness to criticize the project. The client mothers represented two main language groups in the peer supporters' clientele. The interviews with clients were limited to these two groups as it was necessary to balance the diversity of interviewees with the number of research assistants employed in the study. This choice was also made after discussions with the implementing organization, which saw these language groups as representative of its clientele. However, a greater cultural and linguistic diversity among the interviewees could have contributed to further insights into differences in how the various client groups experienced the intervention.

The quantitative data was collected by the peer supporters themselves. Before the data collection for this study started, the first author and the project coordinator refined the activity log tool over the course of 6 months, continuously consulting the peer supporters. The purpose of this was to develop a tool that measured indicators of importance to the organization, was easy to use and that reliably and consistently captured the activities of the peer supporters. However, a small proportion of activities were not logged immediately after they were carried out, but a week or two afterwards. This may have affected the accuracy of the quantitative data, as the nuances of what was done during the recorded activities may have been lost.

The reliability of the results benefited from the triangulation of methods, sources and analysts. The latter involved double coding of all qualitative data by the first and second authors to ensure a consistent interpretation of the data. The diverse backgrounds of the research team also enabled continuous in-depth discussions with different perspectives on emerging findings before consensus was reached.

Ethical considerations

The interviews with peer supporters touched on issues of how they succeeded in their role, which was related to their own work performance. The client mothers were interviewed regarding issues of difficulties with integration into Swedish society and how social exclusion affected their ability to provide the best possible care for their children. These areas could be perceived as sensitive, which made it particularly important to explain the purpose and procedures of the study, as well as the confidential handling of the data before they agreed to participate.

Participants were given oral and written information about the study and time to consider their participation before the interviews were held. All participants were also informed that they could withdraw their participation at any time without having to state any reason and without consequences. The voluntary nature of the research project was again emphasized before the interviews began. All participants signed an informed consent form.

The peer supporters were employed within the program and interviews with them were conducted during working hours. Apart from this, the participants received no financial compensation for their part in the study.

Results

Within the domains of the MRC framework, 17 categories were generated in the qualitative analysis, representing different aspects of the context, implementation process, and mechanisms of impact respectively (Figure 3). The categories are illustrated with selected quotes from the interviews and quantitative process data on the peer supporters' activities. Additional quotes are available in Supplementary material 2.

Context

Several contextual factors were identified both in the internal organizational context and the external context. These constituted both barriers and facilitating factors during implementation.

Mistrust of the social services

The peer supporters and steering group members expressed that a common obstacle they had to overcome was a widespread mistrust of social services among the target group. This mistrust stemmed from a knowledge that social services could separate children from their parents on social grounds. Peer supporters described how this led families from the target group to avoid contact with social services. It could also lead them to avoiding contact with other services such as preschools or mental health professionals, based on a fear of being observed by staff who may

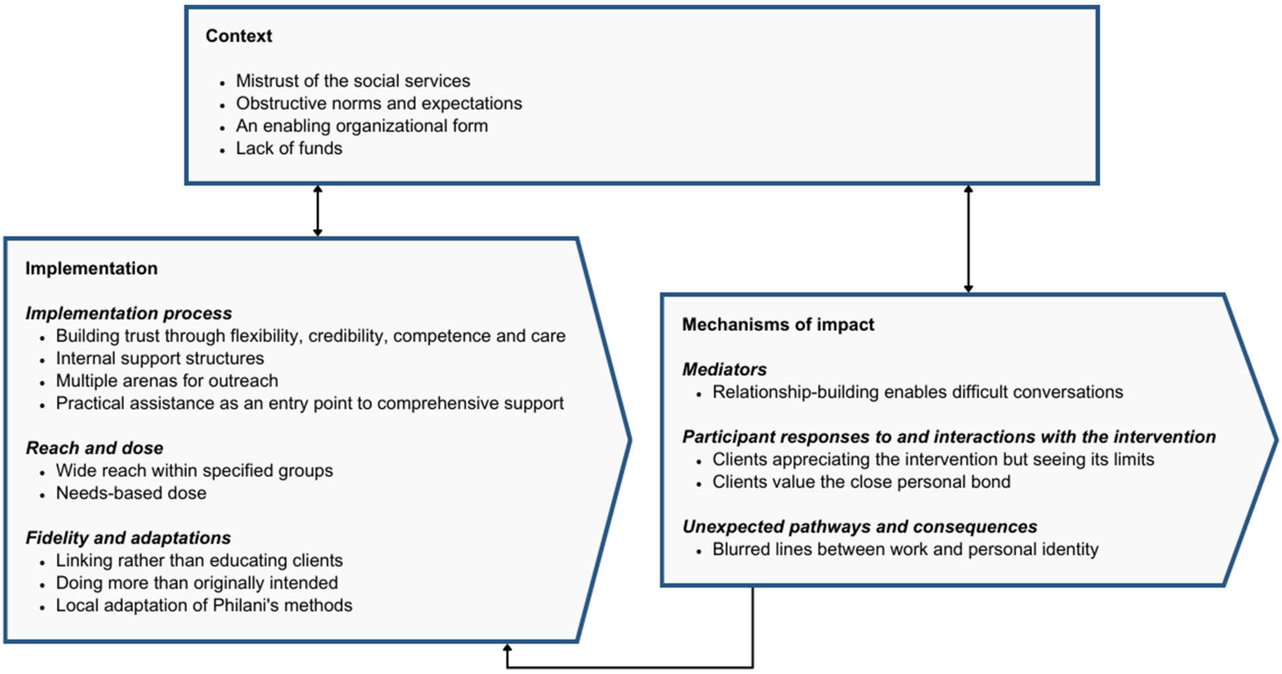

FIGURE 3
Categories sorted by MRC guidance domains.

judge their parenting as inadequate and report them to the social services. Participants described how this avoidance of contact with social services could sometimes lead to families in the target group avoiding contact with peer supports as they perceived them to share certain characteristics with social workers and assumed they were working collaboratively.

> *In the beginning, when I talked to someone about that I work as a peer supporter at Yallatrappan and help those in need, they thought I worked with the social services, and they didn't dare talk about anything. They said no, no, no, in case a second mother wanted to say something, the first mother said [hushing sound]. Why, I said. No, no, we have everything, my husband is doing great, my children are doing great. I said wait, you misunderstand. I don't work with the social services [Peer supporter #2].*

This effect had, however, diminished over time as the peer support intervention became better known among the target group. During the interviews, none of the client mothers brought up any aversive attitudes toward social services or other authorities.

Obstructive norms and expectations

Gender norms around domestic responsibilities and autonomy were described in the interviews as resulting in some men being skeptical of their wives' increased engagement in activities outside the home.

> *When it comes to something that concerns the woman herself, that she should take a course or that she should go on an outdoor trip or that she should do something for her own sake, she always has to ask her husband. And that's a thing that's quite difficult to work out, like, for the peer supporters to work with, it becomes quite difficult right away, I mean, because you might not want to encourage them to like, go home and ask your husband if you are allowed. You might want to talk about that further, like, remember that you are also an individual [Steering group member #6].*

Norms around parenting were also discussed with regard to client mothers sometimes wanting their youngest children to stay at home instead of attending preschool. These factors posed challenges that peer supporters had to navigate in their efforts to increase their clients' agency and participation in society.

An enabling organizational form

A facilitating factor in the internal, organizational, context that was highlighted during the interviews was Yallatrappan's good reputation. Together with their established network and their history of running large projects, this enabled the establishment of the intervention among both the target group and among the community actors that the peer supporters collaborated with and linked the target group to. The organization's role as a non-governmental organization was also described as providing freedom in the management and development of the intervention and enabling them to act as a neutral part between migrant mothers and the welfare system.

> *You only accept information from someone you trust, someone you have a relationship with, someone you have confidence in. It's as simple as that. And that's not always authorities and administrations, but rather us [Yallatrappan], who are more independent in our relationship with the citizens. Plus we have activities that have existed for a long time in the area, that are appreciated and important [Steering group member #2].*

Lack of funds

Participants emphasized that a persistent internal barrier to project implementation was unpredictable funding. This led to difficulties in planning the long-term development of the intervention. It also contributed to difficulties in scaling up the work despite a high perceived need for peer supporters' support. The lack of sustainable funding was discussed as something difficult to understand given the need to work preventively on integration, parenting and health. A factor that was highlighted was that the organization's close cooperation with public actors in other projects had led these actors to prefer to enter into new agreements with other organizations in order to increase their distribution of financing to external projects.

Implementation

The results related to implementation consisted of reach and dose which were found to vary between groups, and the peer supporters' implementation strategies were considered to consist of both explicit and implicit strategies.

Reach and dose

Wide reach within specified groups

A total of 1,294 contacts with client mothers were registered in the activity logs, of which 1,081 (83.5%) were in-person meetings and 213 (16.5%) contacts by phone. Out of the total, 597 (46.1%) contacts with clients were held by two Somali speaking peer supporters, 275 (21.3%) by a peer supporter speaking Dari, Pashto, and Russian, 237 (18.3%) by a peer supporter speaking Urdu, Bengali, and Hindi, and 185 (14.3%) by a peer supporter speaking Arabic (Figure 4).

Overall, peer supporters and steering group members felt that they managed to reach a large number of women in the target area. However, due to the heterogeneous composition of the target group, their coverage was limited to the specific language groups to which they themselves belonged. One language group that fell outside of this was Romani, which participants raised during several interviews.

Another group that was considered difficult for peer supporters to reach was the most isolated women. This was also the group that was perceived to be most in need of the peer supporters' services. One factor in the difficulty of establishing contact with them was the lack of ways to identify them.

> *The peer supporters work a lot in their local area where they live, because they have a pretty good idea of who lives around them and so on. But those who are the most isolated, we don't reach them. You probably have to reach them through the social services, and maybe not even then [Steering group member #6].*

Needs-based dose

The number and frequency of contacts were adapted to individual needs, resulting in a large variation in the amount of contact peer supporters had with individual client mothers. As individual mothers were not followed over time in the log data, the intervention dose could not be quantified. However, peer supporters had about half as many (55.4%) second contacts ($n = 281$) as first contacts ($n = 507$) (Figure 5). This suggested that many client mothers had only a single contact with peer supporters during the data collection period. Peer supporters and client mothers were more likely to talk by phone the longer they had been in contact with each other.

Client mothers voiced that the need for support in practical matters decreased over time, as they became more comfortable with solving the problems they encountered in their daily lives. This meant that contacts with the peer supporter tended to become less frequent with time.

> *You see, in the beginning when I first met her, I used to need her [help] a lot with a lot of things. But you know with time, one will get to know things. You become more aware of things. So my need for her now is not like before, but I still need her [Mother #6].*

Fidelity and adaptations

Linking rather than educating clients

Peer supporters described that their work had a high adherence to the part of the logic model that involved linking client mothers to other services. However, they tended to focus less on direct intervention in the form of educating mothers in parenting techniques or maternal and child health. This was described as a consequence of not feeling comfortable taking on specialized topics where there were other professionals who had deeper knowledge and could explain things better. Peer supporters also felt it unnecessary to replace existing services where client mothers could receive information, such as parenting courses. In cases where they educated the mothers on issues such as parenting, child health or children's rights, they were careful to clarify the limitations of their own knowledge. The degree to which individual peer supporter focused on educating mothers vs. linking varied from person to person:

> *I think some peer supporters [educate mothers] a lot and some peer supporters don't do it at all. I know that [one peer supporter] is very good at doing it, and I've heard her do it too. And she often talks about it, like this, the importance of education. This is very important, this is for the sake of your children. And if your children get a good education, they will*

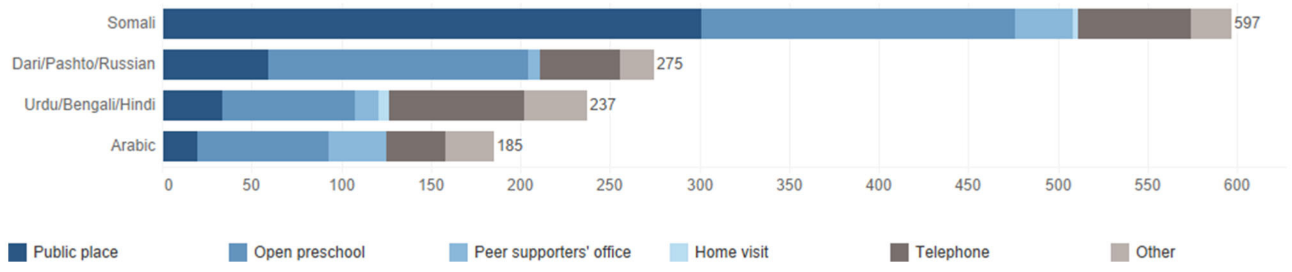

FIGURE 4
Language groups reached and meeting locations.

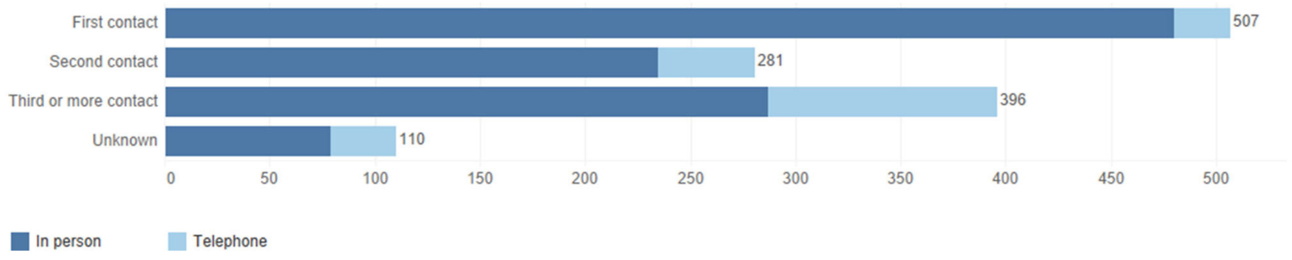

FIGURE 5
Number of first, second and third or more contacts with client mothers.

> *be strengthened in life. Very much like that. A lot about gender equality and women's rights and so on. A lot about old cultural structures from [the country of origin] that she talks about in a very nuanced way. While I know that some peer supporters are very practically oriented [Steering group member #6].*

The log data recorded how the peer supporters worked to link client mothers to different types of services, and whether they provided information about different types of services. In general, peer supporters tended to focus on providing information about open preschools and parenting classes and accompanying mothers to open preschools during the first contacts, while they were more likely to support them in their contacts with the health care providers during later contacts.

Doing more than originally intended

Participants stated that the intervention logic model was not used as a tool in their daily work, but rather as a tool to give the project an overall direction. This was related to the flexible design of the intervention, where activities were largely adapted to the expressed needs of the client mothers. In the work of the peer supporters, they stated that they did not always stick to the scope of the project, but often did more for the client mothers than what was in their job description. This could mean helping them with practical matters related to their housing situation or helping them to buy things for the home.

> *I helped her a lot with housing. She had no housing. She had a child who had a disability. They lived in a hotel and it was a lot. And the child too, he got even worse with epilepsy, and it was a lot. It affected him. And the social services couldn't help with housing. So I used to help her by going to the housing site here in Malmö, registering for an apartment [Peer supporter #1].*

It was also sometimes challenging to restrict themselves to the intended target group, partly because it was difficult to refuse support to women without children or mothers with older children when they had explicit needs. This was justified as a potential way of increasing knowledge of the intervention within the target group.

Local adaptation of Philani's methods

The evaluation showed that the adaptation of the Philani Mother Mentor model—upon which this intervention was based—resulted in several differences from its original inception. For example, Philani's training material for Mentor Mothers was not used in this project. Instead, other types of training materials in counseling techniques and peer support were used.

During the interviews, the participants also described that the meetings that the peer supporters had with client mothers very rarely took place as home visits, which was in contrast to Philani's philosophy on delivering peer support. Out of the 1,081 physical meetings registered in the activity log data, 9 (0.83%) were conducted in the client mothers' homes (Figure 4). The low use of home visits was partly motivated by the fact that the intervention had started to be implemented during the COVID-19 pandemic, as the routines for the project had been established during a period when home visits were difficult to carry out safely. Peer supporters also expressed that home visits felt too personal and were perceived as time inefficient. An additional factor that was raised was that it could be problematic from a work environment point of view to use the homes for meetings, as it was never possible to know what the environment was like before arriving there. It was also not possible to assume that the client mothers experienced their own home as a safe place for meetings.

Implementation process

Building trust through flexibility, credibility, competence, and care

The participants described that an important strategy in the implementation of the intervention was to actively work on building trust. This applied both to relations with clients and to relations with other actors who were in contact with the target group, such as maternity and child health centers. The trust with clients was built by the peer supporters, in their role as generalists, by providing a wide range of knowledge about the structure of the Swedish welfare system, parenting, and children's health and wellbeing, while being clear with the clients about the limits of their knowledge. They were also mindful of having a high level of accessibility, being flexible and sensitive to the locations of meetings that client mothers felt safe and suitable, and actively nurturing relationships with their clients. At the organizational level, stakeholders made sure to enable trust building by making careful choices in the recruitment of peer supporters. In some cases, this was achieved by current peer supporters using their own contact networks to find people they thought might be suitable for the role.

> *The right people in the right place, yes. Well, that's always what it's all about [Steering group member #2].*

Their competence was enhanced through continuous training that responds to their perceived needs. Previous training sessions had covered topics such as child development, early childhood education, children's rights, parenting techniques, maternal health, COVID-19 and vaccinations, the organization of the welfare system, housing rights, and psychosocial support techniques. The participants highlighted a need for further training on sexual and reproductive health, handling cases of domestic violence, mental health and stress in the target group, the Swedish legal system, the organization of the social insurance system, and managing aggressive or conflictual behavior in other people.

Internal support structures

Another implementation strategy was active supervision with high availability and responsiveness to peer supporters' needs, which was provided through weekly group meetings and continuous contact by phone or through meetings in between set supervision sessions. The peer supporters also described that they also actively helped each other by answering questions from the client mothers and referring them between each other in cases where other language competencies were needed.

Multiple arenas for outreach

To reach out to new mothers in need of support, peer supporters used a variety of physical and digital venues. These included spontaneous meetings in public places such as parks or public transport. They could also use venues specifically aimed at the target group, such as open preschools, language courses or meetings at ethnic associations. The digital platforms that enabled contact with new mothers included primarily online groups tied to ethnic associations. The client mothers who took part in the intervention could also pass on the contact within their contact networks, which meant that knowledge of the intervention spread organically to some extent.

Participants also described how staff at child health clinics, maternal health clinics, open preschools and libraries could refer mothers with support needs to them by giving out their phone number or business cards. This was made possible by active networking among these actors to establish knowledge about the intervention which participants described as being effective.

Practical assistance as an entry point to comprehensive support

One strategy for engaging mothers in the intervention and approaching sensitive topics, described by both peer supporters and steering group members, was to focus on practical support early in the contact with mothers. In practice, this meant that discussions around children's participation in early childhood education was often used as a starting point and first topic of conversation with families. This was also evident in the log data (Figure 6). The focus on early childhood education sometimes meant that peer supporters physically accompanied families to open preschools. During the first conversations with new mothers, peer supporters also raised questions about work, or helped them fill out applications or forms to authorities. These activities were described as undramatic and easy to engage in early on.

Once a good relationship had been established, the peer supporters could start identifying needs that required trust to be discussed. These could be issues of a more sensitive nature, such as psychological or medical needs, or issues related to family relationships or parenting practices.

> *It starts with like, can you help me with this paper? There are often very practical concerns to begin with. And then it builds up along the way. [...] So often it's those needs first, and then it's like this... Yes, but knowledge and information. How do you do this? How do you do that? And are you entitled to it and how much does it cost and how do you register, and so on. And one thing often leads to another [Steering group member #6].*

Mechanisms of impact

A variety of mechanisms of impact could be identified in the material. These consisted of both mechanisms that facilitated the intervention and constituted secondary effects.

Mediators

Relationship-building enables difficult conversations

During the interviews, the importance of building relationships with the client mothers was highlighted, as it enabled the peer supporters to gain their trust. A trustful relationship could

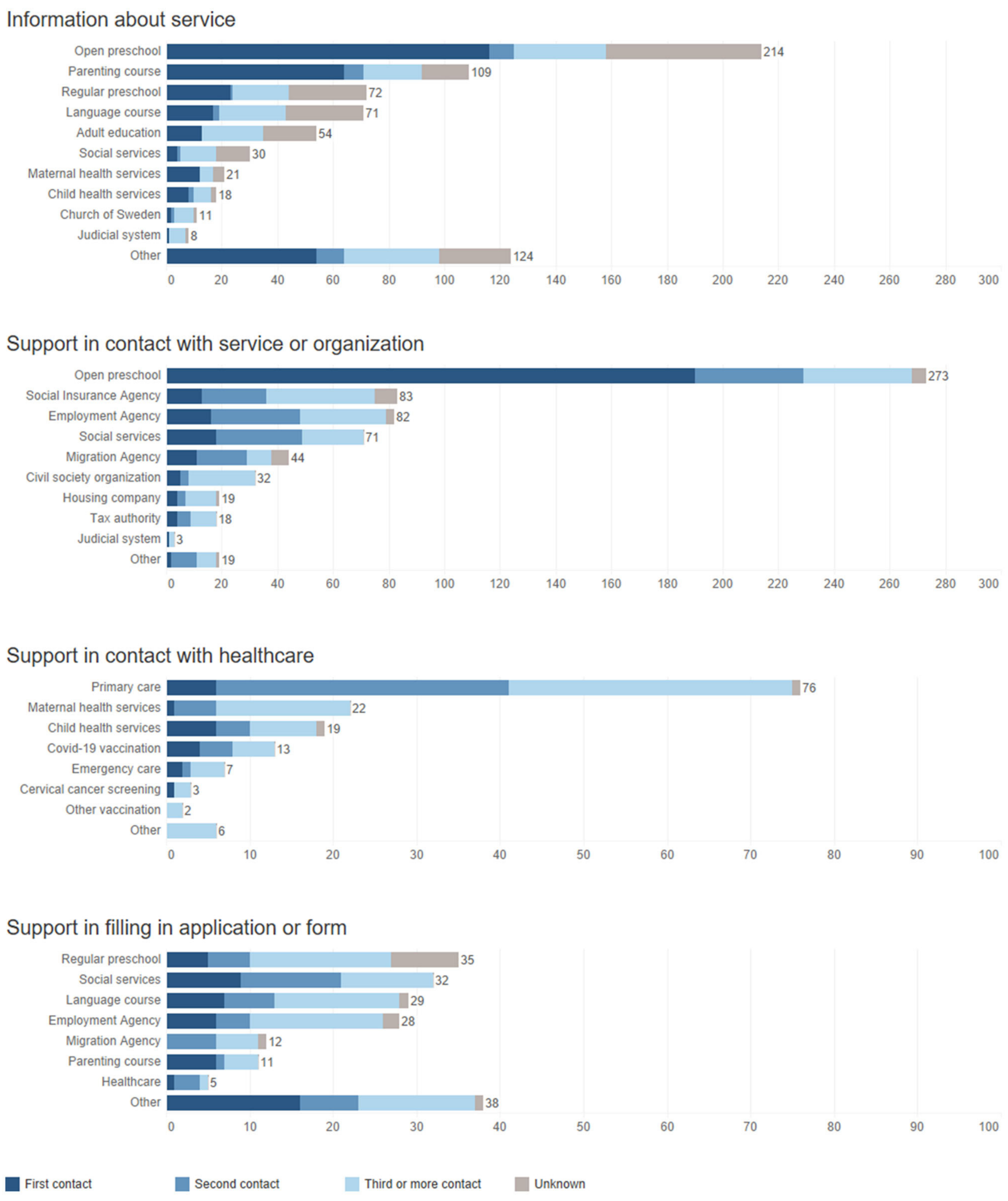

FIGURE 6
Peer supporters' activities.

later open up the possibility to start discussing difficult topics and support them in sensitive matters, e.g., by linking them to health services. In the quantitative data, this could be seen in that contacts with the health services were rarely made during the first meeting, but were more common in later meetings (Figure 6). Relationship building was also described as important to assure mothers of the confidentiality of the conversation.

> *It became a beautiful relationship, friendship, not just a formal or limited relationship. […] This is how this job should be, it shouldn't be that people are just like a train, work, and that's it, their job is done. They have to be friendly, so that people can like them and feel safe and comfortable when they ask for their help. And honestly that's what's happening [Mother #6].*

Participant responses and interactions

Clients appreciating the intervention but seeing its limits

The interviews with client mothers highlighted their appreciation of the support they received and the extent of it. Both the practical and psychosocial support they received was described as helping in reducing their everyday worries and anxiety. Some discussed how the intervention helped them to become more independent in their lives, and how they gained a sense of belonging to society.

> *When I needed help communicating with the children's schools and I couldn't do it myself, they helped. When I wanted to contact the health service, they taught me how to do it and also helped me with the language. When I had problems with financial assistance, they supported me and talked to the social services officer and explained the situation. As a mother, I could sleep well and my mind calmed down and my worries disappeared. My mind, my soul and my body have become calm. This led me to become more motivated and start thinking about how to develop myself [Mother #3].*

During the interviews, the limitations of the project were also highlighted, including that the client mothers wished they could have received support in establishing themselves on the labor market.

Clients value the close personal bond

In describing the relationship with peer supporters, client mothers tended to describe their relationships with peer supporters in terms of "family" or "friendship." The close relationship was highlighted as something positive in itself. The informal feel was also described as contributing to the client mothers feeling that there was always a low threshold to contact the peer supporters and that they could discuss anything with them.

> *You know I would honestly describe her as a sister, a life-long sister truly. […] I mean yes, she is a friend, you feel that she is a friend, I mean our relationship is very, very beautiful. You know, she really connects to a person and makes them talk about their matters. This is something that is very comforting to mothers that have come to Malmö recently. They are in need, especially those that do not have anyone, they do not have sisters or relatives here. They need someone close to listen [Mother #7].*

A contributing factor to this was the shared cultural understanding. This enabled comparisons between the culture in their country of origin and in Sweden and how this related to matters such as different views on parenting.

Unexpected pathways and consequences

Blurred lines between work and personal identity

In the interviews with peer supporters, they expressed that they often experience a blurred line between work and private life. This could manifest itself in their relationship with the mothers they were in contact with, in that they talked about topics outside the scope of the project, or that they provided support in challenges that were not within the intended scope of their work. Several of the peer supporters described that their activities were more than just work, and that their role had become part of their identity.

The blurred boundary between work and private life could also be expressed by working outside office hours. This phenomenon arose both from the fact that the client mothers could contact them by phone in the evenings and at weekends, the perceived high demand for their services, and the fact that the peer supporters enjoyed their work.

> *I work all the time, but I don't feel like it's work. […] You know when you want to do what you do, you don't feel tired or that it's hard or anything. I don't feel that [Peer supporter #2].*

In some cases, the mothers were in urgent need of help with contacts with the health service or other agencies outside of office hours. They could, however, also have non-urgent problems that the peer supporters helped them with as they were easy to resolve quickly. The peer supporters also used occasions when they met new mothers during their free time to introduce them to the intervention. The delimitation of working hours was discussed as something that had decreased somewhat the longer the supporters had worked, as they learned to manage their time.

Discussion

This study aimed to assess how the implementation of a peer support program for immigrant mothers and pregnant women was undertaken and the factors that influenced this process. Our findings highlight that trust was central to both the challenges and the opportunities of the peer support intervention. A critical element in building trustful relationships was a flexible and needs-driven approach to the content of the intervention and how it was delivered. This enabled client mothers to be supported in their interactions with the welfare system, their approach to parenting, and issues relating to health on their own terms. Using this flexibility as a resource in the implementation resulted in an intervention with low fidelity to the educational parts of the program's logic model, where peer supporters tended to focus more on linking their clients to other services.

This study adds to the previous literature on peer support programs aimed at parents. By shedding light on the unique role of peer supporters for migrant parents, it provides information that can inform the development and implementation of this and future interventions. It also contributes to the literature on the transfer of social innovations such as the Philani model between different contexts, by illustrating the value of having an organic approach to local adaptation. Our findings thus link to previous literature on both the role of the peer supporter and debates around flexibility and adaptations of complex interventions.

Peer supporters' role enactment

Previous research has shown how trust in the social services is lower among socially disadvantaged groups in Sweden (30), which can challenge their perceived legitimacy among the groups that need their services the most. Our findings provide examples of how this lack of trust can have a spill-over effect on parents' readiness to use other services, demonstrating the need for a holistic approach to promoting trust in authorities.

Engaging with client mothers through building trustful relationships constitutes a feature of the peer support intervention that might be difficult to attain within public welfare services, as this process is dependent on an informal, highly personal component. Furthermore, previous research has pointed toward how community-based projects with service providers that share a sociocultural background with their clients enhances engagement through context-sensitive delivery (31). This demonstrates the unique position that peer supporters can have in relation to other professional categories, and the benefits of implementing this type of intervention through a non-governmental organization that is unbound by the constraints and expectations of formality of the public sector. It is also in line with the findings of previous research on peer support for socially disadvantaged mothers, highlighting how it can be easier to open up to peer supporters than public professionals about sensitive topics (32).

Studies on how the third sector interact with hard-to-reach groups have highlighted four factors that contribute to successful engagement: respect and trust, flexibility, collaboration with other services and organizations, and user involvement (33). It is worth noting how these align with how peer supporters used trust building through care and flexibility, a focus on linking to other services and using other services as arenas for recruitment, and adapting to the individual client mothers in terms of what they needed help with, where meetings were held and the number and frequency of contacts.

The addition of new activities described by the study participants reflects the need-driven nature of the intervention, as well as its complexity. Part of the complexity lies in the fact that peer supporters are expected to work as generalists, with consequent difficulties in gaining in-depth knowledge of each topic covered by their role. Holding such a generalist role in the presence of specialists, such as midwives and parenting counselors, raises the threshold for educating the mothers directly and lowers it to focus on referring clients.

The generalist role can also make it more difficult to communicate what the intervention is and what the boundaries of the peer supporters' role is. Previous studies on lay-worker support programs have highlighted how it can be difficult to communicate the function of the generalist lay support worker and how that relate to the functions of other professionals (34). To promote effective use of the service, it is important to provide a clear outline of what the support entails and what it does not.

Fidelity, adaptations and flexibility with respect to the logic model

Flexibility as a tool for navigating complexity is a critical component of community-based individual support, especially for hard-to-reach groups. The ability to be responsive, creative and holistic constitutes unique contributions of peer supporters in their relationship with a welfare system that is often rigid and fragmented (35).

Individual tailoring to clients' needs and preferences can take different forms, and peer support interventions for parents tend to be flexible in either their content, their mode of delivery or in availability of peer supporters (15). While standardization and careful definition of an intervention is a prerequisite for reliable evaluation of its effects, the inherent aspect of flexibility in complex interventions can sometimes make it difficult to even define what the intervention is, and what it is not (36). Instead of seeing flexibility and individualization of the content as a challenge to rigorous implementation, it can be seen as a core component in itself. This is in line with how core components of parental support programs have been defined in previous studies in Sweden (37). The literature on scaling and transfer of social innovations has described how innovations can be scaled and replicated either with absolute fidelity to a specified plan and program integrity in mind, or with an overall aim of disseminating principles or methods (38). Replicating social innovations, such as the South African Philani model being implemented in Sweden, can thus involve a more complex process than simply diffusing a fixed model. Rather, it can allow for adaptation to emerging circumstances while preserving the essence of the innovation. With this in mind, low fidelity to a program plan is not necessarily a failure of implementation, but an attempt to ensure the relevance of the program in a context of heterogeneous needs. However, it is important that the adaptations made do not compromise the elements or functions that are central to the intervention's internal logic.

The participants in our study described adaptations in the form of the focus on linking to public services and the tendency to do more for client mothers than what was originally specified, e.g., by engaging in housing issues. These adaptations can be outlined and interpreted using the Framework for Reporting Adaptations and Modifications-Expanded (FRAME) (39). This framework provides a systematic approach to characterize modifications made to interventions. It includes specifications of (1) when and how the modification was made, (2) if it was planned or unplanned, (3) who determined that the modifications should be made, (4) what is modified, (5) at what level of delivery the modification is made, (6) the nature of the modification, (7) if it is consistent with fidelity to a program plan, and (8) reasons for modification.

The focus on linking to public services was a shift away from educating mothers directly, which was made during implementation as a reactive change by the individual peer supporters. The modification was made in response to their perception that there were other services that did this better, aiming to improve feasibility. It can be classified as a way of skipping elements of the intervention that might not have been consistent with fidelity to the logic model, as it changed central functions in the intervention logic.

The peer supporters doing more than intended meant the addition of activities such as helping client mothers with housing issues or helping mothers buy specific items. It constituted a modification that was reactive and undertaken by the individual peer supporters in response to emergent circumstances, aiming to improve fit with client mothers, and increase satisfaction. The modification consisted of adding elements in a way that might not have interfered with fidelity to the logic model, as it did not interact with central functions or elements in an apparent way (40).

Adaptations to improve feasibility and fit with recipients have been described as common in previous studies (41, 42). While such changes to the intervention may make it more relevant to its users, it is valuable to aim for planned adaptations rather than reactive modifications. Such a proactive process can improve both engagement and retainment while maintaining the essential aspects of the intervention (42).

In contact with client mothers, the boundaries of the peer supporters' role and tasks were also flexible. Studies of peer support for mothers in South Africa, where the implemented model was originally developed, have highlighted how the work as a Mentor Mother can dissolve the boundary between personal and professional roles in both positive and negative ways (43, 44). This is a phenomenon that has also been seen among lay health workers in other parts of the world (45). The work as a peer supporter can involve feelings of pride in empowering others and a sense of becoming someone with a respected position in the own community. In parallel, the work can also present burdens in terms of expectations of availability and selflessness as strong personal relationships develop with clients. This liminal position, balancing between the formal and the informal, can be described as a central component in the concept of peer support (16).

A review of the mechanisms of successful peer support presented this as the *therapeutic use of the self*, pointing toward how this can promote a sense of responsibility among peer supporters, and the *reframing of identity*, where peer supporters themselves receive a sense of meaning through a reciprocal relationship with their clients (46). With self-identity as an important instrument in their work, it is perhaps not surprising that peer supporters experience blurred boundaries between work and private life. It is, however, important to see this both as a resource and as an issue that needs to be managed through boundary-setting and self-care to maintain feasible and sustainable working conditions (43).

Implications for practice—Balancing flexibility and standardization

In human-centered design, the success of innovations are considered to rest on three overlapping dimensions: desirability, feasibility and viability (47). Achieving a high degree of all three facilitates the development, implementation and sustainability of the innovation at hand. Using this framework as a lens to reflect on the findings of this study highlights potential implications for future development of the peer support intervention and its implementation.

In the interviews with the clients' mothers, the desirability of peer support was highlighted in various ways. One factor that contributed to the clients' appreciation of the support was its holistic view of their life situation and its ability to help them with a wide variety of problems they encountered, demonstrating the value of not sticking to a delineated project plan with absolute rigidity. To maintain the desirability of the intervention, maintaining the flexibility in the work of the peer supporters is of value.

The feasibility of the peer support intervention reflects the ability of the peer supporters to deliver a high quality intervention also over time. This is partly dependent on clear boundaries for their work in terms of working hours and what their work entails, and their own ability to communicate these boundaries to their clients. The possibility of providing support on sensitive topics was facilitated by relationships built up over time between the peer supporters and their clients. Given that many mothers had only a single contact with peer supporters, it may be worth prioritizing the follow-up of the first contact to enable the identification and addressing of needs that are difficult to discuss in initial meetings.

As highlighted in the interviews with steering group members, the viability of the project was threatened by challenges in securing sustainable funding. While this may reflect a common challenge for third-sector innovations that are dependent on external financing, the chances of sustainable funding may be increased if the benefits of the intervention can be communicated clearly. This in turn is dependent on both clear descriptions of what the intervention is, and outcome evaluations that demonstrate what the eventual effects are, both of which are facilitated by standardization. For complex interventions, this can mean a standardization of processes and functions rather than content (48). In practice, this can translate to consistency in terms of how peer supporters focus on linking or educating mothers respectively rather than consistency in terms of what topics are covered during each meeting with client mothers. Such standardization can permit a flexible approach to meeting the support needs of individual clients, maintaining the holistic model while enabling an intervention that can be clearly communicated and evaluated for effectiveness.

The transferability of the results is limited by the fact that the study was conducted within a specific organization with an intervention that is relatively unique to the Swedish context. However, similar interventions exist in other countries and similar multicultural contexts exist elsewhere in Sweden and internationally. This study's findings can thus inform the development of new interventions and evaluations if they are carefully contextualized.

Conclusion

In implementing a social innovation for peer support for migrant mothers and pregnant women, the peer supporters faced barriers in the form of mistrust of social services in the community, norms and expectations around the role of women and children, and difficulties with funding. The implementation of the intervention was facilitated by the organization's reputation, network, history of running large projects, and their role as a third-sector organization. The intervention was implemented with a needs-based dose and a perceived good reach within the language groups covered by the peer supporters. Peer supporters prioritized linking their clients to other services, which resulted in an implementation with low fidelity to the educational parts of the intervention, and they tended to do more than what was stated in the intervention description. There were local adaptations of the working methods of the program on which the intervention was based. The implementation process was enabled by the use of strategies to build trust, multiple venues to reach clients, internal support structures such as supervision, training and collaboration between peer supporters, and the use of practical help as a gateway to more comprehensive psychosocial support. Client mothers appreciated the intervention and personal connection with peer supporters, and were able to discuss difficult topics after building deeper relationships with them. Peer supporters could sometimes experience a blurring of the boundaries between professional and private roles. In the future development of this and similar interventions, it is of value to maintain a balance between flexibility of methods and content on the one hand, and clarity regarding the functions and role of peer supporters on the other.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by the Swedish Ethical Review Authority. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study.

Author contributions

PK: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Project administration, Software, Visualization, Writing—original draft, Writing—review & editing. LS: Formal analysis, Investigation, Methodology, Software, Writing—original draft, Writing—review & editing. MM: Conceptualization, Funding acquisition, Investigation, Methodology, Project administration, Resources, Supervision, Validation, Writing—review & editing. AB: Conceptualization, Investigation, Methodology, Supervision, Validation, Writing—review & editing. SH: Conceptualization, Investigation, Methodology, Supervision, Validation, Writing—review & editing.

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Conflict of interest

PK and MM both participate in the steering group of the peer support project in Malmö, Sweden.

The remaining authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fpubh.2023.1332738/full#supplementary-material

References

1. Therborn G. Sweden's turn to economic inequality, 1982–2019. *Struct Change Econ Dyn.* (2020) 52:159–66. doi: 10.1016/j.strueco.2019.10.005

2. Socialstyrelsen. *Socioekonomiska faktorers påverkan på kvinnors och barns hälsa efter förlossning.* (2016). Available online at: https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2016-12-14.pdf (accessed May 12, 2023).

3. Ahmadinia H, Eriksson-Backa K, Nikou S. Health-seeking behaviours of immigrants, asylum seekers and refugees in Europe: a systematic review of peer-reviewed articles. *J Document.* (2021) 78:18–41. doi: 10.1108/JD-10-2020-0168

4. Satinsky E, Fuhr DC, Woodward A, Sondorp E, Roberts B. Mental health care utilisation and access among refugees and asylum seekers in Europe: a systematic review. *Health Policy.* (2019) 123:851–63. doi: 10.1016/j.healthpol.2019.02.007

5. Lebano A, Hamed S, Bradby H, Gil-Salmerón A, Durá-Ferrandis E, Garcés-Ferrer J, et al. Migrants' and refugees' health status and healthcare in Europe: a scoping literature review. *BMC Public Health.* (2020) 20:1039. doi: 10.1186/s12889-020-08749-8

6. Brandenberger J, Tylleskär T, Sontag K, Peterhans B, Ritz N. A systematic literature review of reported challenges in health care delivery to migrants and refugees in high-income countries - the 3C model. *BMC Public Health.* (2019) 19:755. doi: 10.1186/s12889-019-7049-x

7. Hedstrom E, Kovshoff H, Hadwin JA. Exploring parenting narratives in asylum seeking populations in Sweden: examining the effect of post-migration stress on families through grounded theory. *J Refug Stud.* (2021) 34:3381–98. doi: 10.1093/jrs/feaa136

8. Mangrio E, Carlson E, Zdravkovic S. Newly arrived refugee parents in Sweden and their experience of the resettlement process: a qualitative study. *Scand J Public Health.* (2020) 48:699–706. doi: 10.1177/1403494819893535

9. Osman F, Klingberg-Allvin M, Flacking R, Schön UK. Parenthood in transition - Somali-born parents' experiences of and needs for parenting support programmes. *BMC Int Health Hum Rights.* (2016) 16:7. doi: 10.1186/s12914-016-0082-2

10. Herzig van Wees S, Fried S, Larsson EC. Arabic speaking migrant parents' perceptions of sex education in Sweden: a qualitative study. *Sex Reprod Healthc.* (2021) 28:100596. doi: 10.1016/j.srhc.2021.100596

11. Region Skåne. *Föräldrastöd i grupp inom mödra-och barnhälsovården i Skåne [Group parental support in maternal and child health care in Scania]*. (2017). Available online at: https://vardgivare.skane.se/contentassets/97f0c2e2bb4e42399755032dcf40c060/foraldrastod-i-grupp-inom-modra--och-barnhalsovarden-i-skane-2017.pdf (accessed June 1, 2023).

12. Mangrio E, Carlzén K, Grahn M, Zdravkovic S. *Kartläggning av nyligen nyanländas hälsa, levnadsvanor, sociala relationer, arbetsmarknad och boendemiljö efter etableringen*. Delrapport från MILSA 2, 0. (2020).

13. European Commission. *Directorate-General for Internal Market, Industry, Entrepreneurship and SMEs. Social Innovation*. European Commission. Available online at: https://single-market-economy.ec.europa.eu/industry/strategy/innovation/social_en (accessed June 1, 2023).

14. van Niekerk L, Manderson L, Balabanova D. The application of social innovation in healthcare: a scoping review. *Infect Dis Poverty.* (2021) 10:26. doi: 10.1186/s40249-021-00794-8

15. Kåks P, Målqvist M. Peer support for disadvantaged parents: a narrative review of strategies used in home visiting health interventions in high-income countries. *BMC Health Serv Res.* (2020) 20:682. doi: 10.1186/s12913-020-05540-8

16. Watson E. The mechanisms underpinning peer support: a literature review. *J Ment Health.* (2019) 28:677–88. doi: 10.1080/09638237.2017.1417559

17. Trickey H. Peer support for breastfeeding continuation: an overview of research. In: *Perspective-NCT's journal on preparing parents for birth and early parenthood.* (2013), p. 15–20.

18. Tomlinson M, Rotheram-Borus MJ, Roux IMl, Youssef M, Nelson SH, Scheffler A, et al. Thirty-six-month outcomes of a generalist paraprofessional perinatal home visiting intervention in South Africa on maternal health and child health and development. *Prev Sci.* (2016) 17:937–48. doi: 10.1007/s11121-016-0676-x

19. Kåks P, Bergström A, Herzig van Wees S, Målqvist M. Adapting a South African social innovation for maternal peer support to migrant communities in Sweden: a qualitative study. *Int J Equity Health.* (2022) 21:88. doi: 10.1186/s12939-022-01687-4

20. Statistics Sweden. *Inrikes och utrikes födda efter region, ålder och kön. År 2000–2022 [Domestic and foreign born by region, age and gender. Year 2000–2022]*. Statistikdatabasen [Statistics database]. Available online at: https://www.statistikdatabasen.scb.se/pxweb/sv/ssd/START__BE__BE0101__BE0101E/InrUtrFoddaRegAlKon/ (accessed April 8, 2023).

21. City of Malmö. *Occupation*. City of Malmö: Facts and statistics in English (2020). Available online at: https://malmo.se/Facts-and-statistics/Occupation.html (accessed April 8, 2023).

22. Commission for a Socially Sustainable Malmö. *Malmö's path towards a sustainable future: Health, welfare and justice.* (2013). Available online at: https://malmo.se/download/18,6c.44cd5c1728328333211d32/1593519743583/malmo%CC%88kommisionen_rapport_engelsk_web.pdf (accessed April 8, 2023).

23. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ.* (2021) 374:n2061. doi: 10.1136/bmj.n2061

24. Schoonenboom J, Johnson RB. How to construct a mixed methods research design. *Kolner Z Soz Sozpsychol.* (2017) 69:107–31. doi: 10.1007/s11577-017-0454-1

25. Moore GF, Audrey S, Barker M, Bond L, Bonell C, Hardeman W, et al. Process evaluation of complex interventions: medical research council guidance. *BMJ.* (2015) 350:h1258. doi: 10.1136/bmj.h1258

26. KoboToolbox. *Kobo.* Available online at: https://www.kobotoolbox.org/ (accessed May 12, 2023).

27. Salesforce. *Tableau 2022.1.0.* Tableau Software. Available online at: https://www.tableau.com/ (accessed May 3, 2023).

28. Lumivero. *NVivo*. (2023).

29. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs.* (2008) 62:107–15. doi: 10.1111/j.1365-2648.2007.04569.x

30. Nilsson K, Landstedt E. Public trust of social workers in Sweden: a repeated cross-sectional study. *J Soc Work.* (2022) 22:1374–93. doi: 10.1177/14680173221094535

31. Lawlor ER, Cupples ME, Donnelly M, Tully MA. Implementing community-based health promotion in socio-economically disadvantaged areas: a qualitative study. *J Public Health.* (2020) 42:839–47. doi: 10.1093/pubmed/fdz167

32. McLeish J, Redshaw M. Mothers' accounts of the impact on emotional wellbeing of organised peer support in pregnancy and early parenthood: a qualitative study. *BMC Pregn Childbirth.* (2017) 17:28. doi: 10.1186/s12884-017-1220-0

33. Flanagan SM, Hancock B. 'Reaching the hard to reach'–lessons learned from the VCS (voluntary and community Sector). A qualitative study. *BMC Health Serv Res.* (2010) 10:92. doi: 10.1186/1472-6963-10-92

34. Murphy CA, Cupples ME, Percy A, Halliday HL, Stewart MC. Peer-mentoring for first-time mothers from areas of socio-economic disadvantage: a qualitative study within a randomised controlled trial. *BMC Health Serv Res.* (2008) 8:46. doi: 10.1186/1472-6963-8-46

35. Ingram M, Reinschmidt KM, Schachter KA, Davidson CL, Sabo SJ, De Zapien JG, et al. Establishing a professional profile of community health workers: results from a national study of roles, activities and training. *J Commun Health.* (2012) 37:529–537. doi: 10.1007/s10900-011-9475-2

36. Datta J, Petticrew M. Challenges to evaluating complex interventions: a content analysis of published papers. *BMC Public Health.* (2013) 13:568. doi: 10.1186/1471-2458-13-568

37. Barboza M, Marttila A, Burström B, Kulane A. Towards health equity: core components of an extended home visiting intervention in disadvantaged areas of Sweden. *BMC Public Health.* (2022) 22:1091. doi: 10.1186/s12889-022-13492-3

38. Riddell D, Moore ML. *Scaling out, scaling up, scaling deep.* McConnell Foundation. JW McConnell Family Foundation & Tamarack Institute (2015).

39. Wiltsey Stirman S, Baumann AA, Miller CJ. The FRAME: an expanded framework for reporting adaptations and modifications to evidence-based interventions. *Implement Sci.* (2019) 14:58. doi: 10.1186/s13012-019-0898-y

40. Carroll C, Patterson M, Wood S, Booth A, Rick J, Balain SA, et al. conceptual framework for implementation fidelity. *Implement Sci.* (2007) 2:40. doi: 10.1186/1748-5908-2-40

41. Strehlenert H, Hedberg Rundgren E, Sjunnestrand M, Hasson H. Fidelity to and adaptation of evidence-based interventions in the social work literature: a scoping review. *Br J Soc Work.* (2023) 17:bcad170. doi: 10.1093/bjsw/bcad170

42. Bromley AR. Flexibility within fidelity: a narrative review of practitioner modifications to child welfare interventions. *Child Youth Serv Rev.* (2023) 149:106908. doi: 10.1016/j.childyouth.2023.106908

43. Laurenzi CA, Skeen S, Rabie S, Coetzee BJ, Notholi V, Bishop J, et al. Balancing roles and blurring boundaries: Community health workers' experiences of navigating the crossroads between personal and professional life in rural South Africa. *Health Soc Care Commun.* (2021) 29:1249–59. doi: 10.1111/hsc.13153

44. Katzen LS, Skeen S, Dippenaar E, Laurenzi C, Notholi V. Roux Kl, et al. Are we listening to community health workers? Experiences of the community health worker journey in rural South Africa. *Res Nurs Health.* (2022) 45:380–9. doi: 10.1002/nur.22220

45. Glenton C, Colvin CJ, Carlsen B, Swartz A, Lewin S, Noyes J, et al. Barriers and facilitators to the implementation of lay health worker programmes to improve access to maternal and child health: a qualitative evidence synthesis. *Cochrane Database Syst Rev.* (2013) 2013:CD010414. doi: 10.1002/14651858.CD010414

46. MacLellan J, Surey J, Abubakar I, Stagg HR. Peer support workers in health: a qualitative metasynthesis of their experiences. *PLoS ONE.* (2015) 10:e0141122. doi: 10.1371/journal.pone.0141122

47. Chasanidou D, Gasparini AA, Lee E. Design thinking methods and tools for innovation. In: *Design, User Experience, and Usability: Design Discourse.* Springer International Publishing (2015), p. 12–23. doi: 10.1007/978-3-319-20886-2_2

48. Hawe P, Shiell A, Riley T. Complex interventions: how 'out of control' can a randomised controlled trial be? *BMJ.* (2004) 328:1561–3. doi: 10.1136/bmj.328.7455.1561

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EDITED BY
Sakari Karvonen,
Finnish Institute for Health and Welfare (THL),
Finland

REVIEWED BY
Cheryl Elman,
Duke University, United States
Henrik Dobewall,
Finnish Institute for Health and Welfare (THL),
Finland

*CORRESPONDENCE
Gunnar Sæbø
✉ gunnar.saebo@fhi.no

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Is the perceived public stigma of smokers associated with value opposites? An exploratory cross-sectional analysis of Norwegian data 2011–2013

Gunnar Sæbø* and Marianne Lund

Norwegian Institute of Public Health, Oslo, Norway

Smoker stigma is a likely unintended consequence of tobacco polices aiming to denormalise smoking. Little is known about the dissemination of stigmatising attitudes toward smokers at the population level, including their associations with personal values. Applying a theoretical approach that conceptualises stigma as a cultural (moral and intersubjective) issue, we analyse the spread of perceived public stigma of smokers in Norway and factors predicting agreement with such a perception. Using merged data from the biennial national survey *Norwegian Monitor* 2011 and 2013 ($N = 7{,}792$), we tested whether the tendency to agree with a perceived public stigma of smokers differs by four indexes of value opposites ('puritanism/emancipation,' 'conformity/individuality,' 'tolerance/intolerance,' 'status/anti-status'), controlling for smoking status, SES, and demographics. Descriptive statistics and block-wise logistic regression models were applied. In the total sample, 59.1% agree with the statement that 'most people think less of a person who smokes.' Two of the four indexes of value opposites tested were associated with tendencies to agree with the perceived public stigma of smokers ('puritanism/emancipation' and 'status/anti-status'). Smokers with current plans to quit expressed the highest perceived public stigma, while ex-smokers expressed a higher perceived public stigma than never-smokers. Women, young people and respondents with high SES agree with a public stigma of smokers more than men, older people and respondents with low SES do. The perceived public stigma of smokers is high in Norway and varies to some extent with personal values, but also with socio-demographics and especially smoking status.

KEYWORDS

public stigma, smoking, tobacco denormalisation, public health ethics, value opposites

Introduction

Tobacco denormalisation and the stigmatisation of smokers

The term tobacco denormalisation designates all policies and interventions that aim to enforce and reinforce the idea that 'tobacco use is not a mainstream or normal activity in society' (Lavack, 1999, p. 82). Introduced in tobacco control in the late 1990s to counter the continuous publicity and advertising of the tobacco industry, the idea has not only been to denormalise the act of smoking, but also to delegitimise all tobacco industry activities and tactics (Sæbø and Scheffels, 2017). Examples of denormalisation measures are indoor smoking bans in all public premises, bans on smoking in private cars when children are present, and prohibition of all forms of direct and indirect advertising (including display bans in shops). No other legal consumer product is regulated as strongly as the cigarette to prevent purchase and use, not even alcoholic beverages.

From a public health point of view, tobacco denormalisation has been a successful population-level approach to reducing the prevalence of smoking (Chapman and Freeman, 2008; Malone et al., 2012). However, increasing anecdotal evidence and findings from several, primarily qualitative, studies suggest that tobacco denormalisation has also had the unintended additional consequence of contributing to stigmatise remaining smokers in the population (Evans-Polce et al., 2015; Machado et al., 2018), including unsuccessful quitters (Sæbø and Lund, 2020) and people already stigmatised due to other conditions (Hefler and Carter, 2019; Lipperman-Kreda et al., 2019). Even if there is no manifest intention in tobacco denormalisation strategies to discriminate against or stigmatise people who smoke, tobacco policy measures that implies restrictions on behaviour or environmental restructuring, such as smoke-free air laws, has contributed to the experience of a 'pillory-like' situation among smokers outside public premises (Bell et al., 2010; Evans and Furst, 2016). Many smokers are addicted to nicotine and tend to communicate a poor self-image and to perceive themselves in a patronising manner, even when they are not smoking (Ritchie et al., 2010). Smokers are also discredited by non-smokers via derogatory stereotypes (Gibson, 1998; Gilbert et al., 1998). The overtly irrational aspect of smoking is provocative to many non-smokers nowadays and may contribute to a view among the latter group that current smokers, having voluntarily decided to smoke and not listen to information and warnings, should bear the full responsibility for this unhealthy behaviour (McCool et al., 2013). Kim and Shanahan (2003) have launched the concept of 'unfavourable smoking climate' to designate the anti-tobacco culture that has developed in the wake of tobacco denormalisation policies. Most likely, this 'unfavourable smoking climate' is a result of smoking being a unique type of social action, in that it is still legal, but simultaneously regulated so strongly that it is considered as illegitimate by the social and political majority.

Even if the perceived and felt stigma among different smaller groups of smokers is relatively well-documented in the literature, few studies have addressed the formation and dissemination of stigmatising attitudes toward smokers among never-smokers, and the scope and role of perceived stigmatisation among current smokers and ex-smokers, at the *national* level. Previous studies show a stronger tendency to stigmatise smokers among people who have never smoked than among ex-smokers (Peretti-Watel et al., 2014; Brown-Johnson and Popova, 2016). Such findings corroborate the social 'us and them' distance between non-smokers and smokers described above, but also suggest that direct experience with smoking and having (had) a certain social identity as a smoker may have a modifying effect on holding stigmatising perceptions of smokers. This effect may extend to people living with smokers in their household, as they too are less likely to stigmatise smokers (Peretti-Watel et al., 2014).

Apart from the obvious significance of smoking status, however, not much is known about what may predict variations in such attitudes, even if media representations (Bain et al., 2017), age and socio-economic status (Peretti-Watel et al., 2014) are all likely to play a role. While media images of smoking historically have tended to normalise and glamorise smokers (Marron, 2017), current media content often represent smoking as a problem (Chapman and Freeman, 2008; Bain et al., 2017). Age may come into play with regard to whether people have grown up with a 'normalised' or a 'denormalised' view of smoking as culturally dominating (with the watershed taking place about 1990). Regarding the role of socio-economic status, and whether the associations between economic and cultural capital and the propensity to stigmatise smokers are negative or positive, previous findings vary (Peretti-Watel et al., 2014; Brown-Johnson and Popova, 2016). Following Bourdieu's theory of class (Bourdieu, 1984; Bernard et al., 2019), however, we may hypothesise that those with the highest economic and cultural capital are more prone to consider smokers a stigmatised group, as these individuals themselves were among the earliest quitters of smoking. Presumably, they are also well aware of smoking having become a declassified low status phenomenon (Sæbø, 2017).

A cultural approach to perceived public smoker stigma

Drawing on Goffman's (1990) view of a stigmatised person as discredited and ostracised from society, the stigma concept has been variously approached in studies of health-related behaviour (Yang et al., 2007; Pescosolido and Martin, 2015). While a social-psychological perspective has emphasised stigma as emotional internal processes, prejudicial attitudes and self-stigma, basically as perceived (at the micro level) among the stigmatised (Major and O'Brian, 2005), structural stigma has been outlined by Link and Phelan (2001), highlighting institutional stigma, structural discrimination and the role of power differences. A third cultural perspective has highlighted the role of social context and normative expectations within a society, emphasising that stigma is essentially a moral and intersubjective issue, and arguing that stigmatising conditions illustrate what is at stake for the social actors in a shared social space (Yang et al., 2007; Rao et al., 2008; Kleinmann and Hall-Clifford, 2009).

With inspiration from this latter cultural perspective of stigma, as well as sociologists like Bourdieu (1984) and Archer (1988), in the following we will consider tobacco culture as both product and context of human agency. Both shared and contested meanings of behaviour and deviance are expressed via language and symbols, which, in turn, shape people's interpretations and social responses to the same behaviours. As stigma is relational in nature, smoker stigma not only resides in individuals or in institutional structures but is also located in the intersubjective space between smokers and non-smokers—in interpersonal actions and communications, as expressions of norms and values. This includes perceptions of *public stigma*—that is, beliefs about stigmatised persons held and communicated by the general public. The concept of public stigma refers both to the perceived level and nature of stigma in overall populations and to the contextual climate of derogatory stereotypes and discrimination regarding certain behaviours (such as smoking) at a certain time and place (Pescosolido and Martin, 2015, pp. 96–101). With smoking having become less cool and glamorous and more marginal and problematic over time (Brandt, 2007), the existence of a public stigma of smokers may be considered as an expression of the historically new 'unfavourable smoking climate' described above. The extent to which the public do in fact agree that smokers are stigmatised is also an indicator of the existence a public stigma of smokers.

In Norway and other countries that have reached the final stage of the cigarette epidemic, the current moral standing of the smoker group as such will be dependent on smokers meeting smoking-behaviour obligations and social norms in everyday settings, which again in turn may be influenced by the underlying beliefs and outlooks on life of both smokers (more often from low SES groups) and their non-smoking onlookers (more often from middle or high SES groups). Given the now standard norm of smoke-free environments, public perceptions of smoker stigma may also be part of—or at least associated with—values. But which values, and in what ways? By values, we mean beliefs about basic goals in life, and beliefs about how to proceed to reach these goals. In other words, values refer to goals and means about what is *desirable* (Hitlin and Piliavin, 2004). Theoretically, values are usually considered as derived from social background variables (gender, age, SES etc.). Furthermore, they are more abstract than (but still formative of) specific attitudes, which again tend to govern actual choices and actions (Rokeach, 1973).

Little attention has hitherto been paid to whether (and if so, how) the 'unfavourable smoking climate' and the public stigma of smokers associated with tobacco normalisation polices connects with other and more general values among smokers and non-smokers. If the perceived public stigma of smokers turns out to be aligned with, or embedded in, widely shared values, it will be much harder for politicians, health authorities and others to repudiate than if it exists more as an 'isolated' and specific attitudinal element of culture.

Smoking and value oppositions

As the role of values barely has been investigated in sociological tobacco research, there are few published studies to draw from when addressing the significance of values and their possible associations with perceptions of smoker stigma. One exception is a simulation based on the introduction of smokefree restaurants and bars in European countries, which suggests that different patterns of compliance is associated with differences in the normative climate (Dechesne et al., 2013). In a sense, this lack of research focus is surprising, given the strong *cultural* foundation of the idea of smoking denormalisation in tobacco policies. On the other hand, the general literature on values, including what values are, how they should be measured, their causes and consequences etc., is vast, but there is currently little intersubjective consensus on these issues (Hitlin and Piliavin, 2004; Beckers et al., 2012; Dobewall and Rudnev, 2014). Rather than adapting to one of the overall 'grand' theoretical perspectives of values as such (for instance those by Inglehart and Welzel, 2005; Schwartz, 2012) at the possible expense of insights into others, we propose instead an exploratory approach, emphasising empirical investigation of four pairs of opposing values. These value oppositions were selected due to their possible relevance (in terms of meaning) to the smoking issue. In the following, we will present these value oppositions, which are previously validated as four out of the 25 'lower-order' value dimensions that are used to construct the two 'higher-order' value dimensions 'modern versus traditional' and 'materialist versus idealist' in the Norwegian Monitor value compass (Hellevik, 1993, 2002). We will also outline how they hypothetically may be linked to the concept of a public stigma of smokers.

Puritanism vs. emancipation

The first value opposition contrasts *puritanism* with *emancipation*. Initially used to designate a religious protestant congregation particularly concerned with religious purity in the sixteenth century, puritanism has in modern societies connotatively come to mean any strong (often religiously grounded) moralism that prescribes temperance. As a value, it is thus rooted in the protestant ethics of vocation that Weber (2002) identified as a significant driver in the development of capitalism. In contrast, emancipation as a value refers to becoming free of previous restraints, for instance liberation from religious moralism or traditional 'non-rational' mores. This value opposition sits well with 'traditional' vs. 'secular-rational' values (Inglehart and Welzel, 2005), which is a familiar dimension in previous values research.

Throughout history, a puritan view of smoking has animated much of the political and cultural thinking about tobacco, especially opposition to smoking (Harley, 1993). From this perspective, indulging in tobacco practises is considered a vice that should be avoided. In contemporary public discourse, the label 'puritan' has been applied to designate the political will to regulate all types of tobacco as strong as possible, preferably by way of prohibition (Morphett et al., 2020). Thus, holding puritan values may be associated with agreeing that smokers are (and perhaps need to be) stigmatised, as this may be effective in curbing smoking. The value contrast to puritanism is the emancipation from life-restraining temperance ideals and prudent lifestyles, with an emphasis on freedom and a liberating view of doing whatever you want to do, including smoking. Such a view may for instance reflect the historical connection between women's emancipation from the 1960s onwards and the growth in female smoking, largely a result of the tobacco industry's deliberate targeting of the autonomous and free female smoker in advertising (Marron, 2017).

Conformity vs. individuality

The second value opposition contrasts *conformity* with *individuality*. Conformity as a cultural value involve support of dominant group norms and collective representations, and adherence to accepted practises and standards (such as customs and traditions). Conformity is thus related to hegemonic maintenance of the *status quo*, as in the sociological functionalism of Parsons (1970). In contrast to conformity and its inherent emphasis of normative action, individuality as a cultural value may be a basis for deviance and/or opposition to conformity but may also refer to individual freedom or egoistical considerations and actions. In moral terms, however, individuality refers to the worth of the individual. This value opposition resembles collectivism/individualism, which is another recurring dimension in research on values (Hitlin and Piliavin, 2004).

When it comes to smoking, a requirement to conform to social norms may be associated with a certainty about the existence of a smoker stigma, as tobacco denormalisation policies and attitudes now clearly suggest that smoking is unacceptable (Chapman and Freeman, 2008). Consequently, a contemporary 'conformist' who considers prevailing laws and norms to be directive for behaviours and outlooks is not only likely to think that smokers are stigmatised, but perhaps even rightfully so (just like the puritans). This stands in contrast to the

1970s and 80s, when conformism was more likely to reflect that smoking was normal and even cool, especially among young people (Stewart-Knox et al., 2005). The value contrast to conformity is individuality: opposing any submission to norms that a person perhaps disagrees with or does not think should be a behavioural norm at all—including the paternalist idea of denormalising smoking (Dennis, 2011).

Tolerance vs. intolerance

The third value opposition contrasts *tolerance* with *intolerance*. Tolerance as a value involves acceptance of actions, utterances, lifestyles or individuals one dislikes or disagrees with. It also involves recognising the rights of others, not only to think differently than oneself or what the majority think, but also to live in accordance with their opinions, e.g., due to religious or political reasons. As such, tolerance is a value orientation directed toward difference (Hjerm et al., 2020), firmly rooted in political liberalism (Mill, 1974), ethics (Rawls, 1999) and human rights, and also related to the value of universalism. Intolerance on the other hand, refers to lack of tolerance, lenience, or open-mindedness toward different opinions than one's own (Verkuyten and Kollar, 2021). This value opposition resembles the 'self-expression/post-materialism' vs. 'survival/materialism' dimension in the works of Inglehart and Welzel (2005).

As long as cigarettes are legal products and smoking is a legal practise, a cultural ideal of tolerance may imply that smoking and smokers should be accepted as is, without the state seeking to disgrace citizens who engage in such practises. As smoking over time has been denormalised and marginalised, the approach of the in-group of non-smokers to the out-group of smokers may vary, however, from a tolerating acceptance of a preference to smoke on the one hand (including in legislation, see Muggli et al., 2010) to an intolerant and moralising condemnation on the other (Rozin and Singh, 1999; Moore, 2005). Thus, holding tolerant views may be associated with a tendency to disagree with devaluating statements such as 'most people think less of people who smoke.' Holding intolerant views may be associated with a tendency to agree with such statements.

Status vs. anti-status

The fourth value opposition contrasts *status* with *anti-status*. In sociology, status refer to the rank, wealth and power deriving from the individuals' placements in hierarchical social positions. Status is rooted in economic capital that again may be converted into social and cultural capital due the logic of lifestyle distinction in social space (Bourdieu, 1984). As a value, status refers to acknowledging symbolic conspicuous consumption and 'abstract goods' like prestige, reputation and respect as legitimate means to gain influence in social interaction and games of power. In contrast, anti-status as a value refers to rejecting the significance of such symbolic power rules in 'status plays,' as they for instance may be considered as superficial, shallow or rigid, or as illegitimate means to control people and resources. Anti-status suggests that other things than material wealth may have value in life, such as authenticity, love, or the wonders of nature. While holding a 'status' value tends to score high on materialism, 'anti-status' often scores higher on idealism (Hellevik, 1993), and thus also on post-materialism.

Regarding status and prestige, cigarettes and smoking have historically moved from being a product and practise that radiated status and being cool to the polar opposite; in a political-cultural context of tobacco denormalisation, regular daily smoking tends to radiate addiction, lack of control and being an uncool 'loser' (Sæbø, 2017). Emphasising status as a value (i.e., wanting to make an impression on others, wishing to gain the respect and admiration of others) may therefore be associated with a denormalised view of smoking, an acknowledgment of smoking as being uncool and having a low status and, consequently, a tendency to agree that, in general, smokers are stigmatised. Being anti-status value-wise, on the other hand, may involve opposition to a view of letting others define what is worthwhile or perhaps refuting 'external conditions' as a guide to judgements of what is impressive in life, and consequently, also disagreeing with smokers being stigmatised.

Research problem

Little is known about the dissemination of stigmatising attitudes toward people who smoke at the national level, including their associations with personal values. In this paper, we explore the existence of a perceived public stigma in Norway and its association with the four value oppositions laid out above as well as other possible predictors. More precisely, we aim to identify (a) the spread of perceived public smoker stigma in the Norwegian population, and (b) whether the tendency to agree with a perceived public smoker stigma differs by expressed value opposites after controls for demographics, socio-economic status and smoking behaviour, including cessation plans among current smokers.

Data and methods

Data

Two data sets from the biennial cross-sectional and nationally representative *Norwegian Monitor* survey were employed: *Norwegian Monitor 2011* ($N = 3,980$, N smokers = 934, N ex-smokers = 1,242) and *Norwegian Monitor 2013* ($N = 3,812$, N smokers = 762, N ex-smokers = 1,211). This survey is organised by the public opinion agency IPSOS/Synnovate in collaboration with the University of Oslo. For the purposes of the analyses in this paper, and to achieve sufficient statistical power to address the relatively small sub-groups of various smoking behaviours, these data sets were merged (total $N = 7,792$, total N smokers = 1,696, total N ex-smokers = 2,265).

Probability sampling based on telephone records was used to draw a random sample of the adult Norwegian population (>15 years). The exact size of the gross sample was not known due to uncertainty about the status of the telephone numbers (i.e., whether they were active or not). Respondents who agreed to participate in a short introductory telephone interview (2011, $N = 10,248$; 2013, $N = 10,098$) were then invited to participate in the main self-administered part of the survey, thereby constituting the eligible sample. Those who responded to the questionnaire constitute the analytical sample of the current study.

Of those respondents who made up the eligible sample, 39% answered their questionnaires in 2011 while the return rate fell to 37% in 2013 (Hellevik, 2015). There was a lower response rate for males and young age groups, and a higher response rate from respondents with long education. Nevertheless, a collation of the final sample with the official statistics on smoking rates from Statistics Norway displays a high degree of correspondence (Hellevik, 2015).

The IPSOS group responsible for the survey has committed to international compliance with data protection law and ESOMAR ethical guidelines. Informed consent was obtained, and the data was anonymised before being submitted to the authors. Thus, indirect identification of respondents is not possible.

Measures

Perceived public smoker stigma was measured through the following question: 'How much do you agree or disagree with the following statement? Most people think less of a person who smokes.' The response categories were: 'totally agree,' 'partially agree,' 'partially disagree' and 'totally disagree.' This indicator of public smoker stigma was borrowed from the devaluation index of Stuber et al. (2009, p. 592). Responses were recoded into 'totally or partially agree' and 'totally or partially disagree.'

To assess *smoking status*, respondents were asked: 'Which of the following statements best describes your situation?' The response categories were: 'I smoke and have no plans to quit in the next 6 months' (=1), 'I smoke but am seriously considering quitting in the next 6 months' (=2), 'I smoke and have decided to quit in the next 30 days' (=3), 'I used to smoke, but quit less than 6 months ago' (=4), 'I used to smoke, but quit more than 6 months ago' (=5), 'I used to smoke, but quit more than 5 years ago' (=6), and 'I have never smoked' (=7).[1] This question was recoded into 'current smoker without any plans to quit' (response 1), 'current smoker with plans to quit' (2,3), 'recent quitter—i.e., quit less than 5 years ago' (4,5), 'long-term quitter - i.e. quit more than 5 years ago' (6), and 'never-smoker' (response 7). All respondents were also asked whether they *live with others who smoke* (no/yes).

Regarding *value oppositions*, four theoretically relevant additive value indexes as defined by the *Norwegian Monitor* value compass (Hellevik, 1993, 2002), were utilised as independent variables. These were:

- *Puritanism/emancipation*. This index is based on the following questions: 'Sexual experiences before marriage helps make the marriage happier' ('totally agree,' 'partially agree,' 'impossible to answer,' 'partially disagree,' 'totally disagree') and 'Do you think so-called pornographic magazines, books and writing should be banned, or do you think such items should be sold freely?' ('should be banned,' 'should be freely available,' 'not sure').
- *Conformity/individuality*. This index is based on the following questions: 'How important do you think it is that on special occasions you dress and act according to custom and practise?' ('very important,' 'quite important,' 'less important,' 'does not matter'), and 'The worst thing I know is people who cannot be like most people' ('totally agree,' 'partially agree,' 'impossible to answer,' 'partially disagree,' 'totally disagree').
- *Tolerance/intolerance*. This index is based on the following questions: 'There are many opinions that should never be expressed on radio and television,' 'People should be able to look, dress and live as they like, whether or not others like it,' and 'It should be reasonable to expect that foreigners who come to settle in Norway live like Norwegians' (response categories on all three questions: 'totally agree,' 'partially agree,' 'partially disagree,' 'totally disagree,' 'impossible to answer').
- *Status/anti-status*. This index is based on the following questions: 'I try to acquire things that make an impression on others,' 'Nice house, expensive car and fancy clothes engender the admiration of others (both 'totally agree,' 'partially agree,' 'partially disagree,' 'totally disagree,' 'impossible to answer') and 'If you had one wish today, which of the following alternatives would you choose?' (Would choose this alternative first: 'To be even more respected by people with whom I associate').

All indexes were thus based on questions with different wordings, to control for possible 'yes-saying.' The utilised variables were first recoded, with 'impossible to answer' and 'not sure' categories being placed in the middle, and then merged into an additive index, with the outer categories representing opposite value 'poles' (Hellevik, 2002). Each respondent was accordingly placed on an additive scale, ranging from 9 to 12 when it comes to our four value indexes. For the analytical purposes of this paper, these value indexes were normalised to vary between 0 and 100 (in respect of the descriptive statistics) and recoded into quartiles (in respect of the regression model).[2]

Regarding background variables, we controlled for SES (the highest level of completed education: 'primary school,' 'lower and upper secondary school,' 'university, low grade,' and 'university, high grade,' and household income: '<NOK 499,000,' 'NOK 500–799,000,' 'NOK 800–999,000,' and '+NOK 1 million'), gender and age group ('15–24,' '25–39,' '40–59,' '60+').

Statistical analyses

To address the extent and dissemination of perceived public stigma, a descriptive statistical analysis was applied. To specifically

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[1] In 2013, a technical filter glitch on the part of IPSOS/Synnovate resulted in around 50% missing responses among non-smokers on this variable. There was no systematic pattern but rather a coincidence about who had answered the question or not, by gender, age, and region. The missing responses were therefore assigned a random response from a matrix of existing data on age (to account for the higher likelihood of having smoked previously by age) in the column and actual responses of those who had answered in the row. Thus, the response probability of those who had answered was used to allocate assigned answers to those who had not answered ('interpolation'). Additional tests were performed on all analyses presented in this article, by 2011 and 2013. The results did not suggest that the interpolations created artificial or deviating results. To achieve statistical power in our analysis, it was therefore decided to pool the two data sets.

[2] As shown in Table 2, this recoding resulted in a somewhat skewed distribution of quartiles for three of the four value indexes. Additional tests were thus performed, entering these indexes as linear variables instead of categorical variables in the logistic regression models. Results did not differ substantially (that is, provide other significant associations) from what is reported in Table 3.

assess the central tendency of the value indexes, a normalised distribution was applied. To address differences between groups, binary logistic regression was utilised. The latter analysis was conducted on two levels. First, the unadjusted associations between all the independent variables and public stigma were explored. Then, multiple controls were performed, using a block-wise approach, to identify any possible mediating role of values. Here, the tendency to agree with a perceived public smoker stigma was regressed on socio-demographic variables (gender, age, education, income) in the first step, socio-demographics and smoking in the second step, socio-demographics and value opposites in the third step, and socio-demographics, value opposites and smoking status in the fourth and last step. To report model goodness of fit and explained variance, Hosmer-Lemeshow and Nagelkerke tests were performed. All results from the logistic regression analysis were based on respondents who had answered all the questions.

Multicollinearity among the value indexes was investigated but was not found to be a statistical problem (see correlation matrix in Table 1).

The analyses were conducted using SPSS v28.

Results

Descriptives

The descriptive distributions of the variables employed are laid out in Table 2.

59.1% of the total sample agree with the statement that 'most people think less of a person who smokes,' rising to 67.7% among daily smokers (table not shown). The tendency to agree that smokers are looked down upon is also shared by a majority of the never-smokers (57.8%, table not shown).

There were 46.1% never-smokers in the sample, 31.5% ex-smokers and 18.1% current smokers. A slight majority of the current smokers express plans to quit.

The mean scores for the value indexes were 61.8% for the 'puritanism/emancipation' index, 47.2% for the 'conformity/individuality' index and 39.3% for the 'tolerance/intolerance' index. Finally, for the 'status/anti-status' index the mean score is 72.0%, suggesting a strong inclination in the sample to express an 'anti-status' rather than 'status' value position.

TABLE 1 Correlation matrix for the value indexes (before recoding into quartiles).

	VI1 (puritanism/ emancipation)	VI2 (conformity/ individuality)	VI3 (tolerance/ intolerance)
VI2 (conformity/ individuality)	0.002 (0.829)	–	
VI3 (tolerance/ intolerance)	0.146 (<0.001)	−0.349 (<0.001)	–
VI4 (status/ anti-status)	−0.132 (<0.001)	−0.122 (<0.001)	0.111 (<0.001)

Pearson's R (significance level in parenthesis). $N = 7{,}792$.

The strongest inter-correlation between the value indexes was found between 'tolerance/intolerance' and 'conformity/individuality' (Pearson's $R = -0.349$, $p < 0.001$), which suggests that 'tolerance' tend to go with 'individuality' and 'intolerance' with 'conformity.' There were statistically significant, but less notable, associations between all the value indexes, bar one (see Table 1).

Regressing public smoker stigma: unadjusted associations

The logistic regression analysis is presented in Table 3. Unadjusted significant associations were found for all variables utilised, except for the 'tolerance/intolerance' value index and 'living with other smokers.'

Adjusted associations between background variables and public smoker stigma

Adjusting for other variables in the block-wise regression, the effects of gender (women more in agreement), age (15–24 years most in agreement) and income (+NOK 1 million most in agreement) were maintained in all the 4 models tested. The unadjusted effect of education disappeared after multiple controls for other socio-demographical variables (model 1) and value opposites (model 3) but reappeared in model 2 and the full model (after the inclusion of smoking status).

Adjusted associations between smoking status and perceived public smoker stigma

'Smokers with plans to quit' is the smoking status sub-group that expresses the strongest tendency to agree with a perceived public smoker stigma, controlling for all other factors (OR = 2.34 in the full model 4). Also, those ex-smokers who quit recently are more often in agreement with the assertion that smokers are stigmatised (OR = 1.58 in model 4) than ex-smokers who quit more than 5 years ago (OR = 1.22 in model 4). (A supplementary test using 'quit >5 years ago' as a reference category suggests that this difference is significant). Living with others who smoke is also associated with lower agreement with public stigma (OR = 0.77) in the full model.

Note that the OR for agreeing with a perceived stigma among current smokers with plans to quit increases from 1.90 unadjusted to 2.34 in the fully adjusted model. This latter finding is most likely due to strong confounding with 'living with others who smoke.'

Adjusted associations between value opposites and perceived public smoker stigma

The four value indexes have no common resemblance to perceived public smoker stigma. However, the associations with the value indexes of puritanism/emancipation and status/anti-status remain significant in the adjusted models. A higher score on the puritanism/emancipation index is associated with higher odds for agreeing with smoker stigma (i.e., emancipates more widely agree with smoker

TABLE 2 Descriptive statistics.

Smoker stigma	Partially or fully disagree	38.6
	Partially or fully agree	59.1
	No info	2.3
Gender	Male	46.2
	Female	53.8
Age	15–24	12.8
	25–39	16.6
	40–59	38.9
	60+	31.7
Education	Primary	10.7
	Secondary	30.7
	University, low grade	34.6
	University, high grade	23.8
	No info	0.2
Income, household	<NOK 499,000	30.5
	500–799	29
	800–999	16.7
	+NOK 1 million	19.6
	No info	4.1
Smoking status	Never-smoker	46.1
	Quit >5 years ago	24.8
	Quit <5 years ago	6.7
	Smoker with plans to quit	9.9
	Smoker with no plans to quit	8.2
	No info	4.3
Live with others who smoke	No	82.9
	Yes	14.8
	No info	2.3
Puritanism/emancipation (value index I)	Q1 (puritanism)	24.8
	Q2	29.8
	Q3	15.6
	Q4 (emancipation)	29.9
	Means	*61,8*
Conformity/individuality (value index II)	Q1 (conformity)	20.4
	Q2	15.7
	Q3	30.7
	Q4 (individuality)	33.1
	Means	*47.2*
Tolerance/intolerance (value index III)	Q1 (tolerance)	20.4
	Q2	26.7
	Q3	25.7
	Q4 (intolerance)	27.1
	Means	*39.3*
Status/anti-status (value index IV)	Q1 (status)	15.3
	Q2	42.9
	Q3	10.2
	Q4 (anti-status)	31.6
	Means	*72*

Percentages, $N = 7{,}792$.

stigma, while puritans agree to a lesser extent). A lower score on the index for status/anti-status values, on the other hand, is associated with higher ORs for agreeing with public smoker stigma, i.e., those who are concerned with status are more likely to agree with the stigma of smokers compared to those holding an anti-status value. The small, significant association between the conformity/individuality index and the outcome variable perceived public smoker stigma disappears after controlling for smoking status.

There was no evidence that values play any mediating role in our modelling.

Discussion

Main findings

The tendency to agree with the statement 'most people think less of a person who smokes' is quite high in the Norwegian population, including among never-smokers, and certainly higher than what was found in a recent French study (Peretti-Watel et al., 2014). People who agree with a perceived public smoker stigma are more likely to be young, female, with a high level of education and income, former or current smokers, and espoused to the values of emancipation and status. Inasmuch as the overall tendency to agree with a perceived public smoker stigma is as high as it is, this opinion is a shared cultural characteristic in Norway. This is noteworthy, as the aim of the policy is to denormalise the act of smoking, not stigmatise people who smoke.

Interpretation of findings as regards value opposites

To overcome the neglect of the role of values in sociological tobacco research in general, and in smoker stigma research in particular, we have in this article suggested an exploratory approach, to test whether four value oppositions with hypothetical relevance to the smoking issue were associated with the stigmatisation of smokers. Our approach is based on the premise that values provide a direction toward what is worth striving for and what is considered important in society; hence, they may also serve as motivational underpinnings of attitudes and perceptions of smokers and smoking behaviour (Hitlin and Piliavin, 2004). However, the indexes for intolerance/tolerance and individuality/conformity were not found to be significantly associated with public smoker stigma in our study after multiple controls. Thus, the perceived public stigma of smokers may appear to belong to other cultural dimensions than these. One should perhaps expect that tolerant people would show a higher acceptance of a norm-deviant behaviour like smoking, but this does not seem to be the case from our data. Or people may support a general ideal of

TABLE 3 Logistic regression.

Variables	Unadjusted ORs	Adjusted ORs (block-wise modelling)			
		Model 1: Socio-demographics (A)	Model 2: Socio-demographics (A) + smoking behaviour (B)	Model 3:Socio-demographics (A) + value opposites (C)	Model 4: Socio-demographics (A) + smoking behaviour (B) + value opposites (C)
Gender					
-Male (ref. cat.)	1.00	1.00	1.00	1.00	1.00
-Female	1.14**	1.14*	1.13*	1.26***	1.24***
Age					
−15–24 (ref. cat.)	1.00	1.00	1.00	1.00	1.00
–25–39	0.96	0.86	0.75**	0.91	0.80*
–40–59	0.77**	0.68***	0.57***	0.78**	0.65***
–60+	0.74***	0.73***	0.63***	0.86	0.74**
Education					
-Primary (ref. cat.)	1.00	1.00	1.00	1.00	1.00
-Secondary	0.92	0.94	0.92	0.93	0.92
-University, low grade	1.07	1.08	1.11	1.1	1.12
-University, high grade	1.23*	1.18	1.24*	1.21	1.27*
Income, household					
-<499,000 (ref. cat.)	1.00	1.00	1.00	1.00	1.00
–500–799	0.94	0.96	1.00	0.96	1.00
–800–999	1.01	1.02	1.07	1.01	1.06
−1 million+	1.53***	1.50***	1.61***	1.42***	1.52***
Smoking status					
-Never-smoker (ref. cat.)	1.00		1.00		1.00
-Quit >5 years ago	1.08		1.25**		1.22**
-Quit <5 years ago	1.50***		1.62***		1.58***
-Smoker with quit plans	1.90***		2.42***		2.34***
-Smoker, no quit plans	1.29**		1.62***		1.57***
Live with others who smoke					
-No (ref. cat.)	1.00		1.00		1.00
-Yes	0.91		0.79**		0.77***
Puritanism/emancipation					
-q1 (ref. cat.)	1.00			1.00	1.00
-q2	1.24**			1.23**	1.17*
-q3	1.25**			1.21*	1.16
-q4	1.53***			1.48***	1.39***
Conformity/individuality					
-q1 (ref. cat.)	1.00			1.00	1.00
-q2	1.04			1.02	1.02
-q3	0.98			0.95	0.96

(Continued)

TABLE 3 (Continued)

Variables	Unadjusted ORs	Adjusted ORs (block-wise modelling)			
		Model 1: Socio-demographics (A)	Model 2: Socio-demographics (A) + smoking behaviour (B)	Model 3:Socio-demographics (A) + value opposites (C)	Model 4: Socio-demographics (A) + smoking behaviour (B) + value opposites (C)
-q4	0.86*			0.86*	0.86
Tolerance/intolerance					
-q1 (ref. cat.)	1.00			1.00	1.00
-q2	1.03			1.03	1.03
-q3	0.97			0.96	0.96
-q4	1.00			1.06	1.07
Status/anti-status					
-q1 (ref. cat.)	1.00			1.00	1.00
-q2	0.79**			0.86*	0.85*
-q3	0.84			0.88	0.88
-q4	0.56***			0.63***	0.63***
Hosmer-Lemeshow		0.260	0.211	0.024	0.526
Nagelkerke		0.018	0.039	0.036	0.054

Dependent variable: agree with the statement 'most people think less of a person who smokes.' Unadjusted and adjusted odd ratios (OR). $N = 6{,}921$. $*p < 0.05$, $**p < 0.01$, $***p < 0.001$.

tolerance, but still evaluate smokers and smoking negatively or positively, depending perhaps on their personal experience of smoking behaviour and/or how they view addictive behaviour in general. It should also be noted that our dependent variable primarily measures the extent to which people agree that smokers are usually looked down upon (or 'devalued'). We have not studied whether or not this is considered 'right' or whether respondents think that smokers 'deserve' to be looked down upon.

What we did find is that respondents favouring puritan values over emancipation values were less likely to suggest that smokers are stigmatised, while those who expressed an emphasis on status values were more inclined to agree with the public stigma of smokers than those who were anti-status. Initially, we expected that puritans were more likely to agree that smokers were stigmatised, but this turned out not to be the case. Puritanism implies expectancy of moral discipline, but even if puritans are likely to be against smoking and pro-denormalisation, they may perhaps be less sensitive to the explicit issue of stigma. Those who support emancipation on the other hand, may be more aware of the unintended consequences of strong regulation and denormalisation of smokers. While, in the case of status values, if status affects you, you are concerned about how other people look at you (Bourdieu, 1984). When opting to move upwards in social hierarchies, you may want to look down on others, not least those positioned socially close to you who do not pay adequate attention to distinctive status behaviour and consumption (such as smokers).

The statistically significant role of status and emancipation values may also reflect that people's notions of smokers are characterised by assumptions of smokers as addicted persons. A dependency on substances such as nicotine and alcohol indicates that the persons are not in complete control, that they are not free, but governed by outside forces. In contemporary cultures and work environments that cherish qualities such as adaptability and flexibility, expressing a lack of control and absence of self-regulation is likely to be regarded as a problem (Gilbert et al., 1998). And while the use of tobacco and intoxicants is often perceived as cool by young people, not even young people think that users who lose control and become addicted are cool (Scheffels and Schou, 2007). Those who favour emancipation and status values are likely to rank autonomy and freedom from dependence highly, and these are qualities that they may think addicted smokers lack.

Furthermore, it is interesting to note that those respondents with the highest economic (income) and cultural (education) capital express higher agreement with the public stigma of people who smoke than those respondents with lower levels of capital. This may suggest a possible paternalistic concern for smokers, but also be associated with distinction (Bourdieu, 1984), as those privileged in terms of capital may distance themselves from smoking as a low status phenomenon and also the notion of 'most people' referred to in the question that measures perceived public smoker stigma. This finding may also reflect the occurrence of a partly elitist and 'degrading' view of smokers among high SES groups, including many public health representatives (Lupton, 1995; Dennis, 2011).

Taken together, the present findings indicate that the perceived public stigma of smokers in Norway is most common among high-status groups, and those who emphasise status (and emancipation) as values. As such, our findings are congruent with the Stuber group's findings from New York City (Stuber et al., 2008, 2009).

When it comes to the effects of age, adolescents, and young adults (<25 years) are more in agreement with a public stigma of smokers than older respondents. In contrast to the youngest, who have been raised with a denormalised view of smoking, older respondents grew up in a period when smoking was considered as normal (and even glamorous), so it may fit with a generational age explanation that older respondents to a lesser extent tend to agree with the public smoker stigma.

Never-smokers and smokers views on the perceived public stigma of smokers

In keeping with our cultural approach to smoker stigma, we have emphasised that the perceived public stigma of smokers is intersubjective and relational (Yang et al., 2007). It does not primarily reside within individuals or in power structures; it is played out in terms of what is at stake, in our case, in negative beliefs about persons who smoke, as these are held and communicated by the general public. Our public stigma measure is thus an operationalisation of what is basically a triangular model, consisting of individual respondents who express their perception of how the relationship between the majority (most people) and people who smoke is today. We have interpreted this measure as an expression of the mood that prevails around the moral status of today's smokers.

However, never-smokers and smokers view the question of smoker stigma from different positions and with different perspectives. For never-smokers, the perceived public stigma of people who smoke is basically a theoretical construct regarding 'others' who are quite likely to be socially distanced from themselves—compare the tendency to social marginalisation of smokers (Graham, 2012) and the existence of smoking enclaves among current smokers (Thompson et al., 2007). An exception to this is those who live with others who smoke (Peretti-Watel et al., 2014). This social distance may involve a greater interpretational variety of smoking as a cultural phenomenon than among smokers, for whom expectations of being smoke-free may have been internalised and embodied in quite a uniform fashion. For people who smoke, the perceived public stigma of smoking is very real and is associated with a habit that is difficult to refrain from and which may have several potentially damaging consequences, such as health hazards and disapproving looks from relatives and onlookers (McCool et al., 2013). The development of new nicotine-delivering devices such as e-cigarettes may possibly 'renormalise' smoking to some degree, but vaping practises may also inherit the stigma associated with cigarette smoking (Tokle and Pedersen, 2019).

As expected, people who smoke agreed the most with the public smoker stigma, in line with previous research in which 80% of smokers reported that society disapproves of smoking (Hammond et al., 2006). In the total sample, 'smokers with current plans to quit' is the smoking status group that expresses the strongest tendency to agree with the perceived public smoker stigma. Smokers who plan to quit (or who recently quit) use several motivational techniques to stay abstinent or to achieve successful cessation. Among motives for quitting reported by smokers are the negative image that smoking has in society, a motive more often expressed by more highly educated smokers (Baha and Le Faou, 2010). In cultures where healthy behaviour and being tobacco-free are widespread social norms, daily smoking may signal a lack of control, psychological reactance, and recklessness (Lupton, 1995; Sæbø, 2017). Even if the perceived public stigma of smokers among people who smoke should not be commingled with self-stigma (Bracke et al., 2019), a social identity as a 'smoker' may obviously be troublesome in cultural contexts where smoking is considered as unacceptable deviance. Nevertheless, in contrast to stigma associated with other health issues (such as HIV/AIDS and chronic mental health ailments), the smoker stigma may be overcome and disappear if smoking cessation proves to be successful (Bayer, 2008). Because stigma (at least in theoretical terms) is a potential stimulus or incentive to smoking cessation, there might have been a higher acceptance of stigma as the 'price to pay' in tobacco control than in other fields of health governance (Bayer and Stuber, 2006). However, the causal direction between intention/motivation to quit and perceived stigma among smokers is not known, nor can it be adequately addressed in our study because of the cross-sectional perspective.

Finally, a possible interesting 'policy implication' of our study should be mentioned. The finding that the perceived public smoker stigma does not seem to be compellingly associated with underlying values (at least as we measured them in the present study) suggests that smoker stigma may be easier for policy makers and health governors to counter than if it had been a greater part of (or more strongly embedded in) values. Future studies should investigate whether other measurements of personal and cultural values—e.g., the operationalisations of Inglehart and Welzel (2005), or Schwartz (2012)—provide any other type of findings that maintain or changes this interpretation of the current findings.

Limitations

There are some important limitations to our study.

First, the applied stigma measure is quite a crude operationalisation of stigma, which is essentially a multidimensional phenomenon (Link and Phelan, 2001; Pescosolido and Martin, 2015). It measures agreement with one aspect of stigma only, although admittedly an important aspect, namely, the tendency to agree that most people look down on, and thus stigmatise, a person who smokes. This is what the literature calls 'public stigma.' It is a measure of what people believe to be the social norm, not necessarily their personal opinion. Importantly, it measures agreement with a descriptive statement only; it does not refer to any acceptance of stigma. This methodological issue may also help explain the missing concordance between some of the values addressed in this study and the stigma of smoking. Future studies using a broader measurement of the stigma complex are needed to address this issue.

Second, the value indexes applied are based on original questions that perhaps may appear a little outdated today. The value indexes are also generic, with wording that does not explicitly relate to smoking. However, these indexes have been applied as components of underlying value dimensions in Norwegian value research since 1985 and are therefore well validated (Hellevik, 1993, 2002). Empirically, they do actually distinguish between people's views and have done so for more than three decades. Still, in the future it may be useful to also explore whether explicit smoking norms possibly acts as intermediaries between cultural values and the perceived public stigma of smokers and whether this mechanism differs between different national cultures (Dechesne et al., 2013).

Third, the data is based on self-reporting, which is always a limitation when it comes to measuring the extension or spread of phenomena (such as public smoker stigma). However, as our dependent variable is actually an attitude or opinion, the self-reporting is probably less of a problem than if the variable had been a behaviour.

Finally, in the sample, highly educated respondents are somewhat overrepresented. As those with low education (many of whom are still smokers) are underrepresented in this sample, we may have underestimated both the level of smoking behaviour and the social inequalities in smoking behaviour underlying the perception of public stigma.

Conclusion

Smoking denormalisation policies have sought to obtain public health goals (lower smoking prevalence and less tobacco-related death and disease) through cultural redefinition of the meaning of smoking. Although this strategy seems to have achieved its missions in many countries, the redefinition of smoking from 'normal' to 'unacceptable' has also had the unfortunate and unintended consequence of contributing to stigmatise the remaining smokers, especially smokers who want to quit but who have not yet succeeded with this task. The perceived stigma of smokers among the public is one (infrequently utilised) way to measure the extent of this stigmatisation. In this article, we have identified factors that predict agreement (or disagreement) with a public stigma of smokers, with a particular emphasis on the role of general value opposites. Our empirical results indicate that the perceived public stigma of smokers is high in Norway and that it varies with two of the four indexes of value opposites assessed ('puritanism/emancipation' and 'status/anti-status') as well as with socio-demographics. The findings also corroborate the existence of a statistically independent cleavage between smokers and non-smokers in the perceived public stigma of smokers, an issue that in itself is culturally charged.

Data availability statement

The original contributions presented in the study are included in the article/supplementary material, further inquiries can be directed to the corresponding author.

Ethics statement

The studies involving humans were approved by the Norwegian Data Protection Authority. The studies were conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation in this study was provided by the participants' legal guardians/next of kin.

Author contributions

All authors listed have made a substantial, direct, and intellectual contribution to the work and approved it for publication.

Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

Archer, MS (1988) *Culture and agency: the place of culture in social theory*. Cambridge: Cambridge University Press.

Baha, M., and Le Faou, A. L. (2010). Smokers' reasons for quitting in an anti-smoking social context. *Public Health* 124, 225–231. doi: 10.1016/j.puhe.2010.02.011

Bain, J., Weishaar, H., Semple, S., Duffy, S., and Hilton, S. (2017). Vulnerable children, stigmatised smokers: the social construction of target audiences in media debates on policies regulating smoking in vehicles. *Health* 21, 633–649. doi: 10.1177/1363459316633279

Bayer, R. (2008). Stigma and the ethics of public health: not can we but should we. *Soc. Sci. Med.* 67, 463–472. doi: 10.1016/j.socscimed.2008.03.017

Bayer, R., and Stuber, J. (2006). Tobacco control, stigma, and public health: rethinking the relations. *Am. J. Public Health* 96, 47–50. doi: 10.2105/AJPH.2005.071886

Beckers, T., Siegers, P., and Kuntz, A. (2012). Congruence and performance of value concepts in social research. *Surv Res Methods* 6, 13–24. doi: 10.18148/srm/2012.v6i1.5093

Bell, K., McCullough, L., Salmon, A., and Bell, J. (2010). 'Every space is claimed': smokers' experiences of tobacco denormalisation. *Sociol. Health Illn.* 32, 914–929. doi: 10.1111/j.1467-9566.2010.01251.x

Bernard, M., Fankhänel, T., Riedel-Heller, S. G., and Luck-Sikorski, C. (2019). Does weight-related stigmatisation and discrimination depend on educational attainment and level of income? A systematic review. *BMJ Open* 9:e027673. doi: 10.1136/bmjopen-2018-027673

Bourdieu, P. (1984) *Distinction: a social critique of the judgement of taste*. London: Routledge & Kegan Paul.

Bracke, P., Delaruelle, K., and Verhaeghe, M. (2019). Dominant cultural and personal stigma beliefs and the utilization of mental health services: a cross-national comparison. *Front. Sociol.* 4:40. doi: 10.3389/fsoc.2019.00040

Brandt, A. M. (2007) *The cigarette century: the rise, fall and the deadly persistence of the product that defined America*. New York, NY: Basic Books.

Brown-Johnson, C. G., and Popova, L. (2016). Exploring smoking stigma, alternative tobacco product use, and quit attempts. *Health Behav Policy Rev* 3, 13–20. doi: 10.14485/HBPR.3.1.2

Chapman, S., and Freeman, B. (2008). Markers of the denormalisation of smoking and the tobacco industry. *Tob. Control.* 17, 25–31. doi: 10.1136/tc.2007.021386

Dechesne, F., Di Tosto, G., Dignum, V., and Dignum, F. (2013). No smoking here: values, norms and culture in multi-agent systems. *Artif. Intell. Law* 21, 79–107. doi: 10.1007/s10506-012-9128-5

Dennis, S. (2011). Smoking causes creative responses: on state antismoking policy and resilient habits. *Crit. Public Health* 21, 25–35. doi: 10.1080/09581596.2010.529420

Dobewall, H., and Rudnev, M. (2014). Common and unique features of Schwartz's and Inglehart's value theories at the country and individual levels. *Cross-Cult. Res.* 48, 45–77. doi: 10.1177/1069397113493584

Evans, D. N., and Furst, R. T. (2016). Stigma and outdoor smoking breaks: self-perceptions of outdoor smokers in Manhattan. *Soc. Theory Health* 14, 275–292. doi: 10.1057/sth.2015.33

Evans-Polce, R. J., Castaldelli-Maia, J. M., Schomerus, G., and Evans-Lacko, S. E. (2015). The downside of tobacco control? Smoking and self-stigma: a systematic review. *Soc. Sci. Med.* 145, 26–34. doi: 10.1016/j.socscimed.2015.09.026

Gibson, B. (1998). Nonsmokers' attributions for the outcomes of smokers: some potential consequences of the stigmatization of smokers. *J. Appl. Soc. Psychol.* 28, 581–594. doi: 10.1111/j.1559-1816.1998.tb01721.x

Gilbert, G. R., Hannan, E. L., and Lowe, K. B. (1998). Is smoking stigma clouding the objectivity of employee performance appraisal? *Public Pers. Manag.* 27, 285–300. doi: 10.1177/009102609802700301

Goffman, E. (1990) *Stigma: notes on the management of spoiled identity*. Harmondsworth: Penguin Books.

Graham, H. (2012). Smoking, stigma and social class. *J. Soc. Policy* 41, 83–99. doi: 10.1017/S004727941100033X

Hammond, D., Fong, G. T., Zanna, M. P., Thrasher, J. F., and Borland, R. (2006). Tobacco denormalization and industry beliefs among smokers from four countries. *Am. J. Prev. Med.* 31, 225–232. doi: 10.1016/j.amepre.2006.04.004

Harley, D. (1993). The beginnings of the tobacco controversy: puritanism, James I, and the royal physicians. *Bull. Hist. Med.* 67, 28–50.

Hefler, M., and Carter, S. M. (2019). Smoking to fit a stigmatised identity? A qualitative study of marginalised young people in Australia. *Health* 23, 306–324. doi: 10.1177/1363459317745690

Hellevik, O. (1993). Postmaterialism as a dimension of cultural change. *Int J Public Opin* 5, 211–233. doi: 10.1093/ijpor/5.3.211

Hellevik, O. (2002). Age differences in value orientation – life cycle or cohort effects? *Int. J. Public Opin. Res.* 14, 286–302. doi: 10.1093/ijpor/14.3.286

Hellevik, O. (2015). Extreme nonresponse and response bias. *Qual. Quant.* 50, 1969–1991. doi: 10.1007/s11135-015-0246-5

Hitlin, S., and Piliavin, J. A. (2004). Values: reviving a dormant concept. *Annu. Rev. Sociol.* 30, 359–393. doi: 10.1146/annurev.soc.30.012703.110640

Hjerm, M., Eger, M. A., Bohman, A., and Connolly, F. F. (2020). A new approach to the study of tolerance: conceptualizing and measuring acceptance, respect, and appreciation of difference. *Soc. Indic. Res.* 147, 897–919. doi: 10.1007/s11205-019-02176-y

Inglehart, R., and Welzel, C. (2005) *Modernization, cultural change and democracy*. New York, NY: Cambridge University Press.

Kim, S. H., and Shanahan, J. (2003). Stigmatizing smokers: public sentiment toward cigarette smoking and its relationship to smoking behaviors. *J. Health Commun.* 8, 343–367. doi: 10.1080/10810730305723

Kleinmann, A., and Hall-Clifford, R. (2009). Stigma: a social, cultural and moral process. *J. Epidemiol. Community Health* 63, 418–419. doi: 10.1136/jech.2008.084277

Lavack, A. M. (1999). De-normalization of tobacco in Canada. *Soc. Mark. Q.* 5, 82–85. doi: 10.1080/15245004.1999.9961068

Link, B. C., and Phelan, J. C. (2001). Conceptualizing stigma. *Annu. Rev. Sociol.* 27, 363–385. doi: 10.1146/annurev.soc.27.1.363

Lipperman-Kreda, S., Antin, T. M. J., and Hunt, G. P. (2019). The role of multiple social identities in discrimination and perceived smoking-related stigma among sexual and gender minority current or former smokers. *Drugs* 26, 475–483. doi: 10.1080/09687637.2018.1490391

Lupton, D. (1995) *The imperative of health: public health and the regulated body*. London: Sage.

Machado, N. M., Richter, K. P., Formagini, T. D. B., and Ronzani, T. M. (2018). A qualitative review of tobacco research related to public and structural stigma. *Stigma Health* 3, 395–405. doi: 10.1037/sah0000110

Major, B., and O'Brian, L. T. (2005). The social psychology of stigma. *Annu. Rev. Psychol.* 56, 393–421. doi: 10.1146/annurev.psych.56.091103.070137

Malone, R. E., Grundy, Q., and Bero, L. A. (2012). Tobacco industry denormalisation as a tobacco control intervention: a review. *Tob. Control.* 21, 162–170. doi: 10.1136/tobaccocontrol-2011-050200

Marron, D. O. (2017). Smoke gets in your eyes: what is sociological about cigarettes? *Sociol. Rev.* 65, 882–897. doi: 10.1111/1467-954X.12404

McCool, J., Hoek, J., Edwards, R., Thomson, G., and Gifford, H. (2013). Crossing the smoking divide for young adults: expressions of stigma and identity among smokers and nonsmokers. *Nicotine Tob. Res.* 15, 552–556. doi: 10.1093/ntr/nts136

Mill, J. S. (1974) *On liberty*. Harmondsworth: Penguin Books.

Moore, R. S. (2005). The sociological impact of attitudes toward smoking: secondary effects of the demarketing of smoking. *J. Soc. Psychol.* 145, 703–718. doi: 10.3200/SOCP.145.6.704-718

Morphett, K., Herron, L., and Gartner, C. (2020). Protectors or puritans? Responses to media articles about the health effects of e-cigarettes. *Addict. Res. Theory* 28, 95–102. doi: 10.1080/16066359.2019.1596259

Muggli, M. E., Lockhart, N. J., Ebbert, J. O., Jimenez-Ruiz, C. A., Miranda, J. A. R., and Hurt, R. D. (2010). Legislating tolerance: Spain's national public smoking law. *Tob. Control.* 19, 24–30. doi: 10.1136/tc.2009.031831

Parsons, T. (1970) *The social system*. London: Routledge & Kegan Paul Ltd.

Peretti-Watel, P., Legleye, S., Guignard, R., and Beck, F. (2014). Cigarette smoking as a stigma: evidence from France. *Int. J. Drug Policy* 25, 282–290. doi: 10.1016/j.drugpo.2013.08.009

Pescosolido, B. A., and Martin, J. (2015). The stigma complex. *Annu. Rev. Sociol.* 41, 87–116. doi: 10.1146/annurev-soc-071312-145702

Rao, D., Angell, B., Lam, C., and Corrigan, P. (2008). Stigma in the workplace: employer attitudes about people living with HIV/AIDS in Beijing, Hong Kong, and Chicago. *Soc. Sci. Med.* 67, 1541–1549. doi: 10.1016/j.socscimed.2008.07.024

Rawls, J. (1999) *A theory of justice. Revised edition*. Oxford: Oxford University Press.

Ritchie, D., Amos, A., and Martin, C. (2010). 'But it just has that sort of feel about it, a leper' – stigma, smoke-free legislation and public health. *Nicotine Tob. Res.* 12, 622–629. doi: 10.1093/ntr/ntq058

Rokeach, M. (1973) *The nature of human values*. New York, NY: Free Press.

Rozin, P., and Singh, L. (1999). The moralization of cigarette smoking in the United States. *J. Consum. Psychol.* 8, 321–337. doi: 10.1207/s15327663jcp0803_07

Sæbø, G. (2017). Cigarettes, snus and status: differences in lifestyle of different tobacco user groups. *Health Sociol. Rev.* 26, 175–189. doi: 10.1080/14461242.2016.1197043

Sæbø, G., and Lund, M. (2020). Are smoking cessation behaviours among daily smokers associated with a perceived public stigma of smokers? Cross-sectional analyses of Norwegian data 2011–2013. *J. Smok. Cessat.* 15, 189–197. doi: 10.1017/jsc.2020.25

Sæbø, G., and Scheffels, J. (2017). Assessing notions of denormalization and renormalization of smoking in light of e-cigarette regulation. *Int. J. Drug Policy* 49, 58–64. doi: 10.1016/j.drugpo.2017.07.026

Scheffels, J., and Schou, K. C. (2007). To be one who continues to smoke: construction of legitimacy and meaning in young adults' accounts of smoking. *Addict. Res. Theory* 15, 161–176. doi: 10.1080/16066350601179464

Schwartz, S. H. (2012). An overview of the Schwartz theory of basic values. *Online Read. Psychol. Cult.* 2, Article 11. doi: 10.9707/2307-0919.1116

Stewart-Knox, B. J., Sittlington, J., Rugkasa, J., Harrisson, S., Treacy, M., and Abaunza, P. S. (2005). Smoking and peer groups: results from a longitudinal qualitative study of young people in Northern Ireland. *Br. J. Soc. Psychol.* 44, 397–414. doi: 10.1348/014466604X18073

Stuber, J., Galea, S., and Link, B. G. (2008). Smoking and the emergence of a stigmatised social status. *Soc. Sci. Med.* 67, 420–430. doi: 10.1016/j.socscimed.2008.03.010

Stuber, J., Galea, S., and Link, B. G. (2009). Stigma and smoking: the consequences of our good intentions. *Soc. Serv. Rev.* 83, 585–609. doi: 10.1086/650349

Thompson, L., Pearce, J., and Barnett, J. R. (2007). Moralising geographies: stigma, smoking islands and responsible subjects. *Area* 39, 508–517. doi: 10.1111/j.1475-4762.2007.00768.x

Tokle, R., and Pedersen, W. (2019). 'Cloud chasers' and 'substitutes': E-cigarettes, vaping subcultures and vaper identities. *Sociol. Health Illn.* 41, 917–932. doi: 10.1111/1467-9566.12854

Verkuyten, M., and Kollar, R. (2021). Tolerance and intolerance: cultural meanings and discursive usage. *Cult. Psychol.* 27, 172–186. doi: 10.1177/1354067X20984356

Weber, M. (2002) *The protestant ethic and the 'spirit' of capitalism and other writings*. Harmondsworth: Penguin Books.

Yang, L. H., Kleinman, A., Link, B. G., Phelan, J. C., Lee, S., and Good, B. (2007). Culture and stigma: adding moral experience to stigma theory. *Soc. Sci. Med.* 64, 1524–1535. doi: 10.1016/j.socscimed.2006.11.013

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EDITED BY
Rubal Kanozia,
Central University of Punjab, India

REVIEWED BY
Masoud Mohammadnezhad,
University of Bradford, United Kingdom
Amrit Kumar Jha,
Lalit Narayan Mithila University, India

*CORRESPONDENCE
Kibur Engdawork
✉ kibur.engdawork@aau.edu.et

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Experiences and lessons from structural interventions against COVID-19 in Addis Ababa, Ethiopia

Kibur Engdawork*, Ezana Amdework, Samuel Assefa, Desta Ayode and Getnet Tadele

Department of Sociology, College of Social Sciences, Addis Ababa University, Addis Ababa, Ethiopia

Introduction: Fighting pandemics like COVID-19 requires implementing successful structural and behavioral interventions that attempt to change the social and political environments to increase adherence to preventive behavior among community members. However, studying structural interventions implemented during pandemics and their challenges remains to be uncharted territory in developing implemented countries.

Objectives: Given this, we documented the experiences of implementing such interventions in Ethiopia with the aim of drawing lessons for future efforts to fight similar outbreaks in resource limited and low-income settings.

Methods: We conducted a qualitative study between September and October 2021. Data were collected through face to face and telephone interviews from purposefully selected stakeholders from government and private sectors engaged in social interventions to prevent COVID-19. The systematization and the analysis of the data were conducted with MAXQDA 2020 software.

Results: Ethiopia implemented structural and social interventions to respond to the COVID-19 pandemic. This included: developing national policy and guidelines, mainstreaming COVID-19 interventions to local organizations, implementing capacity development programs, and developing strategies to engage the community, through traditional institutions, in intervention activities. In addition, a mass communication approach was used to deliver risk messages. This yielded a promising result in slowing down the spread of COVID-19 in the capital of Ethiopia-Addis Ababa. On the other hand, competing interests, misconceptions, capacity constraints among professionals and organizations, limited capacity to enforce legislation and lack of motivation for change from the community side affected the implementation and the outcomes of interventions.

Conclusion: Going forward, these challenges need to be taken into consideration when designing and implementing structural interventions to contain disease outbreaks effectively. The study highlighted that attempts to withstand pandemic in low- and middle-income settings shall successfully utilize local resources, act swiftly when pandemics outbreak and adjust themselves to the dynamic challenges and limitations of structural interventions.

KEYWORDS

COVID-19, structural intervention, lesson for future pandemics, challenges of interventions, low- and middle-income setting, Ethiopia

Introduction

On December 31, 2019, the outbreak of a coronavirus disease was reported from Chinese authorities in Wuhan City and named by the world health organization (WHO) as COVID-19 on January 30, 2020 and subsequently declared as public health emergency realizing the spread of the virus in other parts of the world outside of China (Güner et al., 2020). The COVID-19 pandemic has led to a dramatic loss of human life worldwide and presented an unprecedented challenge to public health (Mishra et al., 2020; WHO, 2021). The economic and social disruption caused by the pandemic was devastating. The impact was more overwhelming to low-and middle-income countries (LMICs) than global north due to dire limitations of healthcare infrastructure and expertise. According to the latest update report by WHO, as of 12 March 2023, there were over 760 million confirmed cases and over 6.8 million deaths globally (WHO, 2024). Although the vast majority of those infected survive, some survivors of COVID-19 are known to be at-risk for a variety of sequelae- a condition that has been known as post-acute COVID-19, commonly referred to as long COVID (Sudre et al., 2021; Ziauddeen et al., 2022).

Despite the number of new cases and death tolls declining overtime, the pandemic has continued to be a public health threat. Recently, WHO has lifted the Public Health emergency status of COVID-19 with a warning to the world that the disease should be managed alongside other infectious diseases (Laine and Moyer, 2023). According to WHO, worldwide, nearly 4.1 million new cases and 28,000 deaths were reported from 13 February to 12 March 2023, a decrease of 40% and 57%, respectively, compared to the previous month (WHO, 2024) of which Africa accounts for 12,712 (1%) new confirmed cases and 26 deaths (WHO, 2024). In Ethiopia, during the same period, 113 new cases were reported. A total of 500,163 COVID-19 confirmed cases have been detected and 7,572 deaths was reported as of 12 March 2023 (Ethiopia Public Health Institute, 2023). However, the true number of incident cases is likely to be underestimated due to a decline in testing nationally. In the same period, a total of 44,285,561 people have been vaccinated with at least one dose of vaccine, whereas about 37,796,736 people received full doses, bringing overall one dose and full dose coverage of 66.3% and 56.6% from the target population respectively (Ethiopia Public Health Institute, 2023).

The burden of COVID-19 has been well observed in recent studies. As an evolving disease, COVID-19 is associated with anxiety and depression (Pierce et al., 2020; Alat et al., 2023). The effect of COVID-19, however, goes far beyond this and is associated with social and economic stresses that disturb normal routine activities and interpersonal interaction. Fear of losing jobs, safety seeking behavior, avoidance of public spaces have been reported as the consequence of the pandemic (Arora et al., 2020).

Various Non-Pharmaceutical Health Interventions (NPHIs) have been used by different countries to control the spread of the virus, such as containment strategies, personal protective measures, economic support, and travel-related measures (WHO, 2020; Li et al., 2021). Evidence indicated that in a situation where non-pharmaceutical interventions are the major preventive options, public health social measures are paramount for outbreak management during the early phase of the pandemic (Hailemariam et al., 2021). According to WHO, public health social measures (PHSM) include non-pharmaceutical individual and societal interventions to control COVID-19 (Perra, 2021). Individual level interventions have been shown to yield promising results in preventing mental health problems associated with the pandemics (Alat et al., 2023). Social and behavioral prevention activities are considered the best strategies to reduce the healthcare burden, as they help slow transmission of the virus in the general population (Hailemariam et al., 2021). Experiences from Ebola outbreaks in Africa and the four decades of interventions on HIV/AIDS provide credible evidence about the effectiveness of public health interventions where resources for biomedical treatments were limited and interventions relied mainly on social and behavioral change models (Eaton and Kalichman, 2020). These experiences informed the need to create an enabling environment to support behavior change (Raguin and Girard, 2018). Enabling safer behaviors means addressing structures that constrain or enable people's choices. A study by Suar et al. (2023) further showed that effective leadership can succeed in designing and implementing multisector context tailored interventions to reduce economic hardship and discrimination. The COVID-19 pandemic also requires a similar intervention approach driven by a social-ecological framework that acknowledges personal motivations, meaningful involvement of communities, and consideration of cultural and political contexts for building social capital, trust, and community cohesion to foster change (Jang, 2022). Evidence however suggests that the effectiveness of the public health and social measures in controlling COVID-19 depends on the intensity of transmission and must be continuously adjusted to the magnitude of transmission and capacity of the health system in a country with full participation and engagement of the community (WHO, 2020).

Lessons from the earlier pandemics also recommend the importance of preparedness measures essential to design, characterize, and evaluate interventions that can shape behavior (Calnan et al., 2018). A good practice documented in three West African countries (Guinea, Liberia and Sierra Leone) reported that in these countries, most of the selected readiness measures were instituted before confirmation of the first COVID-19 case, and response measures were initiated rapidly after the outbreak confirmation (Impouma et al., 2021). This suggests that the rapid readiness and response measures instituted by the three countries can be attributed to the lessons learned from past pandemics.

In response to the COVID-19 outbreak, the Ethiopian Government has taken prompt action during the initial phase of the pandemic, emphasizing containment measures and implementing a wide range of structural interventions to change the social, political and social environment to promote health behaviors. The government attempted to put in place robust surveillance systems, and rigorous isolation and quarantine operations. Additionally, steps such as the temporary closure of schools, limitations on public transportation, prohibitions on large gatherings, and the suspension of sporting and religious events have been taken to mitigate the spread of the virus (Baye, 2020). A state of emergency has been put in effect urging people to stay and work from home. The Ethiopian Ministry of Health and Public Health Institute also rolled out a national COVID-19 prevention and treatment guideline based on a recommendation by WHO. The guideline aims to contain the pandemic by guiding policy makers and health professionals at various levels (FMoH, 2020).

The capital of Ethiopia, Addis Ababa was the epicenter of the pandemic experiencing a sharp increase in the number of cases and death rate (Bizuneh et al., 2022). Although the administration exerted its effort to control the spread of the disease, available evidence showed that public adherence was a daunting challenge to effectively adopt recommended measures. A study conducted to assess public knowledge, attitude, and practice (KAP) during the first year of the pandemic in Addis Ababa found a moderate positive correlation between knowledge and attitude, whereas the correlations between knowledge and practice and attitude and practice were weak (Desalegn et al., 2021). A recent study on vaccine acceptance also showed that a considerable proportion of the people in Addis Ababa had concerns on COVID-19 vaccines and are unwilling to accept them (Dereje et al., 2022). This was due to misconceptions, negative attitudes, and use of social media as their primary source of information. Another study in selected towns including Addis Ababa reported that a considerable number of informants believed they were not at risk of contracting the disease (Harris et al., 2020). According to the qualitative findings of the same study, the perceived low prevalence of COVID-19 and the low perceived susceptibility to the disease seem to have contributed to a decline in the practice of preventive measures (Harris et al., 2020). Evidence also suggests intervention efforts in the country in general and in Addis Ababa in particular, faced myriads of challenges mainly related to public attitude and perception of risk, lifestyles, poor health system, limited resources and insufficient protective supplies (Okonji et al., 2021). A recent study showed that the weak testing infrastructure and statistical capacities in the country may mean that the full extent of the overall COVID-19 impact has been underestimated (Obande et al., 2021; Okonji et al., 2021).

Current evidence shows that the pandemic and its impacts have declined over time and WHO has declared that COVID is no longer an international public health emergency concern (Laine and Moyer, 2023). However, the experience has left the world a wake-up call on preparedness to tackle similar outbreaks in the future and raised both international and national interest to draw lessons from interventions. This study aims to investigate the effectiveness of structural interventions during the earlier period of the pandemic in promoting adoption of preventive actions, challenges encountered during implementation and draw lessons for future pandemic responses in low- and middle-income settings.

Materials and methods

Study design and setting

A cross-sectional qualitative study was employed, using key informant interviews conducted from September 05 through October 10, 2021. The study was conducted in Addis Ababa. Being the largest city in Ethiopia, Addis Ababa had a population of 4.8 million in 2020 (World Population Review, 2020). Addis Ababa was the most affected city compared to other cities in the country, and as such, was one of the epicenters of COVID-19 during the study period (Bizuneh et al., 2022).

Participants

Study participants include various stakeholders from the government and private sectors engaged in social interventions to prevent COVID-19 in Addis Ababa. A purposive sampling technique was employed to recruit respondents. The inclusion criteria were institutions implementing public health social interventions in Addis Ababa and willingness to participate in the study. The researchers identified categories of institutional sectors such as government sector offices, NGOs and civic societies, law enforcement bodies, media authorities, religious institutions, and policymakers in the Addis Ababa Administration. We excluded two key informants who were not willing to take part in the intervention and who just joined the selected institution as they may have little information about implemented intervention. From each category, participants were selected with convenience sampling considering gender composition, stakeholder representation, accessibility, and willingness of the participants. Data collection progressed until saturation was reached as demonstrated by redundancy of information. Accordingly, 21 key informants participated in the study.

Instruments

Guided by the social-ecological model and the literature, we developed an interview checklist. The interview checklist contained five with a total of 20 topical guides which explored the opinion of the key informants. These include: the extant social and structural interventions to address COVID-19, opinion about the effectiveness and feasibility of these interventions, major barriers influencing the interventions, and lessons for future recommendations. The set of issues in the checklist was revised in the course of the interview sessions to accommodate emerging issues.

Data collection

Interviews were conducted by three trained and experienced male acadamics who had master's and a PhD degree in social sciences. We submitted a letter of introduction to each organization. The organizations referred to their staff who were in charge of overseeing programs and interventions against COVID-19. We approached the staff and purposefully selected them considering our inclusion and exclusion criteria. Most of the interviews were conducted in two steps. In the first step, introductory contact was made with the potential informants to introduce them to the study, obtain verbal and written consent, and make appointments for interview dates. In the second, the actual interviews were conducted either face-to-face or virtually (telephone or zoom interviews). All interviews were conducted in the Amharic language. Field notes were taken for all interviews, while audio records were captured from some informants who consented to be recorded. After the data collection, a debriefing session was conducted with data collectors to discuss the key issues that emerged in the interviews, and challenges encountered. The interviews were conducted privately in the offices of the key informants. The average duration of the interview was 48 min, ranging from 40 to 56 min.

Data analysis

Before data analysis, all the audio-recorded interviews were transcribed verbatim by the interviewers and then translated into English. The translations and the transcripts were checked by the PI of the study for quality and accuracy. A sample of interviews were also checked by professionals for validity and consistency of the transcriptions. MAXQDA 2020 software was used for data analysis. We then performed structural coding. Structural Coding applies a content-based or conceptual phrase representing a topic of inquiry to a segment of data that relates to a specific research question used to frame the interview (Saldaña, 2009). Research team members agreed on the coding and themes. To ensure reliability, three coders were involved to organize the data based on themes from the interview guides and themes derived from the data. The coders resolved overlapping themes and inconsistencies through regular meetings and incorporated additional themes identified through their discussion. After the completion of each interview, we summarized the main points and read them out to our interviewees for confirmation. Most respondents confirmed the data while some of the respondents provided additional information about their personal experiences. We used verbatim quotations as evidence to substantiate our themes and arguments. We provided detailed accounts about the contexts in which the interventions and the programs against COVID-19 were implemented.

Ethical considerations

Addis Ababa University granted permission to conduct research. The study had minimal physical and psychological impact on participants. Participation in the study was voluntary. Confidentiality was maintained during the data collection, analysis and report. Personal data are not mentioned in this report. Written informed consent was obtained from all participants.

Results

Most informants claimed the target of their interventions was to achieve optimal preventive measures among the populace in Addis Ababa. As one informant from the National COVID-19 Taskforce noted, "our primary objective was to attain the COVID-19 prevention measures as outlined in the WHO and Ethiopian Public Health Institute (EPHI) guidelines." The optimal preventive measures most stakeholders envisioned include improving face mask use, hand washing, and physical distancing. Some organizations also included self-isolation, adherence to testing, vaccine and treatment as primary expected outcomes of their behavioral interventions. The study identified an arsenal of interventions that were implemented by various stakeholders in the city to stimulate and enforce the adoption of these preventive measures, broadly categorized into structural interventions and risk communication.

Structural interventions

Policy/legal frameworks

A State of Emergency was declared on April 8, 2020. Following this national decision, several proclamations and directives were issued that introduced measures such as a nationwide ban on public gatherings, making the wearing of masks compulsory outdoors, and regulating the operation of transportation services, hotels, and restaurants under reduced capacity, etc. According to participants, these measures were widely practiced in Addis Ababa during the initial phase of the pandemic. Most key informants also share the idea that these policy and legal decisions have significantly contributed to the slowing down of the spread of the coronavirus. A notable measure taken by the Addis Ababa city administration was the formation of a COVID-19 task force spearheaded by the city council and comprising various sectors. The task force was the central command responsible for developing a city-wide COVID mitigation plan and guiding and monitoring its implementation. Similar interim structures were formed at lower levels to facilitate intersectoral collaborations. As a key informant noted in this regard, "*the regional COVID-19 intervention policy has promoted stakeholders' collaboration established across all sectors during the outbreak of the pandemic*."

Mainstreaming COVID interventions

The institutional service delivery system is another locus of structural interventions that received a momentum in COVID-19 prevention. At the institutional level, most organizations have undertaken a covid adaptation strategy and planned to engage in COVID-19 prevention interventions by setting up interim structures and allocating resources to deal with the pandemic. Internal work guidelines were developed tailoring the national COVID-19 prevention guideline such as work from home where possible, arrangements for a shift work system in offices and schools, application of covid preventive measures in service delivery settings, etc. An informant from the NGO sector noted, "*Our COVID-19 adaptation strategy enabled all programs to mainstream COVID-19 prevention in their programmatic operations*." Informants also noted that many organizations made funding arrangements or were soliciting funds to supplement the prevention activities. A key informant from an NGO stated, "*the senior management requested our donors to shift some of the budget from the WASH project to COVID-19 prevention program*."

Capacity building

Informants highlighted that there were clear capacity gaps in surveillance and testing, contact tracing, risk communication, etc. at the initial period of the pandemic. Accordingly, different measures were taken by the city Administration in line with the national measures to bridge this gap through capacity building training, financial support from stakeholders, facilitating collaborations, and partnership with various actors. The role played by professional associations such as Ethiopian Public Health Associations (EPHA) was noted as being highly instrumental. The following excerpts provide insights into efforts undertaken in capacity building. "*We were able to produce 4,500 well-trained health workers in Addis Ababa and at national level. This contribution created significant backup to the regional and national interventions efforts*." Due to the proactive measures taken by the city administration task force, progress was made in the testing capacity with adequate technical and financial support rendered to this effort. As a key informant from one sub city office mentioned, unlike during the outbreak period, all the health Centers in the city are now well equipped and are able to provide COVID-19 testing services.

Community engagement

Most of the key informants have reiterated the use of community-based structures such as mobilizing community organizations (e.g., self-help associations) influential role models, youth volunteers, community policing structures, etc. for disseminating messages in the community, reaching out vulnerable populations, and delivering support to those affected by the pandemic. "*During the outbreak of the pandemic community-based organizations. NGOs and religious leaders mobilized residents to support poor families*." A key informant from Addis Ababa Emergency Operation Center (EOC) describing the role of community participation in promoting preventive actions reported the following:

> The risk communication team in our office is responsible for mobilizing the community on prevention activities. A family health team also works with the community structures moving door to door with youth volunteers to sensitize the community about COVID-19 and its preventive measures. They also report affected individuals to the case management team for immediate actions.

However, some informants argued that the community engagement process is not as inclusive as it should be. It appears that in most cases the process sticks to the top-down model of operations. Community groups and leaders have taken the role in implementing the directives but played little role in planning, codesigning contextually feasible programs, and in monitoring and evaluations. Explaining this, a key informant mentioned, "*it should not be limited to providing awareness by community leaders. Efforts should be made to involve the community to plan together in a bottom-up fashion of operation and participate in decision-making process as well*."

Challenges influencing structural interventions

Competing interests

One of the main barriers mentioned by the informants affecting the adoption of preventive behavior among individuals was the influence of other competing interests preoccupying their attention. It was broadly noted that during COVID-19 partial lockdown period, families with low economic status, particularly women, experienced increased financial hardship, food insecurity, domestic violence, and mental health challenges. Due to this, people leading subsistence life were left in greater dilemma to deal with adherence to preventive measures and striving for economic survival. A key informant from the interreligious council reported, "*many poor people were out of their homes searching for opportunities to earn daily income for their survival giving a deaf ear to restrictions of movements, staying at home and social distancing*." Other informants also explained the impacts of competing interests in terms of significant incidents such as national elections, conflicts in the country, etc. that may have forced reallocation of resources to these events during the pandemic. A key informant form Bole Sub city health office noted that most people were overwhelmed with news about the conflict in the northern part of Ethiopia and preoccupied with the then political instability than the COVID-19 messages.

Misconceptions

Most informants pointed out the prevailing misconceptions and negligence among many people in the city as a hindering factor for taking sustained preventive measures. Misconceptions included individuals denying the presence of the Coronavirus or misunderstanding the risk communication messages. One key informant said, "*during the outbreak, people considered COVID-19 as a false fabrication, not a disease.*" Misconceptions were also reinforced by the infodemic during the pandemic where most people were indiscriminately taking up information distributed from noncredible sources such as social media. As one key informant from the media sector reported, "*many people considered the pandemic as a doom's day evil with no solution, and many others also believed vaccines to be microchips maliciously distributed by western countries. This created vaccine hesitancy and skepticism towards other preventive measures.*" Some informants also claimed that such misconceptions and negligent behaviors against COVID-19 stem from the peoples' low perceived risk or low perceived susceptibility to the coronavirus. The following excerpt vividly describes this assertion:

> There are people who do not use facemasks and we also see less adherence to physical distancing measures, especially among young people assuming they had low risk or vulnerability to the virus. During our campaign, we used to receive feedback from some young people telling us that coronavirus would not affect them as they are regularly doing physical exercises and eat well.

Inaccessibility of personal protective equipment

Another impeding factor underlined by informants for the implementation of measures for prevention of COVID 19 was the shortage of personal protective equipment (PPE) such as facemasks and scarcity of hand cleaning solutions such as lack of water, soap, alcohol, and sanitizer. A key informant from one of the City's schools noted "*we often inform students to adhere to hand hygiene practice, however, shortage of water and soap in our school and in students' homes were a critical problem discouraging our students and staff to consistently adopt this behavior*." Shortage of water was a critical barrier reported in most sectors that influenced consistent practice of hand hygiene, especially in communities with limited resources. Emphasizing on this problem, a key informant noted, "*as a good practice, hand hygiene and washing were a regular routine early in the pandemic, and locally made hand washing stations were placed outdoors in several institutions and public places, but soon these became non-functional due to lack of water*." Inability to afford and inconsistent access to these protective materials have created an intermittent adherence to preventive measures. In connection to this issue, a journalist reported, "*in an interview we made regarding the practice of facemask use, I got the impression that many people are in favor of using masks but are not doing so, claiming that it is very expensive*."

Capacity constraints

Key informants also identified various capacity limitations affecting their efforts to promote prevention activities. The main challenges reported in this regard were shortage of financial resources and the lack of trained and skilled human resources. Health professionals and informants from academic institutions highlighted the shortage of trained health communication professionals as the main challenge in health promotion activities at the national and city level. They suggested the need to provide more attention by the higher education sectors and public health institutions to produce skilled human resources in this aspect. Explaining this point, a key informant from a professional association reported, "*Social and behavioral change communication (SBCC) is the best tool for public health emergencies…higher institutions should expand such disciplines or academic fields to produce more workforce in this profession*." Those who reported financial resource limitations stated that the challenge led them to carry out irregular intervention and forced them to function under capacity. "*Our financial capacity did not allow us to work on prevention and awareness creation activities as much as we would have liked*." (Key informant from Addis Ababa Bureau of Women and Social Affairs).

Limited law enforcement

Despite essential legal frameworks being set to augment COVID-19 prevention endeavors, inconsistent law enforcement practices observed in the city during the pandemic were reported as one barrier to COVID-19 intervention. Most informants acknowledged better law enforcement activity was employed in the transport sector than others. "*The police were cracking down on controlling facemask use of passengers and carrying capacity of transport vehicles as per limits, but little effort was made on other service sectors*." Others also reported their concerns over the reluctance of some law enforcement officers themselves who did not take protective measures while on duty. One informant said, "*If law enforcement officers do not abide by the law, their legal measures would create a double standard; leading others to follow suit*."

Lack of motivation for change

Adoption of preventive actions was also challenged by the apathetic response of the public toward COVID-19 prevention measures due to longstanding and strong cultural and religious norms. There were instances where some people were influenced by their strong social norms and religious stands. As one of the key informants pointed out "*many people were disregarding public health measures; seeking solutions to come only from their faith*." Another informant from the NGOs sectors also mentioned, "*the long-standing culture of practicing social events, compromised the public acceptance of preventive measures against the pandemic*." This was reported as one of the hindering factors specially for social distancing and facemask use and vaccine acceptance.

Risk communication interventions

Mass communication was the most widely employed strategy reported by informants in delivering risk communication messages to the residents of Addis Ababa. As a key informant from the NGOs sector noted, "*we used community-based campaigns, religious institutions, TV and radio programs, and reached more than 3 million people*." Another informant from the government trade sector pointed out, "*we passed COVID-19 messages across to the business community and the public through our telegram channel and Facebook pages*." Similarly, a key informant from the transport sector mentioned, "*… we conducted rounds of big public campaigns accompanied by marching bands, city buses, traffic police vehicles around public squares and distributed fliers informing facemask use in public transports*."

Another set of reported interventions were group-based risk communication strategies which were delivered to smaller groups of target populations in the community or institutional settings. Informants mainly from the health sector, NGOs, and community-based organizations highlighted a range of group interventions. These include community mobilizations, community conversations, trainers of training for a group of volunteers who would transfer knowledge to community members, workshops, and neighborhood group discussions on COVID-19 prevention measures. Explaining these interventions, a key informant from a city's health office reported, "*in collaboration with NGOs we trained youth volunteers to disseminate information about risk factors and preventive messages in marketplaces, slum neighborhoods, and taxi stations, which made an enormous contribution to controlling the spread of the virus*." Some key informants also pointed out social networks as one of their communication strategies employed to reach groups and individuals in the community. Through this approach, they were able to disseminate messages on preventive actions to a group of people in social circles. An informant from the NGO sectors noted, "*we have employed a community-based risk communication strategy through the network groups where trained members provided information about face covering, handwashing, and physical distancing to individuals in their social circle*."

Various institutions also widely used local *iddirs* (self-help voluntary association that serves as economic and social insurance at times of death and other crises) and religious leaders to reach out to community groups and individuals with COVID messages. As one of the NGO leaders mentioned, "*we set up community-based information dissemination centers in each sub city. We worked with the association of iddirs and religious leaders to disseminate messages about the pandemic. This was effective because we were able to reach families with information on prevention measures at an early stage of the pandemic*." Another prominent example of the individual and group-based risk communication approach applied was the rolling out of a family health team (each team comprising 5–8 people drawn from the health, education, and social sectors) by the Addis Ababa health bureau. This strategy was extended to all-sub cities and woreda-level structures that helped to successfully perform door-to-door COVID-19 surveillance, referral, and sensitization works, especially during the first wave of the pandemic.

Risk communication messages

Most key informants hold the impression that risk communication messages disseminated were informative and met the EPHI guideline. However, when it comes to the *appropriateness* of the risk communication messages, informants reflected mixed findings. Some informants claimed a contextualized application of the preventive messages was used to make them suitable to their audiences and constituencies. For instance, a key informant from an NGO reported, "*developing preventive messages in* various *languages targeting children and their families via a TV spot, TV programs and through the religious institutions*." Others also noted the effectiveness of risk communications claiming that the wider public misconceptions and bewilderments surfaced at the initial wave of the pandemic gradually dwindled due to extensive and diversified behavioral intervention messages communicated at all levels. Describing this point, a unit leader from Addis Ababa Emergency Operation Center (EOC), explained, "*initially messages were focusing mainly on the proper use of face ask, hand hygiene, and physical distancing. Alternative messages such as open ventilation and taking vaccinations were introduced to the public at the later stage to consolidate the prevention.*"

Some informants suggested the risk communication messages should consider the unintended positive benefits of the pandemic as motivators to reinforce positive behavior change (improved facemask use, hand hygiene, and less physical contact) to prevent from other infectious or contagious diseases. Informants from the health sector claimed that communicable diseases and respiratory infections have substantially declined since the outbreak of the pandemic due to behavioral and structural intervention such as facemask and hand sanitation becoming a new normal. The key lesson to draw from this experience is that effective communication messages should involve content to strengthen people's perception about the potential benefits of protective measures.

However, many informants argued that some communication messages lacked clarity and were disseminated without paying sound attention to the target audience and the context they represent. As one informant from Ethiopian Public Health Professionals Association suggested, "*messages were mostly developed with a cut and paste approach without being contextualized to the objective realities on the ground. Messages should be evaluated with an interdisciplinary team of experts paying attention to the context.*" Describing this view, another key informant also highlighted, "*… for example, some short messages such as 'When you are sick stay home' was highly confusing and not clear specially for people with low literacy unless supported with further clarifications by skilled health professionals.*" An expert at the Addis Ababa EOC noting the difference between the concept of physical and social distancing reported, "*this should be clarified properly to the audience. These two terms have different meanings, but people were using them interchangeably. It does not mean avoiding socializing with people but keeping physical distance.*" There was also inconsistency in using some messages by various organizations such as in informing and enforcing physical distancing. On this point, a key informant from Ethiopian Inter-religious council explains "*I saw posted messages in many places in the city to inform the audience to maintain at least 2 meters physical distance while the EPHI's guide required one meter. These messages should be carefully evaluated and presented to the audience.*"

Participants also reported gaps in the message development process. For instance, an official from the Addis Ababa City Health Bureau highlighted, "*the message development did not undergo a rigorous assessment of the context of the community or the target audience. This was partly due to emergency response required during the outbreak of the pandemic and limited resources or capacity.*" The other main challenge reported regarding the appropriateness of message was the lack of pretesting. Explaining this point, an expert from the Ethiopian Orthodox Church noted "our office employed a communication expert on a contract base for designing messages and messages were designed considering various target groups, but we did not conduct pretesting the drafts before distributing them to the public."

Discussion

The present study illuminated several social interventions in Addis Ababa, Ethiopia that could contribute to adopting optimal preventive measures against public health emergencies like COVID-19. The coronavirus pandemic is not a concern of the health sector only. Hence, a key takeaway of our qualitative work is that the diverse impacts of the pandemic on social, economic, and psychological life of the people in Addis Ababa required multipronged interventions to address the challenges holistically. The complex nature of the pandemic and its variability also demand employing a combination of preventive measures in tandem to achieve optimal results in preventive practices. Indeed, this will be made possible by revitalizing and strengthening intersectoral collaborations among stakeholders which is instrumental to improve preventive behaviors, and ultimately to halt transmission of COVID-19 and evolving new variants. In our findings, heightened collaborative effects and a swift multisectoral engagement plan designed by the Addis Ababa City Administration and their concerted actions demonstrated at the initial phase of the pandemic have meaningfully contributed to slowing down the pandemic. This proactive synergy has left a lauder lesson informing all actors to remain steadfast on sustained collaborations to overcome the multifaceted challenges during such outbreaks. This finding is consistent with findings from countries hit by past disease outbreaks, suggesting that greater decreases in incidence and mortality of COVID-19 were shown when authorities enforced collaborative interventions at the early stages of the pandemic (Kraemer et al., 2020; Iezadi et al., 2021; Piovani et al., 2021).

Our findings highlighted the essential practices of community-based interventions as fundamental learning points in response to COVID-19. Participation of the community was significant in supporting high-risk/vulnerable people to cope with the economic and social challenges caused by the pandemic. Involving survivors and vulnerable groups in the prevention process is also instrumental. The active role played by religious institutions, youth volunteers associations, professional associations, and community policing structures, in disseminating COVID-19 messages to their constituencies, assisting in contact tracing and mobilizations of resources was a prominent example of this endeavor. Good practices seen under these community-based initiatives inform the need to enhance the capacity of community-based organizations and empower local institutions as part of the preparedness plan of the regional administration. The fundamental benefit of community engagement in the wake of the pandemic has been documented in many research findings (Anoko et al., 2020; Smith and Judd, 2020). Despite these initiatives, our finding suggested the need to make community engagement more meaningful in the sense that participation should be scaled up from informing or consulting to meaningfully involving them to be able to jointly design and implement and monitor interventions. Looking along the spectrum of participation, we found community's initiative to own interventions and to facilitate public adherence to preventive behavior to be essential. Experience gained from the Ebola response also asserts that implementing community-led action to control COVID-19 are likely to be successful (Smith and Judd, 2020).

Findings pointed to the need for relevant and appropriate messages. One of the key limitations in the message mapping process during the initial phase of the pandemic was the fact that messages were not informed by a community assessment and little effort was made to identify context-specific concerns of various stakeholders and the needs of diverse vulnerable populations. Communication messages should be tailored to the context and targeted to the appropriate groups. This should be made possible through context assessments and participation of the community. Behavior change is more likely if the target population is given the platform to actively participate in the intervention process. This lesson goes in line with the experience of risk communication in times of disasters that suggests information should be adapted to the literacy needs of the people it intends to reach, with special attention for those who are the most vulnerable in pandemics (Baral et al., 2013; Corbin et al., 2021).

Our findings also provided implications for message framing in risk communication programs. Risk communication interventions discussed by the participants indicated that messages disseminated to the public need an updated review. Periodic assessment of the effectiveness of the COVID-19 messages is crucial to take an up-to-date response that fits to the realities on the ground. For instance, people's reaction and response to COVID-19 during the first phase of the pandemic was full of fear, panic, stigma, and confusion, but the perceptions of threat changed over time. Hence, the tone of the message and its contents should change along with the evolving realities of the pandemic. Warning messages during the initial periods of the pandemic might have increased the adoption of preventive practices. However, similar messages may not work later during the pandemic as the fear among the residents has gradually subsided. This is in line with the social-ecological model that suggests the stage of the epidemic will determine the risk of disease acquisition for the individual (Baral et al., 2013). Therefore, risk behavior and the adoption of preventive action should be interpreted within the context of the stage of the epidemic.

There were also unintended outcomes of interventions. For example, the unintended positive impacts produced from social interventions (such as face covering, physical distancing and hand hygiene) in reducing other communicable and contagious diseases would motivate the public to positively receive messages on preventive practices. This is in line with the principle of various behavioral change theories such as Health Belief Model (HBM) which holds that, when perceptions of benefits are substantially greater than costs, people are more likely to intend to search for health information and enact health-protective behaviors (Karimy et al., 2021). Similarly, some studies on facemask use also identified that perceived benefits of mask use did have significant effects on mask-wearing compliance as well (Tadesse et al., 2020; Yasa et al., 2021). Hence, this finding points to the need for including all potential benefits of protective measures in risk communication approaches for COVID-19, to maximize behavior change outcomes.

Our findings acknowledged the importance of water, sanitation, and hygiene (WASH) in the response to COVID-19. During the pandemic, various initiatives that relate to the intensification of behavior change and awareness-raising campaigns for the promotion of handwashing measures were widespread in the city and have been widely adopted by the residents. Installation and operation of hand washing stations in public spaces was a common phenomenon during the pandemic. However, the extant huge disparities in access to WASH facilities posed a serious challenge. Therefore, a prominent lesson one can draw from our findings is the need to build resilience against future outbreaks through the integration and expansion of WASH intervention programs and promoting behavioral changes in environmental sanitation and personal hygiene. Properly managed WASH services are needed to support at-risk populations to build resilience against future pandemics. Specially, improving access to water supply and sanitation in slums is an urgent issue for building a resilient city not only to address COVID-19 but also for other future infectious diseases.

Our study provided better insights drawn from multi sectoral responses against COVID-19 in low- and middle-income settings. Data were collected from a wide range of key informants that represent diverse perspectives. Despite the richness of qualitative data, the study also has some limitations. As our findings are based on qualitative data only, further investigation may be needed to validate the findings with quantitative data to ensure generalization into other settings. Moreover, while our participants were assured of confidentiality and their responses appeared to be very candid, we cannot rule out the possibility of socially desirable responses. Gathering information only from key informants through in-depth interviews might affect the transferability of the result.

Conclusion

What has been learnt effectively from the current COVID social interventions shall have broad relevance for managing future public health emergencies. A louder message echoed from the past 3 years trajectory of the pandemic is the need for setting a robust public health emergency preparedness strategy that effectively challenges future emergencies of similar kind. The key lessons from this study are manifold. Behavioral change interventions should be context specific and sensitive to the dynamism of the evolving COVID-19 trajectory. The current trend of risk perception and adaptation of the public to live with the pandemic could inform the need to modify risk communication strategies focusing more on the potential benefits of preventive actions. Consistent and sustainable coordinated efforts among stakeholders are necessary to contain COVID-19 and future pandemics through context-specific prevention strategies. Community based responses are vital to effectively control the social transmission pathways, which may be particularly important to reach marginalized populations. Hence, extensively employing existing community engagement structures is paramount to maximize adoption of preventive actions against pandamics. Since dynamics of pandemics can change, interventions targeted to adopt preventive actions need to follow dynamic trends.

Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation.

Ethics statement

The studies involving humans were approved by Addis Ababa University, Department of Sociology. The studies were conducted in accordance with the local legislation and institutional requirements. The participants provided their written informed consent to participate in this study. Written informed consent was obtained from the individual(s) for the publication of any potentially identifiable images or data included in this article.

Author contributions

KE: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Software, Supervision, Writing – original draft, Writing – review & editing. EA: Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Software, Validation, Writing – original draft, Writing – review & editing. SA: Validation, Writing – review & editing. DA: Data curation, Formal analysis, Investigation, Supervision, Writing – original draft. GT: Funding acquisition, Validation, Writing – review & editing.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

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References

Alat, P., Das, S. S., Arora, A., and Jha, A. K. (2023). Mental health during COVID-19 lockdown in India: role of psychological capital and internal locus of control. *Curr. Psychol.* 42, 1923–1935. doi: 10.1007/s12144-021-01516-x

Anoko, J. N., Barry, B. R., Boiro, H., Diallo, B., Diallo, A. B., Belizaire, M. R., et al. (2020). Community engagement for successful COVID-19 pandemic response: 10 lessons from Ebola outbreak responses in Africa. *BMJ Glob. Health* 4:e003121. doi: 10.1136/bmjgh-2020-003121

Arora, A., Jha, A. K., Alat, P., and Das, S. S. (2020). Understanding coronaphobia. *Asian J. Psychiatr.* 54:102384. doi: 10.1016/j.ajp.2020.102384

Baral, S., Logie, C. H., Grosso, A., Wirtz, A. L., and Beyrer, C. (2013). Modified social ecological model: a tool to guide the assessment of the risks and risk contexts of HIV epidemics. *BMC Public Health* 13:482. doi: 10.1186/1471-2458-13-

Baye, K. (2020). *COVID-19 prevention measures in Ethiopia: current realities and prospects*. ESSP Working Paper 141. Washington, DC: International Food Policy Research Institute (IFPRI); Federal Democratic Republic of Ethiopia Policy Studies Institute.

Bizuneh, H., Mohammed, S., and Yesuf, A. (2022). COVID-19 precautionary practices and associated factors among clients visiting a tertiary hospital, Addis Ababa, Ethiopia. *PLoS One* 17:e0267000. doi: 10.1371/journal.pone.0267000

Calnan, M., Gadsby, E. W., Kondé, M. K., Diallo, A., and Rossman, J. S. (2018). The response to and impact of the Ebola epidemic: towards an agenda for interdisciplinary research. *Int. J. Health Policy Manag.* 7, 402–411. doi: 10.15171/ijhpm.2017.104

Corbin, J. H., Oyene, U. E., Manoncourt, E., Onya, H., Kwamboka, M., Amuyunzu-Nyamongo, M., et al. (2021). A health promotion approach to emergency management: effective community engagement strategies from five cases. *Health Promot. Int.* 36, i24–i38. doi: 10.1093/heapro/daab152

Dereje, N., Tesfaye, A., Tamene, B., Alemeshet, D., Abe, H., Tesfa, N., et al. (2022). COVID-19 vaccine hesitancy in Addis Ababa, Ethiopia: a mixed-method study. *BMJ Open* 12:e052432. doi: 10.1136/bmjopen-2021-052432

Desalegn, Z., Deyessa, N., Teka, B., Shiferaw, W., Hailemariam, D., Addissie, A., et al. (2021). COVID-19 and the public response: knowledge, attitude and practice of the public in mitigating the pandemic in Addis Ababa, Ethiopia. *PLoS One* 16:e0244780. doi: 10.1371/journal.pone.0244780

Eaton, L. A., and Kalichman, S. C. (2020). Social and behavioral health responses to COVID-19: lessons learned from four decades of an HIV pandemic. *J. Behav. Med.* 43, 341–345. doi: 10.1007/s10865-020-00157-y

Ethiopia Public Health Institute. (2023). *Coronavirus total cases and deaths*. Available at:https://www.worldometers.info/coronavirus/country/ethiopia/.

FMoH (2020). *National compheresnisive COVID-19 management handbook*. Ministry of Health, Ethiopia.

Güner, R., Hasanoğlu, I., and Aktaş, F. (2020). COVID-19: prevention and control measures in community. *Turk. J. Med. Sci.* 50, 571–577. doi: 10.3906/sag-2004-146

Hailemariam, D., Kumie, A., Wakuma, S., Tefera, Y., Abegaz, T., Tefera, W., et al. (2021). Trends in non-pharmaceutical intervention (NPI) related community practice for the prevention of COVID-19 in Addis Ababa, Ethiopia. *PLoS One* 16:e0259229. doi: 10.1371/journal.pone.0259229

Harris, D., Teklu, A., Medhin, G., Mitiku, I., Tadesse, B., and Demissie, M. (2020). *The effect of COVID-19 and government response measures on poor and vulnerable groups in urban areas in Ethiopia*. London: Oxford Policy Management.

Iezadi, S., Gholipour, K., Azami-Aghdash, S., Ghiasi, A., Rezapour, A., Pourasghari, H., et al. (2021). Effectiveness of non-pharmaceutical public health interventions against COVID-19: a systematic review and meta-analysis. *PLoS One* 16:e0260371. doi: 10.1371/journal.pone.026037

Impouma, B., Williams, G. S., Moussana, F., Mboussou, F., Farham, B., Wolfe, C. M., et al. (2021). The first 8 months of COVID-19 pandemic in three west African countries: leveraging lessons learned from responses to the 2014-2016 Ebola virus disease outbreak. *Epidemiol. Infect.* 149:e258. doi: 10.1017/S0950268821002053

Jang, S. H. (2022). Social-ecological factors related to preventive behaviors during the COVID-19 pandemic in South Korea. *PLoS One* 17:e0266264. doi: 10.1371/journal.pone.0266264

Karimy, M., Bastami, F., Sharifat, R., Heydarabadi, A. B., Hatamzadeh, N., Pakpour, A. H., et al. (2021). Factors related to preventive COVID-19 behaviors using health belief model among general population: a cross-sectional study in Iran. *BMC Public Health* 21:1934. doi: 10.1186/s12889-021-11983-3

Kraemer, M. U. G., Yang, C. H., Gutierrez, B., Wu, C. H., Klein, B., Pigott, D. M., et al. (2020). The effect of human mobility and control measures on the COVID-19 epidemic in China. *Science* 368, 493–497. doi: 10.1126/science.abb4218

Laine, C., and Moyer, D. V. (2023). COVID-19 is no longer a public health emergency: implications for patients and clinicians. *Ann. Intern. Med.* 176, 983–984. doi: 10.7326/M23-1338

Li, Y., Ge, L., Zhou, Y., Cao, X., and Zheng, J. (2021). Toward the impact of non-pharmaceutical interventions and vaccination on the COVID-19 pandemic with time-dependent SEIR model. *Front. Artif. Intell.* 4:648579. doi: 10.3389/frai.2021.648579

Mishra, N. P., Das, S. S., Yadav, S., Khan, W., Afzal, M., Alarifi, A., et al. (2020). Global impacts of pre- and post-COVID-19 pandemic: focus on socio-economic consequences. *Sens. Int.* 1:100042. doi: 10.1016/j.sintl.2020.100042

Obande, G. A., Bagudo, A. I., Mohamad, S., Deris, Z. Z., Harun, A., Yean, C. Y., et al. (2021). Current state of COVID-19 pandemic in Africa: lessons for today and the future. *Int. J. Environ. Res. Public Health* 18:9968. doi: 10.3390/ijerph18199968

Okonji, E. F., Okonji, O. C., Mukumbang, F. C., and Van Wyk, B. (2021). Understanding varying COVID-19 mortality rates reported in Africa compared to Europe, Americas and Asia. *Trop. Med. Int. Health* 26, 716–719. doi: 10.1111/tmi.13575

Perra, N. (2021). Non-Pharmaceutical Interventions during the COVID-19 Pandemic: A Review. *Physics Reports* 913, 1–52. doi: 10.1016/j.physrep.2021.02.001

Pierce, M., Hope, H., Ford, T., Hatch, S., Hotopf, M., John, A., et al. (2020). Mental health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *Lancet Psychiatry* 7, 883–892. doi: 10.1016/S2215-0366(20)30308-4

Piovani, D., Christodoulou, M. N., Hadjidemetriou, A., Pantavou, K., Zaza, P., Bagos, P. G., et al. (2021). Effect of early application of social distancing interventions on COVID-19 mortality over the first pandemic wave: an analysis of longitudinal data from 37 countries. *J. Infect.* 82, 133–142. doi: 10.1016/j.jinf.2020.11.033

Raguin, G., and Girard, P. M. (2018). Toward a global health approach: lessons from the HIV and Ebola epidemics. *Glob. Health* 14:114. doi: 10.1186/s12992-018-0435-9

Saldaña, J. (2009). *The coding manual for qualitative researchers.* London: Sage.

Smith, J. A., and Judd, J. (2020). COVID-19: vulnerability and the power of privilege in a pandemic. *Health Promot. J. Austr.* 31, 158–160. doi: 10.1002/hpja.333

Suar, D., Jha, A. K., Gochhayat, J., and Samanta, S. R. (2023). Public leadership during the COVID-19 pandemic: can leadership theories explain it? *Glob. Bus. Rev.* doi: 10.1177/09721509221149604

Sudre, C. H., Murray, B., Varsavsky, T., Graham, M. S., Penfold, R. S., Bowyer, R. C., et al. (2021). Attributes and predictors of long COVID. *Nat. Med.* 27, 626–631. doi: 10.1038/s41591-021-01292-y

Tadesse, T., Alemu, T., Amogne, G., Endazenaw, G., and Mamo, E. (2020). Predictors of coronavirus disease 2019 (COVID-19) prevention practices using health belief model among employees in Addis Ababa, Ethiopia, 2020. *Infect. Drug Resist.* 13, 3751–3761. doi: 10.2147/IDR.S275933

WHO (2020). *Mental health and COVID-19: early evidence of the pandemic's impact: scientific brief* World Health Organization WHO/2019-nCoV/Sci_Brief/Mental_health/2022.1.

WHO (2021). *Considerations for implementing and adjusting public health and social measures in the context of COVID-19: interim guidance* World Health Organization Available at:https://iris.who.int/handle/10665/341811.

WHO. (2024). *Coronavirus (COVID-19) dashboard.* Available at:https://covid19.who.int/.

World Population Review. (2020). *Addis Ababa population*. Walnut, CA: World Population Review.

Yasa, N. N. K., Rahmaynati, P. L. D., Telagawathi, N. L. W., Witarsana, G. A. G., and Liestiandre, H. K. (2021). COVID-19 perceptions, subjective norms, and perceived benefits to attitude and behavior of continuous using of medical mask. *Linguist. Cult. Rev.* 5, 1259–1280. doi: 10.21744/lingcure.v5nS2.1805

Ziauddeen, N., Gurdasani, D., O'Hara, M. E., Hastie, C., Roderick, P., Yao, G., et al. (2022). Characteristics and impact of long Covid: findings from an online survey. *PLoS One* 17:e0264331. doi: 10.1371/journal.pone.0264331

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EDITED BY
Andrzej Klimczuk,
Warsaw School of Economics, Poland

REVIEWED BY
Viraj Brahmbhatt,
Union College, United States
Sofia Farizi,
Airlangga University, Indonesia

*CORRESPONDENCE
Aguinaldo José de Araújo
✉ aguinaldo,araujo@ufrn.br

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Alignment and specifics of Brazilian health agencies in relation to the international premises for the implementation of digital health in primary health care: a rhetorical analysis

Aguinaldo José de Araújo[1]*, Ísis de Siqueira Silva[1], Renan Cabral de Figueirêdo[2], Rayssa Horácio Lopes[1], Cícera Renata Diniz Vieira Silva[3], Osvaldo de Goes Bay Junior[4], Richard T. Lester[5] and Severina Alice da Costa Uchôa[6]

[1]Collective Health, Federal University of Rio Grande do Norte, Natal, Brazil, [2]Family Health, Federal University of Rio Grande do Norte, Natal, Brazil, [3]Technical School of Health of Cajazeiras, Federal University of Campina Grande, Campina Grande, Brazil, [4]Faculty of Health Sciences of Trairi, Federal University of Rio Grande do Norte, Natal, Brazil, [5]Division of Infectious Diseases, Department of Medicine, University of British Columbia, Vancouver, BC, Canada, [6]Public Health Department, Federal University of Rio Grande do Norte, Natal, Brazil

Digital health and sustainable development goals have had strong impacts with the COVID-19 pandemic. In Brazil, the health crisis scenario required changes in social welfare programs and policies, based on recommendations from international agencies, such as the UN and WHO. This study aims to analyze the alignment of the arguments of Brazilian and international organizations for the adoption of digital health in Primary Health Care based on the COVID-19 pandemic. This is a qualitative documentary study of the rhetorical analysis type, based on Perelman and Obrechts-Tyteca's Theory of Argumentation. The search for documents was carried out by two independent researchers, between December 2021 and June 2022, through the websites of the World Health Organization, the Pan American Health Organization, the Brazilian Ministry of Health, and the Federal Councils of Medicine and Brazilian nursing, with the terms "digital health," "telehealth," "telemedicine," "e-health," "telehealth," "telenursing," "telemedicine," and "digital health." Twenty official documents were analyzed and identified in terms of context, authorship, authenticity, reliability, nature, and key concepts. The international and Brazilian arguments emphasize the applicability of Information and Communication Technologies (ICTs) in the health field. In logical arguments, based on the structure of reality, international agencies emphasize the overlap between health needs and the conditions for the applicability of ICTs. In Brazil, however, there was a need to regulate the digital practices of health professionals. In the international discourse, in the structuring of reality, there are illustrations of the relationship between the context of the health crisis caused by COVID-19 and the concrete conditions for the applicability of digital health; while in the Brazilian discourse, the need to strengthen an environment conducive to digital health is explicit. The Brazilian alignment in relation to the international premises is evident. Yet, there is a need, socially and economically sustainable, to strengthen the inclusion of digital health in PHC policy.

KEYWORDS

telemedicine, telehealth, digital health, COVID-19, public health, primary health care

1 Introduction

Digital tools have been transforming health services (Pan American Health Organization (PAHO), 2020a) and contributing to ensure a healthy life and promote well-being, Sustainable Development Goal (SDG) 3 of the 2030 Agenda, proposed by the United Nations (UN) (Novillo-Ortiz et al., 2018). Digital health includes using information and communication technologies (ICTs) to solve health care problems, such as distance and poor access, especially in primary health care (PHC). Digital health was already encouraged by the World Health Organization (WHO) in middle-income countries (e.g., Brazil) and enhanced during the coronavirus disease (COVID-19) pandemic, being used in private practices, clinics, and in the Brazilian unified health system (SUS) (Caetano et al., 2020).

PHC attends to many health demands close to users and territories (World Health Organization, 2019; Rastogi, 2022). It played an important role in health promotion, prevention and education, treatment, rehabilitation, and monitoring during the COVID-19 pandemic. PHC used safe means for professionals and users to mitigate disease spread with conduct that impacted world health (Medina et al., 2018; WHO, 2020a; Silva et al., 2022).

Many countries followed the WHO guidelines on ICTs use in health. A scoping review (Silva et al., 2022) showed that phone and video calls, patient portals, cell phone applications, text messages, e-mail, electronic medical records, and social networks were highly used in health services worldwide during the pandemic. In Brazil, health professionals used mobile devices and applications to conduct appointments, safely maintain care offers, and reduce discontinuity and worsening of users under treatment (Medina et al., 2018; Celuppi et al., 2021).

The ICTs provide remote assistance services for health care users and professionals, administrative management, training, evaluation, and collaborative network research (Pan American Health Organization (PAHO), 2020b). In Brazil, the most used services are teleconsultation or teleinterconsultation, formative second opinion, telediagnosis, and tele-education (Rede APS, 2021a). A survey conducted by the PHC network of the Brazilian Association of Collective Health found that 14.5% of professionals performed teleconsultations, 16% sent prescriptions over the internet, and 42.8% used WhatsApp® for teleconsultations and patient contact. Telehealth centers also conducted several tele-education activities to fight COVID-19 (Rede APS, 2021b).

Mobile digital devices allow answering questions, patient monitoring, therapeutic assistance, interaction with professionals and health services worldwide, work continuity, self-diagnosis support, access to reliable knowledge and information, interpersonal relationships, and encouragement of healthy practices. However, their use presents some challenges that have been highlighted as obstacles to the social and economic sustainability of the use of digital health, such as information overload and management, cybersecurity (i.e., ethical and legal aspects of confidentiality of personal data), and the exclusion of people who are not digitally connected (Ramsetty and Adams, 2020; Nadav et al., 2021).

Implementing digital health in PHC needs normative regulation and adequate operation conditions to improve the adhesion of professionals and users since it is influenced by how regulations and other guiding instruments are exposed. This discussion must consider the speech adaptation, which may directly interfere with the persuasion level and adherence to the arguments (Lima, 2020), and which strategies are used to persuade heterogeneous audiences with disordered reasoning. Perelman and Olbrechts-Tyteca (2005) state that in a scenario of disorder there is a need to use multiple arguments, to adapt the speaker to the audience and order the reasoning with realistic supports that consider values, hierarchies, contexts, essences, and positions based on democratic values.

In Brazil, the public health emergency required changes in digital health regulations. During this process of changes in Brazilian legislation, national and international agencies published documents with evidence-based arguments about the importance of using and implementing digital health to expand access and optimize the provision of health services. The publication of these documents opened a space for movement between health agencies, with consonances and specificities about the challenges for the implementation of digital health care. In this sense, Brazilian and international guidelines and norms encouraged the analysis of arguments about PHC adoption of digital health in Brazil from WHO, the Pan American Health Organization (PAHO), and the Brazilian Ministry of Health (MH), Federal Council of Medicine (CFM), and Federal Council of Nursing (COFEN). Therefore, this study analyzed the arguments for adopting digital health in PHC in Brazil during and after the COVID-19 pandemic.

Thus, the rhetorical analysis of arguments from institutional documents allows the discussion about adopting digital health as a health care tool in PHC, when considering that the way in which the speaker's deliberative speech is adapted, can directly interfere with the degree of persuasion and consequently the adhesion to the theses that are presented for convincing, since the argumentation aims at the transfer of the fundamentals and arguments of the speaker to the audience, to that, in the end, everyone comes to the same conclusion (Lima, 2020). In this context, our question is: *What arguments were used by national and international agencies for the adoption of digital health in PHC in Brazil?*

With this, the objective of this study is to analyze the alignment of arguments from Brazilian organizations to international ones for the adoption of digital health in PHC starting from COVID-19.

2 Methods

This qualitative document analysis used a rhetorical analysis based on the theory of argumentation of Perelman and Olbrechts-Tyteca (2005), which considered that discursive techniques and convincing arguments overlap the spoken language. Moreover, spoken language can develop using pre-selected persuasive elements as a starting point for an argument, that is the articulation of ideas, dialogs, and controversies, these being essential requirements for a pluralistic society. The rhetorical analysis consists of looking for the conditions that allow qualifying the speech about an action or a rule; it means determining what is valid and deserves to be adopted in human relationships. This approval depends on how the arguments are used to motivate the audience to make certain choices over others and, above all, to justify these, so that they become acceptable and approved by others (Lima, 2020).

The rhetorical analysis considered the analysis of techniques and arguments aimed at managers and health professionals (private auditorium) by WHO and PAHO (universal speakers), and MH, CFM, and COFEN (private speakers).

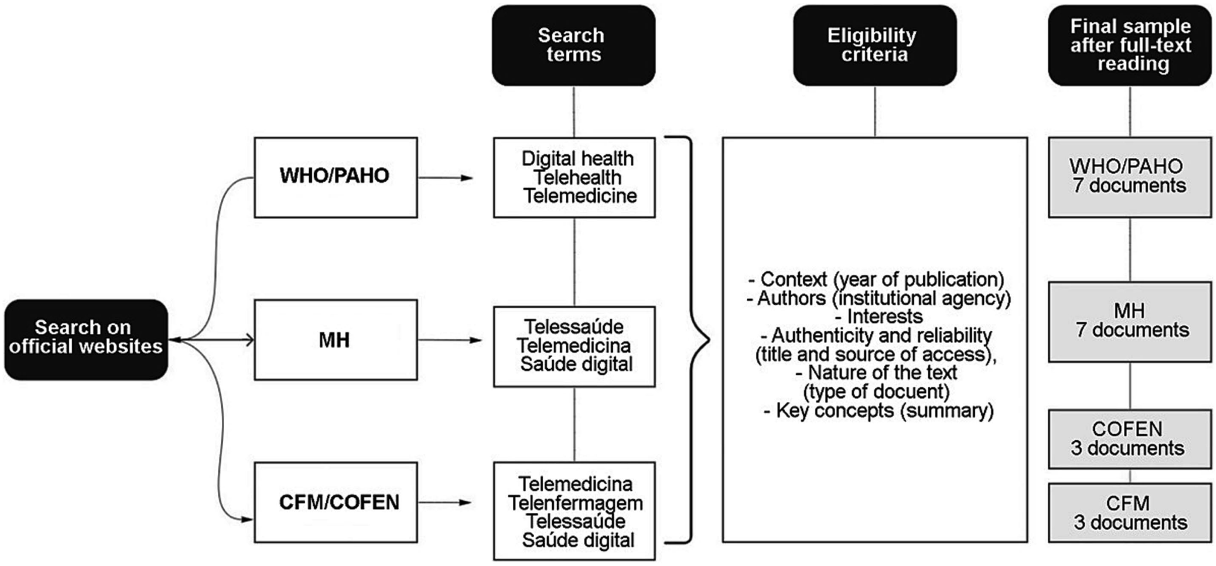

FIGURE 1
Scheme for document search.

The document analysis considered the social context and health crisis of the COVID-19 pandemic to search for official publications from WHO, PAHO, MH, CFM, and COFEN regarding digital health as care, coping, and solving strategy of PHC. PHC teams in Brazil must have at least a physician and a nurse, justifying the inclusion of documents from CFM and COFEN (Brasil, 2017).

The scheme for document search is presented in Figure 1. The documents were searched and selected between December 2021 and June 2022 on the official websites of WHO,[1] PAHO,[2] MH,[3] CFM,[4] and COFEN.[5] The search terms individually used were "digital health," "telehealth," "telemedicine," "e-health," *"telessaúde," "telenfermagem," "telemedicina,"* and *"saúde digital."* Two independent researchers (AJdA and IdSS) scanned the websites twice and found 47 documents. For inclusion in the study considered the following documents for analysis: recommendations, informative pages, guidelines, resolutions, laws, and ordinances published from March 1, 2020, to June 3, 2022. After applying the selection criteria, 27 documents were excluded for not complying with the pre-analysis of the documents recommended by Cellard (2012).

The documents met the premises proposed by Cellard (2012) before document analysis: elements of the problem or theoretical framework (theme), context (year of publication), authors (institutional agency), interests, authenticity and reliability (title and source of access), nature of the text (type of document), and key concepts (summary).

Twenty documents met the eligibility criteria, of which three were from WHO (one informative page and two guidelines), four from PAHO (four informative pages), seven from MH (one law and six ordinances), three from CFM, and three from COFEN. The critical pre-analysis of documents is presented in Chart 1 in Supplementary material.

Data were accessible to the public and directed to the universal auditorium of health systems. Data also composed the second stage of a broader study entitled "Evaluation of the quality of telemedicine in Primary Health Care in the context of COVID-19," which was approved by the research ethics committee of the Hospital Universitário Onofre Lopes of the Federal University of Rio Grande do Norte, Brazil (registry no. 48655521.9.0000.52).

2.1 Contextualization and analysis of the documents

In this sense, WHO and PAHO developed instructional and informative pages (01, PAHO, 02, PAHO, 03, PAHO, 04, PAHO, 05, WHO; 06, WHO) with linking arguments that led to agreements related to the real and preferable context considering the coexistence of the pandemic with health needs. The arguments were based and justified on the structure of reality and contained strategies and guidelines for using ICTs as a digital solution to manage the new challenges in health care during the COVID-19 pandemic. In addition, the WHO launched the "Global strategy on digital health 2020–2025" (07, WHO) to help governments, ministries, and secretaries improve health using the development, adoption, and access to digital solutions. The aim was also to prevent, detect, and respond to epidemics and pandemics using infrastructure and applications that allowed countries to use data for promotion and well-being and achieve health-related sustainable development goals.

In March and April 2020, PAHO released information about teleconsultations during the COVID-19 pandemic, using the information pages "Teleconsultation during a pandemic" and "The potential of frequently used information technologies during the pandemic." The documents encouraged diagnostic or therapeutic

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[1] https://apps.who.int/iris/
[2] https://www.paho.org/pt
[3] https://www.gov.br/saude/pt-br
[4] https://portal.cfm.org.br
[5] http://www.cofen.gov.br/

counseling using digital health, considering it an important strategy for public health emergencies. In addition, PAHO predicted the collapse of health services, defended the use of ICTs for information and interaction, stimulated teleconsultation to virtually help services or situations, and indicated minimum requirements for its use in PHC (01, PAHO, 02, PAHO).

On May 23, 2020, PAHO released an informative page (03, PAHO) arguing that a solid health information system may help the PHC in health promotion, prevention, and rehabilitation during the COVID-19 pandemic. In addition, the focus should be on responding to COVID-19 by integrating national and local systems, digital health, and ICTs to effectively identify, inform, and analyze cases and contacts, promptly search and detect cases, and identify and follow up on the population at risk. A solid health information system would maintain essential services during the COVID-19 pandemic and allow hospital discharge using teleconsultations. Besides, the hospital discharge would rely on follow-up, control, and rehabilitation monitoring, using medical records and electronic prescriptions in high-risk groups for severe COVID-19. Moreover, PAHO indicated that ICTs improve the cost-effectiveness of treatments, enabling the regular and uninterrupted operation of essential services.

On August 11, 2020, PAHO published the document “Digital health: a strategy to maintain health care for people living with non-communicable diseases during COVID-19” (04, PAHO), containing the three types of linking arguments. The document evidenced, with examples, how digital health tools may be applied in PHC for people with non-communicable diseases (e.g., cardiovascular or respiratory diseases, cancer, diabetes, smoking) to encourage the continuity of care during the COVID-19 pandemic. The document also considered the relocation of health professionals to combat COVID-19 and the interruption of the offer of essential services, such as public transportation (hampering the commuting of individuals and health professionals), outpatient clinics, and appointments.

The WHO published two documents (05, WHO, 06, WHO) addressing the importance of digital solutions for proximity and contact tracing. With universal writing and based on the structure of reality, the WHO stated that member States could use digital health to achieve public health goals, protect fundamental rights, and consider ethical principles (e.g., transparency, data minimization, and data storage that preserves privacy, security, accountability, and social engagement). As universal speakers, PAHO and WHO used connection arguments that influenced countries to develop digital health solutions that possibly improved and managed the quality of health care services.

Regarding the adoption of digital health in PHC by Brazilian health agencies, the initiatives were mostly conditioned to the exceptionality of the pandemic moment. The MH published Ordinance No. 467 of March 20, 2020 (08, MH), about the exceptional and temporary use of telemedicine to regulate and operationalize the SUS and supplementary and private health. This ordinance was endorsed with Law No. 13989 of April 15, 2020 (09, MH), which deliberated the use of telemedicine during a public health emergency of international importance. In addition, Ordinance No. 1768/2021 (12, MH) integrated the National Health Information and Informatics Policy (PNIIS) to assist information systems in health, support a digital transformation of the work process, improve governance in the use of information, ICT solutions, and digital health, and maintain transparency, security, and access to health information by the population.

With connection arguments based on the structure of reality, Ordinance No. 467 (08, MH) and Law No. 13989 (09, MH) stated that remote interaction could contemplate pre-clinical care, support assistance, consultation, monitoring, and diagnosis using ICTs. Also, the law determined that telemedicine should follow the usual normative and ethical standards of face-to-face care, including financial ones, since telemedicine was a medical exercise to assist, research, prevent disease and injury, and promote health.

Law No. 13989 (09, MH) encouraged the expansion of digital health along with the CFM, which regulated the emission of digital medical documents and established an integrated system to collect them with Resolutions No. 2299 (16, CFM) and 2,296 (17, CFM). These resolutions guided the medical activity during the validity of Law No. 13989, aiming to improve communication between the CFM and professionals and data security and standardize the emission of digital medical documents.

COFEN standardized telenursing during the pandemic by Resolution No. 634/2020 of March 26, 2020 (15, COFEN). Supported by arguments based on the structure of reality, the decision of the autarchy aimed to regulate population access to nursing consultations and minimize the risks of COVID-19 transmission.

On February 3, 2022, COFEN published Resolution No. 689/2022 (18, COFEN), which regulated electronic prescriptions by the nursing team. In this context, on May 4, 2022, the CFM released Resolution No. 2314/2022 (19, CFM), regulating telemedicine for physicians in Brazil. The resolution resulted from a debate with medical entities and specialists and regulated digital health regardless of the health crisis, replacing CFM Resolution No. 1643/2002. Furthermore, COFEN published Resolution No. 696/2022 (20, COFEN), standardizing the permanent use of telenursing. Via arguments based on the structure of reality (e.g., evidence proving the effectiveness of use and strict ethical, technical, and legal parameters), professional councils, as private speakers, aimed to adapt to the Brazilian scenario and strengthen the implementation of digital health.

On June 2, 2022, the MH published Ordinance No. 1348 (13, MS), regulating the definitive use of digital health in Brazil. Following COFEN and CFM, the MH reinforced the importance of digital health as a complementary strategy in health actions. It also launched a pilot project entitled Basic Digital Health Unit (BDHU) to encourage municipalities to adopt digital health in PHC, considering the national geographic diversity and remote municipalities with poor access to essential services. The pilot project was regulated by its ordinance, and criteria were established for adherence and funding based on PNIIS and the National Policy for Primary Care.

BDHU was established in PHC using Ordinance No. 1355 of June 3, 2022 (14, MH), aiming at remote rural municipalities. The goal was to spread digital health in basic health units to expand access, solvability, and integration of PHC services with Health Care Networks. With this ordinance, the MH showed city managers interest in financing and encouraging digital health implementation in PHC from 2020 to 2028, starting in remote municipalities and expanding to the entire Brazilian territory.

3 Results

The arguments for adopting digital health in PHC in Brazil and the world were identified by the serial number and author or agency, as specified in Chart 1 and shown in Chart 2 as Supplementary material.

Every arguments were divided into three groups according to Perelman and Olbrechts-Tyteca (2005): (1) quasi-logical arguments to guide reasoning based on evidence of information technologies in health; (2) arguments based on the structure of reality, applied to the relationship of coexistence of health needs and ICTs that may be used as digital solutions to improve and expand health care; and (3) the arguments that support the structure of reality, to perform generalizations from links between the health crisis, audiences, and the applicability of digital health, using examples, illustrations, and models of elucidation.

4 Discussion

WHO and PAHO demanded commitment from governmental organizations worldwide to face the international health crisis caused by the COVID-19 pandemic. In a structured PHC, ICT platforms connect components and establish specialized services when needed (Gudi et al., 2021).

In this sense, the arguments used by WHO and PAHO consolidate the need for countries to improve investment policies in technological resources and the adoption or development of digital platforms that enable the longitudinally of care and strengthen the link between users and health services (Gómez-Ramírez et al., 2021). Although there are barriers to the application of these technologies in places with limited resources (Bardosh et al., 2017; McCool et al., 2022), there is evidence that proves, for example, that the use of mobile telephony is significant for approaches to population health, such as support for oral health, stopping smoking cessation, sexual and reproductive health, and therapeutic adherence (Santiago-Torres et al., 2022; Sun et al., 2023).

Despite MH acting as a private speaker at a national level, the councils are responsible for regulating and standardizing the role of each professional. The role of physicians in digital health during the COVID-19 pandemic in Brazil was regulated by a CFM letter sent to MH (Brasil, 2020a). This disagreement resulted from CFM Resolution No. 2228 of February 26, 2019 (Brasil, 2019), which revoked CFM Resolution No. 2227/2018 of February 6, 2019 (Brasil, 2018), indicating telemedicine for medical services. Resolution No. 2228 also reinstated the validity of CFM Resolution No. 1643 of August 26, 2002, which disciplined telemedicine services. However, the COVID-19 pandemic hindered the regulation of the demands of digital medical services (Brasil, 2022a).

The WHO director-general stated on April 11, 2022, that the pandemic was far from over and that COVID-19 had a worldwide effect with an unpredictable behavior of genetic variations (World Health Organization, 2022a). Contrarily, on April 22, 2022, the Minister of Health of Brazil, Marcelo Antônio Cartaxo Queiroga Lopes, declared the end of the COVID-19 public health emergency of national importance. The MH statement extinguished the resolutions about the practice of digital health by physicians and nurses during the COVID-19 pandemic and led to regulations updates by the councils.

CFM and COFEN have followed the advances in digital health in recent years, updates, and recommendations from national and international health agencies (Lopes et al., 2019; World Health Organization, 2019). However, COFEN regulations on digital health could have been formalized earlier, considering that MH and WHO were already encouraging digital health (Barbosa et al., 2016; Sarti and Coelho, 2022), and telenursing was present in the country before the pandemic, focusing on guidelines and health promotion (World Health Organization, 2019).

The regulation of digital health in Brazil was sanctioned by the President of the Republic on December 27, 2022, through Law N° 14,510 (Brasil, 2022b), supported by previous legislation that regulates the civil framework for internet use, data protection, and the exercise of health professionals. However, each municipality has the autonomy to adhere to and develop digital health (Marengo et al., 2022).

The initiatives of the Brazilian government to encourage adherence to digital health in PHC were influenced by the experience of countries that have health systems with universal coverage (Brasil, 2023). Canada used the Canada Health Infoway to successfully develop interoperable electronic records in PHC (Canada Health Infoway, 2022), and the (Australian Digital Health Agency, 2022) used the My Health Record to expand electronic medical records.

The pandemic and the arguments used by WHO and PAHO (universal speakers) pressured the decisions and recommendations of national speakers, revealing consonances and paradoxes. As private national speakers, Brazilian agencies acted cautiously during the pandemic, possibly limiting the decision-making process of managers and professionals (private auditoriums). The uncertainty in the final regulation of digital health perhaps delayed the implementation of systematized strategies (e.g., safer platforms for patient-professional interaction) that required technological investment and financial resources (Garattini et al., 2021).

The digital health adoption by MH followed recommendations of WHO and PAHO, regardless of divergences between WHO and MH arguments about the end of the COVID-19 public health emergency. However, structuring digital PHC in Brazil needs effort and an agreement about the roles of the MH and state and city health departments in implementing, maintaining, qualifying, and continuously evolving digital health (Brasil, 2020b; Gehrke et al., 2023).

The strengthening of a universal system is closely linked to the quality of access to health, regardless of geographical conditions. Digital health has a lot to contribute to strengthening the organization of services and health care actions in the PHC and SUS, considering the large territorial extension and remote communities with poor access to health professionals and services (de Faria, 2020). Besides, digital health has the potential to reduce access inequalities. However, one of the main challenges is to overcome the Brazilian socioeconomic vulnerability, which demonstrates the existence of a digital divide, since 33.9 million people are not connected to the internet and another 86.6 million are unable to connect daily, according to Instituto Locomotiva and PwC consultancy (PWC - Pricewaterhousecoopers Brasil, 2022). Overcoming the challenges linked to socioeconomic inequality requires effective intersectoral public policy efforts, which reduce inequalities and contribute to a sustainable and conducive environment for the promotion of health and well-being.

The document analysis presented the evolution of national legislation on regulating digital health. The pressure caused by the COVID-19 pandemic expanded it. In 2022, digital health was definitively regulated, strengthening the arguments supporting actions to encourage and increase its use and guaranteeing a normative structure in Brazil. Although the country overcame legal fragility, some obstacles to implementing digital health still exist regarding integrating digital strategies with national health systems. Moreover, we highlight the importance of seeking interoperability and standardizing technological tools, clinical guidelines, scientific assessment systems, and research funds to describe and assess pandemic effects and the lack of data sharing with public health authorities for epidemiological surveillance (Ohannessian et al., 2020; World Health Organization, 2020b).

The process of digital transformation of health actions driven by ICTs focuses on the creation mechanisms, strategy, and organizational value structure of a universal health system, creating new opportunities and challenges for remodeling the way it operates and impacting health promotion and people's well-being (Wen, 2011). In this sense, the consolidation of digital health in universal systems can contribute to achieving SDG 3 of the 2030 Agenda for Sustainable Development proposed by the UN. However, it is important to consider that commercial determinants and the digital society are dimensions of the social determinants of health and are closely linked to the sustainability of economic and social systems, and it is necessary to consider the interfaces of implementation, with public policies aligned to combat exclusion and health inequalities (Pan American Health Organization (PAHO)/WHO Brasil, 2018).

Study limitations included the analysis of documents not specific to the use of digital health in PHC, even though they address strategies about it. Also, the need for successive searches for documents and study deadlines may have excluded records posteriorly published that could be important to the rhetorical analysis and understanding of the national expansion of digital health. Therefore, a future analysis update is suggested to verify the arguments justifying the results and limitations of digital health in Brazilian PHC.

5 Conclusion

The arguments of WHO and PAHO influenced digital health implementation in PHC. Although some analyzed documents were not specifically about its use in PHC, addressed strategies were digital solutions for PHC, focusing on promotion, prevention, monitoring, and rehabilitation.

Despite the moderate position of the MH against WHO and PAHO guidelines, the COVID-19 pandemic accelerated the adoption of digital health. After MH declared the end of the public health emergency, professional councils encouraged MH to regulate the definitive use of digital health as a complementary health strategy. However, Brazil still needs to develop concrete actions on digital health as a safe, sustainable and complementary policy in PHC.

This study allowed us to ponder the implementation of digital health in PHC and highlighted the relevance of legislation ensuring ethics of professional practice and contributing to digital health adoption by managers and professionals. It underscores the urgency needed to dynamically adapt health ICTs and the regulatory framework to the current context to drive progress toward SDG 3. In addition, this study revealed dissonances between Brazil and international health agencies regarding the end of the COVID-19 pandemic. New studies must discuss the impacts of the arguments for health program adherence and policies.

Thus, we expect this rhetorical analysis may contribute to the theoretical and critical reflection of the actors responsible for decision-making to undertake actions that favor the promotion of health and the reduction of inequalities during the regulation, implementation, and improvement of devices and digital health systems supported by evidence, and that the methodology used can support the carrying out of other documentary research with argument analysis. Better professional performance and PHC quality with sustainability and strength beyond the pandemic context are also expected.

Author contributions

AA: Conceptualization, Data curation, Formal analysis, Investigation, Methodology, Software, Supervision, Visualization, Writing – original draft, Writing – review & editing, Validation. ÍS: Data curation, Investigation, Methodology, Validation, Visualization, Writing – review & editing. RF: Data curation, Methodology, Visualization, Writing – original draft, Validation. RL: Data curation, Validation, Visualization, Writing – original draft. CS: Supervision, Validation, Visualization, Writing – original draft. OG: Validation, Visualization, Writing – original draft. RL: Validation, Visualization, Writing – original draft. SC: Conceptualization, Data curation, Supervision, Validation, Visualization, Writing – original draft.

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Conflict of interest

The authors declare that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

Supplementary material

The Supplementary material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/fsoc.2024.1303295/full#supplementary-material

References

Australian Digital Health Agency Conectando a Austrália a um futuro mais saudável. Agência Australiana de Saúde Digital. (2022). Available at: https://www.digitalhealth.gov.au/

Barbosa, I. A., Silva, K. C. C. D., Silva, V. A., and Silva, M. J. P. (2016). The communication process in telenursing: integrative review. *Rev Bras Enferm* 69, 765–772. doi: 10.1590/0034-7167.2016690421i

Bardosh, K. L., Murray, M., Khaemba, A. M., Smillie, K., and Lester, R. (2017). Operationalizing mHealth to improve patient care: a qualitative implementation science evaluation of the WelTel texting intervention in Canada and Kenya. *Glob. Health* 13:87. doi: 10.1186/s12992-017-0311-z

Brasil. Ministério da Saúde. Portaria n° 2.436, de 21 de setembro de 2017. Aprova a Política Nacional de Atenção Básica, estabelecendo a revisão de diretrizes para a organização da Atenção Básica, no âmbito do Sistema Único de Saúde (SUS). Brasília, DF: Ministério da Saúde (2017). Available at: https://bvsms.saude.gov.br/bvs/saudelegis/gm/2017/prt2436_22_09_2017.html

Brasil. (2018). Resolução CFM n° 2.227/2018, de 6 de fevereiro de 2018. Available at: https://portal.cfm.org.br/images/PDF/resolucao222718.pdf (accessed July 24, 2023)

Brasil. (2019). Resolução CFM n° 2.228, de 26 de fevereiro de 2019. Available at: https://www.in.gov.br/web/guest/materia/-/asset_publisher/Kujrw0TZC2Mb/content/id/65864894/

Brasil. *Ofício CFM n° 1756/2020 – COJUR. Brasília, 19 de março de* (2020a). Available at: https://portal.cfm.org.br/images/PDF/2020_oficio_telemedicina.pdf (accessed July 24, 2022).

Brasil. *Ministério da Saúde, Secretaria-Executiva. Departamento de Informática do SUS. Estratégia de Saúde Digital para o Brasil 2020–2028 [recurso eletrônico]/Ministério da Saúde, Secretaria-Executiva, Departamento de Informática do SUS.* Brasília: Ministério da Saúde (2020b).

Brasil. (2022a). Lei N° 14.510, de 27 de dezembro de 2022. Available at: https://www.planalto.gov.br/ccivil_03/_ato2019-2022/2022/lei/l14510.htm (accessed July 11, 2023).

Brasil. (2022b). *Resolução CFM n° 1.643/2002, de 26 de agosto de 2002.* Available at: https://sistemas.cfm.org.br/normas/visualizar/resolucoes/BR/2002/1643 (accessed July 21, 2023)

Brasil. (2023). Estudo De Modelos Internacionais De Governança Em Saúde Digital. Available at: https://www.gov.br/saude/pt-br/assuntos/saude-digital/material-de-apoio/ModelosinternacionaisdeGovernanaemSadeDigital.pdf (accessed July 24, 2023).

Caetano, R., Silva, A. B., Guedes, A. C. C. M., Paiva, C. C. N., Ribeiro, G. R., Santos, D. L., et al. (2020). Desafios e oportunidades para telessaúde em tempos da pandemia pela COVID-19: uma reflexão sobre os espaços e iniciativas no contexto brasileiro. *Cadernos de Saúde Pública* 36:e00088920. doi: 10.1590/0102-311X00088920

Canada Health Infoway. *Integrando a saúde digital na experiência de cuidados de saúde*. (2022). Available at: https://www.infoway-inforoute.ca/en/ (accessed July 24, 2023)

Cellard, A. A análise documental. A pesquisa qualitativa:enfoques epistemológicos e metodológicos. (2012). 295–316.

Celuppi, I. C., Dos Lima, G. S., and Rossi, E. (2021). Wazlawick RS, Dalmarco EM. Uma análise sobre o desenvolvimento de tecnologias digitais em saúde para o enfrentamento da COVID-19 no Brasil e no mundo. *Cadernos de Saúde Pública* 37:e00243220. doi: 10.1590/0102-311X00243220

de Faria, R. M. (2020). A territorialização da Atenção Básica à Saúde do Sistema Único de Saúde do Brasil. *Ciência Saúde Coletiva* 25, 4521–4530. doi: 10.1590/1413-812320202511.30662018

Garattini, L., Badinella Martini, M., and Mannucci, P. M. (2021). Melhorando os cuidados primários na Europa além do COVID-19: da telemedicina às reformas organizacionais. *Intern. Emerg. Med.* 16, 255–258. doi: 10.1007/s11739-020-02559-x

Gehrke, M. A., Dos Dias, P. S., Do Natividade, T. S. S., De Magalhes, A. C. C., Braun, N., and Dos Pessoa, S. M. (2023). Perfil dos teleatendimentos realizados pelo núcleo telessaúde-Pará de 2018 a 2019. *Rev Bras Med Fam Comunidade [Internet]* 18:3364.

Gómez-Ramírez, O., Iyamu, I., Ablona, A., Watt, S., Xu, A. X. T., Chang, H. J., et al. (2021). On the imperative of thinking through the ethical, health equity, and social justice possibilities and limits of digital technologies in public health. *Can. J. Public Health* 112, 412–416. doi: 10.17269/s41997-021-00487-7

Gudi, N., Konapur, R., John, O., Sarbadhikari, S., and Landry, M. (2021). Telemedicine supported strengthening of primary care in WHO South East Asia region: lessons from the COVID-19 pandemic experiences. *BMJ Innov.* 7, 580–585. doi: 10.1136/bmjinnov-2021-000699

Lima, J. C. (2020). O papel da argumentação em processos deliberativos nas instâncias de controle social do Sistema Único de Saúde. Interface - Comunicação, Saúde. *Educação* 24:e190495. doi: 10.1590/Interface.190495

Lopes, M. Q., De Oliveria, G. M. M., and Maia, L. M. (2019). Digital health, universal right, duty of the state? *Arquivos Brasileiros de Cardiologia* 113, 429–434. doi: 10.5935/abc.20190161

Marengo, L. L., Kozyreff, A. M., Moraes, F. S., Maricato, L. I. G., and Barberato-Filho, S. (2022). Tecnologias móveis em saúde: reflexões sobre desenvolvimento, aplicações, legislação e ética. *Rev. Panam. Salud Publica* 46:e37. doi: 10.26633/RPSP.2022.37

McCool, J., Dobson, , Whittaker, R., and Paton, C. (2022). Saúde móvel (mHealth) em países de baixa e média renda. *Revisão Anual de Saúde Pública* 43, 525–539. doi: 10.1146/annurev-publhealth-052620-093850

Medina, M. G., Giovanella, L., Bousquat, A., De Mendonca, M. H. M., and Aquino, R. (2018). Atenção primária à saúde em tempos de COVID-19: o que fazer? *Cadernos de Saúde Pública* 36:e00149720. doi: 10.1590/0102-311X00149720

Nadav, J., Kaihlanen, A., Kujala, S., Laukka, E., Hilama, P., Koivisto, J., et al. (2021). How to implement digital Services in a way that They Integrate into Routine Work: qualitative interview study among health and social care professionals. *J. Med. Internet Res.* 23:e31668. doi: 10.2196/31668

Novillo-Ortiz, D., De Fátima Marin, H., and Saigí-Rubió, F. (2018). The role of digital health in supporting the achievement of the sustainable development goals (SDGs). *Int. J. Med. Inform.* 114, 106–107. doi: 10.1016/j.ijmedinf.2018.03.011

Ohannessian, R., Duong, T. A., and Odone, A. (2020). Global telemedicine implementation and integration within health systems to fight the COVID-19 pandemic: a call to action. *JMIR Public Health Surveill.* 6:e18810. doi: 10.2196/18810

Pan American Health Organization (PAHO). *Saúde Digital: Uma Estratégia Para Manter A Assistência À Saúde De Pessoas Que Vivem Com Doenças Não Transmissíveis Durante A Pandemia De Covid-19, Departamento De Evidência E Inteligência Para Ação Em Saúde Vice-Diretoria.* (2020a). www.paho.org/ish Página informativa N.11. Available at: https://iris.paho.org/bitstream/handle/10665.2/52576/OPASEIHISCOVID-19200015_por.pdf?sequence=4&isAllowed=y (accessed July 4, 2023)

Pan American Health Organization (PAHO). A COVID-19 e o papel dos sistemas de informação e das tecnologias na atenção primária [Internet]. (2020b). Available at: https://iris.paho.org/bitstream/handle/10665.2/52206/OPASEIHISCOVID19200022_por.pdf?sequence=18&isAllowed=y

Pan American Health Organization (PAHO)/WHO Brasil "*Diálogo Estratégico para a Preparação do Documento de Referência para a Renovação da Promoção da Saúde no Contexto dos Objetivos de Desenvolvimento Sustentável. (Brasília, 6 a 8 de agosto de 2018).* Brasilia: OPAS (2018).

Perelman, C, and Olbrechts-Tyteca, L. *Tratado da argumentação: a Nova Retórica. 6. ed* São Paulo: Martins Fontes, (2005).

PWC - Pricewaterhousecoopers Brasil. *O abismo digital no Brasil.* São Paulo, (2022).

Ramsetty, A., and Adams, C. (2020). Impact of the digital divide in the age of COVID-19. *J. Am. Med. Inform. Assoc.* 27, 1147–1148. doi: 10.1093/jamia/ocaa078

Rastogi, N. (2022). Healthcare's new frontier: the digital front door. *BMJ Innov.*:132. doi: 10.1136/bmjinnov-2021-000874

Rede APS (2021a). Rede de Pesquisa em APS Abrasco. Recomendações - Incorporação de recursos de telessaúde na APS no Brasil (2021). Available at: https://redeaps.org.br/wp-content/uploads/2021/10/DT-incorporacao-de-recursos-de-telessaude-na-APS-.pdf

Rede APS (2021b). Rede De Pesquisa em APS. Nota técnica, Dezembro, 2021. Incorporação de recursos de telessaúde na Atenção primária no Brasil, 1–35, 2021. Available at: https://redeaps.org.br/wp-content/uploads/2022/01/NT_Telessaude.pdf.

Santiago-Torres, M., Mull, K. E., Sullivan, B. M., Ferketich, A. K., and Bricker, J. B. (2022). Efficacy of an acceptance and commitment therapy-based smartphone application for helping rural populations quit smoking: results from the iCanQuit randomized trial. *Prev. Med.* 157:107008. doi: 10.1016/j.ypmed.2022.107008

Sarti, T. D. A., and Coelho, A. P. S. (2022). Incorporação de telessaúde na atenção primária à saúde no Brasil e fatores associados. *Cadernos de Saúde Pública* 38:PT252221. doi: 10.1590/0102-311XPT252221

Silva, C. R. D. V., Lopes, R. H., De Goes Bay, O. Jr., Martiniano, C. S., Fuentealba-Torres, M., Arcêncio, R. A., et al. (2022). Digital health opportunities to improve primary health Care in the Context of COVID-19: scoping review. *JMIR Hum. Factors* 9:e35380. doi: 10.2196/35380

Sun, L., Qu, M., Chen, B., Li, C., Fan, H., and Zhao, Y. (2023). Effectiveness of mHealth on adherence to antiretroviral therapy in patients living with HIV: Meta-analysis of randomized controlled trials. *JMIR Mhealth Uhealth* 11, 11:e42799. doi: 10.2196/42799

Wen, C. L. (2011). "Telemedicina e telessaúde: inovação e sustentabilidade" in *Organizadores. Gold book: inovação tecnológica em educação e saúde*. eds. I. Mathias and A. Monteiro

WHO. (2020a). *Digital implementation investment guide: integrating digital interventions into health programmes.* Geneva: World Health Organization.

World Health Organization *World Health Organization guideline: Recommendations on digital interventions for health system strengthening.* Geneva: World Health Organization; (2019).

World Health Organization. (2022a). *Director-General's opening remarks at the 11th meeting of the emergency committee for COVID-19.* Available at: https://www.who.int/director-general/speeches/detail/who-director-general-s-opening-remarks-at-the-11th-meeting-of-the-emergency-committee-for-covid-19---11-april-2022 (accessed July 24 2022)

World Health Organization (2020b). Digital health and COVID-19. *Bull. World Health Organ.* 98, 731–732. doi: 10.2471/BLT.20.021120

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*CORRESPONDENCE
Patricia Elung'ata
✉ Thesis.pelungata@yahoo.com

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Medical mesocosms and cohort differences in victim decisions in spousal violence in Sub-Saharan Africa

Patricia Elung'ata*

Department of Sociology, McGill University, Montreal, QC, Canada

Background: Contradictory evidence exists on whether medicine explicates social disparities in health perceptions. This study evaluates healthcare systems as mesocosms to understand social differences in spousal violence perceptions in sub-Saharan Africa, concretely, cohort differences in victim decisions in spousal violence (VDSV).

Conceptual framework: Medical dominance theory criticizes medical power asymmetry, while socio-ecological theory illuminates social disparities in human behavior. This study investigates socio-behavioral patterns in medicine as parallels to spousal violence behaviors, analyzing how power asymmetry influences VDSV in sub-Saharan Africa.

Methods: A cross-sectional study analyzed data from the latest Demographic and Health Surveys (2001–2024) across 31 countries, focusing on 193,232 women aged 15–49 years and their VDSV patterns: none, Discordant, and Other types. Unadjusted odds ratios (ORs) examined associations between VDSV patterns and birth cohorts (BCs) while adjusting for confounders. Interaction terms assessed the impact of neighborhood ethnic diversity, relationship power differences, and healthcare access. A two-level hierarchical multinomial logistic regression model analyzed VDSV variation, considering individual, cluster, and household-level confounders with random country effects. Spatial interpolation addressed geographical clustering. Analyses were performed using the McLogit package in R (Version 4.4.0).

Results: Across BCs, a greater percentage change in predicted marginal probabilities was observed for Other type VDSV compared to Discordant VDSV. Overall, women with recent healthcare access had smaller percentage changes; those with a large relationship power difference, especially, showed the opposite trend. Notably, observed healthcare access effects persisted beyond socioeconomic disparities.

Discussion: Higher VDSV amongst younger birth cohorts suggests lower SV-accepting attitudes. VDSV differences across healthcare access intimate anti-violence intervention exposure effects; relationship power differences play moderating roles. Persistent adjusted healthcare access effects suggest roles for narrowing socio-health inequalities in SSA.

Conclusion: The study results advocate for macro-societal policies within healthcare that address social issues, particularly through theory-based approaches. Future research may evaluate the potential influence of healthcare funding cuts.

KEYWORDS

victim behavior, social inequality, gender-based violence, social determinants, health inequalities

1 Purpose of study

1.1 Medicine and social problems

Evidence indicates that unethical medical practices can exacerbate persistent social issues, like the racial health inequalities highlighted by the controversial Tuskegee syphilis study (Thomas and Quinn, 1991; Gamble, 1997). Conrad (1992) outlines pathways (Conrad, 1992, 2007) for medical social control (Zola, 1972; Illich, 1976), including medical ideology, such as the medical model (Parsons, 1975; Silverman, 1983), medical collaboration, such as workplace screening and intervention for infectious diseases or substance abuse (R. Williams and Williams-Morris, 2000; Marcotte, 2004), incremental population-based medical surveillance (Foucault, 1975; Armstrong, 1995), and the use of medical technology for social control (Conrad and Schneider, 1992; Rose, 2001), such as genetic screening (Rose, 2001; National Research Council (U.S.) et al., 2008).

Some research studies on medical approaches to social problems (Conrad and Schneider, 1992; Ityo, 2010; Dillon, 2020) extend the medical ideology pathway (Conrad, 1992, 2007), proposing macrocosm, mesocosm, and microcosm research analogies. These view research experiment environments as microcosms, explaining larger or equal environments (macrocosm or mesocosm environments) and vice versa (Odum, 1984; Carpenter, 1996). This study examines medicine as a mesocosm to understand social differences in perceptions of spousal violence (SV) in sub-Saharan Africa (SSA). It focuses on cohort differences in medical dominance (MD) victim decisions as mesocosms to understand cohort disparities in spousal violence victim decisions (VDSV).

Research on social aspects of medicine explores social problems at macro-, mezzo-, and micro-levels, their effects on medicine, and vice versa (Evans et al., 1994; Marmot and Wilkinson, 2006), to support evidence-based national policy (Solar and Irwin, 2010). It also examines social problems within medicine and their impacts (Starr, 1982; Conrad, 1992). However, gaps remain in understanding how these interaction effects occur.

1.2 Healthcare systems and victim decisions in spousal violence

Surviving SV is partly about victim decisions. VDSV are discussed in various ways, such as whether victims sought help (Ahmad et al., 2009; Itimi et al., 2014; Metheny and Stephenson, 2019), distinguishing between short-term and long-term responses (Kaye et al., 2007; Ahmad et al., 2009), and whether victims utilized attitudinal or emotional responses instead of behavioral responses (Kanagaratnam et al., 2012; Swart, 2013; Arestoff and Djemai, 2016). Some discussions center on barriers to help-seeking, distinguishing between group-level barriers (Rizo and Macy, 2011; Prosman et al., 2014; Huntley et al., 2019; Satyen et al., 2019). Another method contrasts direct and indirect sources of violence (Swart, 2013; Balogun and John-Akinola, 2015; Mannell et al., 2016), such as violence due to victim poverty (Swart, 2013) compared to wealth (Balogun and John-Akinola, 2015). Other studies examine the motivation for victim behavior, whether self-initiated, aka individual agency (Horn et al., 2016; Mannell et al., 2016; McCleary-Sills et al., 2016) or other-initiated, aka structure-initiated (Allen and Devitt, 2012; Horn et al., 2016; Mannell et al., 2016). Regarding other-initiated VDSV, several studies in SSA postulate that SV experiences precede healthcare system contact (Allen and Devitt, 2012; Horn et al., 2016; Mannell et al., 2016); evidence from SSA's high maternal mortality rates, for example, links SV experience among the urban poor to compromised help-seeking during pregnancy and delivery, including mortality-risk exacerbating decisions (Essendi et al., 2011), resulting in higher maternal mortality (Ziraba et al., 2009a; Izugbara and Ngilangwa, 2010). Furthermore, however, evidence suggests that socio-behavioral patterns within medicine may explain those outside medicine and vice versa (Parsons, 1975; Conrad, 2005; Timmermans and Oh, 2010). However, contradictory evidence exists on whether medicine may explain health perceptions, including SV perceptions, while some views disagree (McKeown, 1979; Fogel and Costa, 1997) and others concur (Parsons, 1975; Conrad and Schneider, 1992).

1.3 Healthcare systems and social differences in spousal violence perceptions

Generally, social inequalities in health perceptions exist, such as socioeconomic inequalities (Quesnel-Vallee, 2004; Lutfey and Freese, 2005). However, limited evidence exists on social disparities in SV perceptions, including help-seeking behavior (Solar and Irwin, 2010). SV perpetrated by current or former intimate partners is high in SSA, higher among women, and even higher among adolescents (ICF, 2012b; UN-WOMEN, 2024), yet overall, <50% of victims seek help (ICF, 2012b; UN-WOMEN, 2024). Some victims, supposing SV-accepting family or community social norms, such as protecting family honor (Kanagaratnam et al., 2012; Mannell et al., 2016), ineffectively seek help from family and friends (UN-WOMEN, 2024). Moreover, despite higher SV incidence amongst younger spousal partners, effective responses, including reporting, were less likely, such as with powerful partners (ICF, 2012b; Kenya National Bureau of Statistics et al., 2015). Help-seeking is further unlikely due to the high femicide risk (UN-WOMEN, 2024). The 2024 anti-femicide protests in Kenya, for instance, underscored the exacerbating effect of delayed SV penalties on femicide (Africapractice, 2024). Despite higher female life expectancy estimates worldwide, higher lifetime female disability-life adjusted years estimates are reported for depressive anxiety and headache disorders (Patwardhan et al., 2023), frequently associated with SV (Balogun and John-Akinola, 2015; Hatcher et al., 2022; Metheny et al., 2024). Finally, there is diminished help-seeking, including reporting, due to the intersectionality of disadvantage. Amongst the urban poor, for example (Wilson, 1987; Small and Newman, 2001; African Population and Health Research Center, 2002), environmental degradation exacerbates sexual violence risk and hampers subsequent help-seeking via increased crime and the resulting disruptions in essential service provision disruptions (Corburn and Hildebrand, 2015; Corburn and Sverdlik, 2017).

Contradictory evidence exists on healthcare system approaches to social disparities in health perceptions, including SV perceptions.

Some equity perspectives highlight healthcare systems' failure to narrow social inequality. Certain studies indicate incorrect associations between preceding healthcare system improvements and succeeding population health inequality narrowing (Great Britain Working Group on Inequalities in Health et al., 1982; Mackenbach et al., 1997; Lutfey and Freese, 2005). Other studies indicate an incorrect attribution of ongoing population health improvements to current healthcare system enhancements (McKeown, 1979; Fogel and Costa, 1997). Supporting studies, however, link value-free physician–patient interactions (Parsons, 1975) to diminished population health inequalities (Ananth et al., 2001; Alexander et al., 2002; Rittenhouse et al., 2003), whereas value-influenced physician–patient interactions (Abbott, 1988; Conrad, 2005) were associated with persistent health inequalities (Hollingshead and Redlich, 1953; Silverman, 1981, 1983; Solar et al., 2007).

While some SSA studies mention linkages between healthcare systems and SV, limited literature focuses on social differences in SV perceptions. Research in SSA indicates that healthcare systems can integrate health service responses to SV (Colombini et al., 2008, 2017; Joyner and Mash, 2011), enhancing victim support and provider insights. These systems enable comprehensive testing of health service responses to SV (Sprague et al., 2016; Hatcher et al., 2019), leading to improved implementation models (Jacobs and Jewkes, 2002; Joyner and Mash, 2012a). In fact, clinic-tested SV responses were often positively received (Christofides and Jewkes, 2010; Joyner and Mash, 2014). Even basic screening tests effectively identified SV victims among clinic attendees (Christofides and Jewkes, 2010; Joyner and Mash, 2012b). Healthcare systems also help raise community awareness, beyond victim and care provider awareness (Colombini et al., 2008, 2017), and facilitate victim referrals to social services (Colombini et al., 2008, 2017). Furthermore, healthcare systems provide a suitable sampling frame (Prabhu et al., 2011; Delamou et al., 2015; Gibbs et al., 2017) for understanding victims' SV experiences and sociodemographic backgrounds (Hampanda et al., 2014; Hampanda, 2016a,b), although findings may have limited generalizability (Hampanda et al., 2014; Punch, 2014; Hampanda, 2016a). Furthermore, framing SV as a health issue rather than a social one promotes recognition of healthcare's potential impact (Joyner, 2013; Rees et al., 2014a).

Regarding *theoretical limitations*, some SSA studies acknowledge inadequate social theory application, such as impact evaluations, where inadequate socio-contextual information hinders understanding (Colombini et al., 2008; Hatcher et al., 2015; Sprague et al., 2017). Some SSA studies test theories on cross-sectional rather than longitudinal data (Ezeanochie et al., 2011; Prabhu et al., 2011; Delamou et al., 2015; Tusiime et al., 2015; Bernstein et al., 2016; Mahenge et al., 2016; Gibbs et al., 2017; Berhanie et al., 2019), which better captures changes over time (Menard, 2002). Some propose social theories tested on qualitative as opposed to quantitative data (Rees et al., 2014b), others use purposively selected samples (Rees et al., 2014b) instead of representative ones (Shryock et al., 1975), or small data samples (Bernstein et al., 2016; Mahenge et al., 2016; Mohammed et al., 2017), hindering generalizability (Luker, 2008; Greenwell and Salentine, 2018). Other studies do not clearly define their sampling methods (Tusiime et al., 2015), hindering sample validity evaluation (Lee and Forthofer, 2006). Some studies rely on quantitative data without a clear theoretical basis (Ezeanochie et al., 2011; Prabhu et al., 2011; Delamou et al., 2015; Tusiime et al., 2015; Bernstein et al., 2016; Mahenge et al., 2016; Gibbs et al., 2017; Berhanie et al., 2019), other studies propose well-defined theories (Colombini et al., 2008; Joyner and Mash, 2012a) that are not effectively tested, while other studies lacked a named social theory which guided the empirical analysis process (Umeora et al., 2008; Onoh et al., 2013; Delamou et al., 2015).

This study evaluates whether medicine may explicate social differences in SV perceptions in SSA. Hereafter, I define SV perceptions as VDSV, medicine based on the "medical dominance (MD)" theory, and social differences as birth cohort differences. Subsequently, the literature review focuses on *critical debates* surrounding cohort differences in MD victim behavior as mesocosms to elucidate cohort differences in VDSV in SSA. The SSA focus explicates disagreements between health service-based response advocacy (Joyner, 2013; World Health Organization, 2013) and ongoing health disparities (The Africa Health Agenda International Conference Commission et al., 2021). Furthermore, birth cohort differences provide a historical lens (Abramsky et al., 2014; Ezenweke, 2016) to disagreements between high SV rates in low- and middle-income settings, including SSA (World Health Organization, 2013), persistent socio-cultural intervention barriers (Ezenweke, 2016), and various effective time-based behavior change interventions in the region (Abramsky et al., 2014; Kapiga et al., 2019). Additionally, the study examines SV perceptions in SSA, presuming perceptions underlying behavior, particularly where high social desirability bias risk in social normative behavior reporting exists (Mackie et al., 2015; Ezenweke, 2016); furthermore, perceptions can illuminate associated perceptions and related prioritization processes (Porter, 1985; Zedelius et al., 2017).

1.4 Background

1.4.1 Mesocosms

According to Odum (1984), mesocosms describe controlled environments where natural behaviors may be observed; in this study, MD illuminates socio-behavioral patterns within medicine, specifically proposing relationship power asymmetry and its effects within medicine (Freidson, 1970; Starr, 1982; Toth, 2015). Bioscience employs mesocosms to compare complex real-world natural systems against bounded and partially enclosed experimental environments (Odum, 1984). In this study, the MD mesocosm explicates socio-behavioral patterns within spousal violence in households in SSA through relationship power asymmetry and its effects (Freidson, 1970; Starr, 1982; Toth, 2015). Parsons proposes teacher–student relationship mesocosms to model physician–patient relationships (Dillon, 2020), while Conrad and Schneider (1992) postulate physician–patient relationship mesocosms for interactions between medical boards and physicians (Conrad and Schneider, 1992); our mesocosm hypothesis proposes comparable interpersonal relationships to elucidate similar social contexts, specifically physician–patient relationship mesocosms of spouse–partner relationships. Across similar social contexts, there are also micro, mezzo, and macro socio-contextual similarities, including analogous cross-system interactions. Furthermore, within similar social contexts, socio-behavioral patterns in interpersonal relationships can elucidate each other; for instance, MD, its socio-contextual influences, and their interactions can explain equivalent interpersonal relationships beyond medicine. Notably, however, equality between the compared environments is assumed (Odum, 1984). Nonetheless, unforeseen inequality may arise for various reasons (Carpenter, 1996); these reasons include environments at different stages of evolution, incomparable environmental boundaries, and unexpected effects of the compared environments on observed social behavior. Generally, however, proof of the viability of medical mesocosms may advance medical SV interventions (Joyner, 2013), surmounting documented challenges within legal redress systems in SSA (Odero et al., 2014; Mannell et al., 2016).

1.4.2 Cohort-related differences and victim decisions

This review examines vital debates surrounding cohort-related differences in MD and SV victim decisions. The limited MD theory in SSA literature suggested a pattern-matched inclusion of related studies, increasing the risk of measurement biases (Trochim, 2005; Punch, 2014). Few hospital-level studies assess intergenerational differences related to MD. Two such studies (Silverman, 1981, 1983) defined generations as parent generations compared to child generations and found differing parent–child responses based on whether the child was below the consenting age. Additionally, parent responses dominated when they differed from children's; however, physician opinions prevailed where the physician's view conflicted with either or both parents and children (Silverman, 1981, 1983). Other studies indicate that temporal changes in hospital policy or regulations resulted in shifts in physicians' relationships with MD victims and corresponding victim behavior toward these changes (Weiss and Sutton, 2009; Cooper et al., 2012; Lennan, 2014; Zhou et al., 2019). Several population-level studies suggest that intergenerational differences may explain VDSV in SSA. Some studies evaluate intergenerational differences as variations between the VDSV of parents and their children (Kaye et al., 2007; Kanagaratnam et al., 2012; Decker et al., 2013), birth cohort disparities, or changes across temporal periods (Arestoff and Djemai, 2016; Mannell et al., 2016); at times, these changes were linked to implemented SV interventions (Njuki et al., 2012; Abramsky et al., 2014; Harvey et al., 2018; Naved et al., 2018). Previous debates were somewhat limited (Simister, 2010; Kanagaratnam et al., 2012; Mannell et al., 2016); this study aimed to fill that gap. One expectation from the review is that cohort differences may explain VDSV in SSA, with younger cohorts less accepting of SV (Hypothesis 1).

1.4.3 Medical mesocosms and victim decisions

Below, various debates surrounding medical mesocosm approaches to social disparities in victim decisions are explored, particularly concerning MD theory. MD theory posits that physicians strategically disempower other stakeholders within their field (Freidson, 1970; Starr, 1982); consequently, they gain medical sovereignty (Freidson, 1970; Toth, 2015), technical and professional autonomy (Freidson, 1970; Sandstrom, 2007), and cultural authority (Freidson, 1970; Toth, 2015). Contra-MD arguments highlight that existing research predominantly centers on physicians as perpetrators rather than victims (Freidson, 1970; Starr, 1982). Several reviewed MD studies employed qualitative data, and efforts to derive comparable quantitative data may exacerbate research biases. Finally, autonomous decision-making regarding the mechanisms through which social conditions influence MD (Coburn, 1993, 1999) also increases the risk of measurement biases. Pro-MD arguments recognize a two-way interaction, wherein either the physician or patient can be victims (Gerhardt, 1989), respond uniquely (Silverman, 1981, 1983), with social patterning (Abbott, 1988), but also be value-influenced (Silverman, 1981, 1983; Conrad and Schneider, 1992). The above arguments suggest that MD "mesocosms" may explain cohort differences in VDSV in SSA.

1.4.4 Conceptual framework

Adopting pattern-matching (Trochim, 2005; Punch, 2014) and socioecological theory approaches (Bronfenbrenner, 2005; Mackie et al., 2015), this section proposes how, based on existing evidence, an MD theory (Freidson, 1970; Starr, 1982; Toth, 2015) mesocosm (Odum, 1984) may elucidate cohort differences in VDSV in SSA. Pattern-matching posits hypotheses generation from comparisons of observed and expected conceptual patterns (Trochim, 2005; Punch, 2014); it employs a grounded-theory strategy (Punch, 2014).

1.4.4.1 Socio-ecological theory and cross-system interactions

A study expectation predicated on pattern-matching theory (Trochim, 2005; Punch, 2014) and socio-ecological theory (Bronfenbrenner, 2005) posits that interactions among micro, mezzo, and macro systems may elucidate VDSV in SSA. Mackie et al. (2015) suggest that socio-ecological theory (Bronfenbrenner, 2005) may explain human behavior within SV (specifically across three main sub-systems: microsystems encompassing the conflict arena, the perpetrator (male partner), the victim (female partner), their relationship, and specific SV experiences; mesosystems comprising neighborhoods; and macrosystems incorporating socio-historical factors, such as socioeconomic stratification (Dillon, 2020). Additionally, socio-ecological theory posits that interactions across exosystems (Bronfenbrenner, 2005), such as overarching public policy (Quesnel-Vallée et al., 2021), explain SV.

Despite limitations, some household-based evidence indicates that cross-system interactions, such as socioeconomic inequalities (Wright, 1997; Phelan et al., 2010), explain social disparities in VDSV in SSA. For instance, despite higher SV incidence amongst lower socioeconomic status couples (Itimi et al., 2014), within this group, lower education levels and reduced help-seeking for SV are further associated (Simister, 2010; Bhuwania and Heymann, 2022), sometimes due to government service fee payments (Njuki et al., 2012; Odero et al., 2014). Associations are also reported between MD victim resistance and victim-perpetrator power differences, socioeconomic differences (Sandstrom, 2007; Alubo and Hunduh, 2017), and institutional and government support differences (Coburn, 1999; Alubo and Hunduh, 2017). Notably, however, beyond SV, VDSV emphasizes roles for individual agency (Swart, 2013; Horn et al., 2016), suggesting that SE theory applicability (Assari, 2013; Jefferies, 2016) to VDSV remains unclear.

1.4.4.2 Macrosystem, mesosystem, and microsystem environments

Following pattern-matching theory (Trochim, 2005; Punch, 2014) and socio-ecological theory proposed macrosystems (Mackie et al., 2015), some hospital-based research studies indicate that despite theoretical and methodological limitations, "pre-assigned role change" may explain social differences in MD victim responses (Weiss and Sutton, 2009; Cooper et al., 2012). Pattern-matched (Trochim, 2005; Punch, 2014) household-based studies also indicate that, despite limitations, "pre-assigned social roles" may elucidate social disparities in VDSV in SSA (Kanagaratnam et al., 2012; Gillum et al., 2018). Indeed, structural-functionalism theory (Dillon, 2020), partly characterized by "pre-assigned social roles," posits that despite theoretical limitations (Parsons, 1975), at the macrosystem level, society dictates accepted victim behavior, gatekeeper behavior, and rules for behavior change through institutional interventions, which vary across social stratification (Dillon, 2020).

Conformable with pattern-matching theory (Trochim, 2005; Punch, 2014) and the socio-ecological theory proposed mesosystems (Mackie et al., 2015), various hospital-based research studies suggest that, notwithstanding theoretical and methodological limitations, the concept of "knowledge exchange across social interactions" may explain social differences in MD victim responses (Wilson et al., 2007; Goldman et al., 2016). Pattern-matched household-based studies (Trochim, 2005; Punch, 2014) indicate roles for "knowledge exchange across social interactions," such as religious interactions (Swart, 2013; Itimi et al., 2014) in comprehending VDSV social differences, particularly victim resistance planning efforts (Swart, 2013; Kohli et al., 2015). Indeed, symbolic interactionism theory (Goffman, 1974), partly characterized by "knowledge exchange across social interactions," suggests that despite recognized theoretical limitations (Sandstrom and Kleinman, 2004; Ritzer, 2005; Ritzer and Ryan, 2011), at the mesosystems level, social processes impact the victim's self once or repeatedly depending on whether a fundamental self already exists. However, the effect varies across the corresponding victim reactions, society's reaction to the victims and those like them, and the social processes which connect the two (Goffman, 1974), such as group social interactions.

Finally, according to pattern-matching theory (Trochim, 2005; Punch, 2014) and socio-ecological theory proposed microsystems (Mackie et al., 2015), specific hospital-based evidence suggests that despite theoretical and methodological limitations, "artifactual effects" may elucidate social differences in MD victim responses (Sandstrom, 2007; Ghasi et al., 2020). Additionally, pattern-matched household-based evidence (Trochim, 2005; Punch, 2014) indicates that despite limitations, "artifactual effects" may similarly elucidate VDSV social differences (Arestoff and Djemai, 2016; Kapiga et al., 2019). Furthermore, some proponents of MD theory (Starr, 1982; Toth, 2015) suggest that despite known theoretical limitations (Parsons, 1975), at the microsystems level, "artifactual effects," such as ineffective bias handling (Sica, 2006; Pannucci and Wilkins, 2010), systematic error biases (Sica, 2006; Morgensten, 2018), and limited reliability and validity of research study approaches (Coggon et al., 2009; Pannucci and Wilkins, 2010), may explain observed MD-related result patterns. As such, a second study expectation, predicated on pattern-matching theory (Trochim, 2005; Punch, 2014) and socio-ecological theory (Mackie et al., 2015) is that cross-system interactions between macrosystem social role change, mesosystem knowledge networks, and microsystem artifactual effects may explain VDSV in SSA (Hypothesis 2).

1.4.4.3 Exosystem environment

Unlike Mackie et al. (2015), Bronfenbrenner (2005)'s version of socio-ecological theory additionally emphasizes roles for exosystems, which include higher-level socio-political determinants, such as changes in governance or overarching public and social policies (Solar et al., 2007; Quesnel-Vallée et al., 2021). Some hospital-based evidence indicates that, despite methodological limitations, national healthcare policy changes can elucidate social disparities in MD victim responses (Coburn, 1993, 1999). Similarly, the Evolutionary Social Change Theory (Dietz et al., 1990), partly characterized by "public policy change," posits that despite recognized theoretical limitations (Parsons, 1975), at the macrosystems level, victim behavior results partly from co-evolutionary perspectives, integrating both micro-process and macro-process societal change effects on human behavior, including immanent social forces changes, and culture, social organization, and institutional changes (Dietz et al., 1990). In contrast, limited household-based evidence conclusively highlights this same aspect. As such, a third study expectation predicated on pattern-matching theory (Trochim, 2005; Punch, 2014) and socio-ecological theory (Bronfenbrenner, 2005) was that interactions between microsystem artifactual effects, mesosystem social networks, macrosystem social role change, and exosystem healthcare policy may explain VDSV in SSA (Hypothesis 3). Hypothesis 3 also postulates medical mesocosms (Odum, 1984), that MD theory may illuminate socio-behavioral patterns within spousal violence in households in SSA.

2 Materials and methods section

2.1 Data

The study used demographic and health survey data (DHS), nationally representative household surveys conducted every 5 years across selected low- and middle-income countries. Further information regarding data collection (ICF, 2020), sampling strategy (ICF International, 2012), ethical approval, and other details concerning the study can be found elsewhere (ICF, 2012a; Measure DHS/ICF International, 2013; Croft et al., 2023). Ethical consent was obtained from ICF International, the distributor of these data. Analysis was limited to the most recent country surveys, which included a complete SV module, capturing household-level SV experiences and surrounding circumstances (ICF, 2020); a total of 31 countries in SSA were considered. Survey-specific logical rules and related record-matching facilitated data cleaning and imputation (Gelman and Hill, 2007; Sauro, 2015); fewer than 2% of records were affected. All data cleaning was conducted using Stata 16.0. The final study sample, described in Tables 1–5, comprised

TABLE 1 Weighted victim decisions in spousal violence estimates among females aged 15–49 in Sub-Saharan Africa, Latest Country DHS 2003–2024, West Africa.

Country code	Survey year	Females 15/49	DV Module	SV	VDSV1		VDSV2		VDSV3	
					Other	Discord	Other	Discord	Other	Discord
		N	*N*	Row %	Row %	Row %	Row %	Row %	Row %	Row %
SSA	2000–24	512,269	193,232	45.5	24.0	21.5	32.3	13.2	31.7	13.8
WA	2000–24	226,170	76,157	50.3	27.0	23.3	37.2	13.2	36.1	14.2
BF	2021	17,659	10,863	53.4	26.7	26.7	46.0	7.5	44.5	9.0
BJ	2017–18	15,928	5,408	51.2	33.0	18.2	39.3	11.9	39.9	11.4
CI	2021	14,877	5,040	35.4	23.8	11.6	26.5	9.0	25.2	10.2
CM	2018	14,677	6,682	44.5	29.8	14.8	30.6	13.9	31.0	13.5
TD	2014–15	17,719	4,283	57.5	11.9	45.6	44.6	12.9	44.7	12.9
GA	2019–21	11,043	4,163	35.2	21.8	13.4	20.8	14.4	18.5	16.6
GH	2022	15,014	5,737	37.5	27.6	9.9	26.9	10.5	25.3	12.2
GM	2019–20	11,865	2,470	42.1	17.3	24.7	29.9	12.2	23.2	18.8
LB	2019–20	8,065	3,120	51.8	28.9	22.9	32.6	19.2	36.8	15.0
ML	2018	10,424	3,784	64.3	10.1	54.2	51.0	13.4	37.7	26.6
NG	2018	38,948	10,678	50.2	32.7	17.5	39.6	10.6	38.6	11.6
SL	2019	16,658	5,248	60.5	27.5	33.0	35.9	24.6	41.0	19.5
ST	2008–09	15,574	1,980	79.5	62.0	17.5	65.2	14.1	67.4	12.1
TG	2013–14	17,719	6,701	41.8	25.4	16.4	31.7	10.1	32.3	9.5

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

SSA, Sub-Saharan Africa; DV Module, Domestic Violence Module; VDSV, Victim Decisions in Spousal Violence; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions; SV, Spousal Violence Experience Last 12 Months; VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Violence Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience Notwithstanding Attitudes; WA, Western Africa; BF, Burkina Faso; BJ, Benin; CI, Ivory Coast; CM, Cameroon; TD, Chad; GA, Gabon; GH, Ghana; GM, Gambia; LB, Liberia; ML, Mali; NG, Nigeria; SL, Sierra Leone; ST, Sao Tome & Principe; TG, Togo.

TABLE 2 Weighted victim decisions in spousal violence estimates among females aged 15–49 in Sub-Saharan Africa, Latest Country DHS 2003–2024, East Africa.

Country code	Survey year	Females 15/49	DV Module	SV	VDSV1		VDSV2		VDSV3	
					Other	Discord	Other	Discord	Other	Discord
		N	*N*	Row %	Row %	Row %	Row %	Row %	Row %	Row %
SSA	2000–24	512,269	193,232	45.5	24.0	21.5	32.3	13.2	31.7	13.8
EA	2000–24	153,955	68,860	44.8	18.4	26.4	30.8	14.0	30.2	14.6
BU	2016–17	17,269	10,188	40.0	11.8	28.2	24.3	15.7	20.9	19.1
CD	2013–14	18,827	6,811	58.8	11.6	47.3	36.7	22.1	36.5	22.3
ET	2016	15,683	5,860	53.6	15.5	38.1	44.7	8.9	37.6	16.0
KE	2022	32,156	16,926	37.7	21.7	16.0	24.7	13.1	26.8	11.0
MD	2021	18,869	7,308	54.2	29.3	24.9	40.8	13.4	40.3	13.9
MR	2019–21	15,714	4,184	27.0	16.0	10.9	22.6	4.4	21.3	5.7
RW	2019–20	13,497	2,788	36.5	16.3	20.2	21.1	15.4	25.9	10.6
TZ	2022	13,266	5,563	42.1	18.5	23.6	29.2	12.9	28.9	13.2
UG	2016	8,674	9,232	53.2	24.6	28.6	32.7	20.5	33.9	19.3

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

SSA, Sub-Saharan Africa; DV, Domestic Violence; VDSV, Victim Decisions in Spousal Violence; Discord, Discordant Decision; Other, Unknown or Concordant Decision; SV, Spousal Violence Experience Last 12 Months; VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Violence Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience Notwithstanding Attitudes; Discord, Discordant Decision; EA, East Africa; BU, Burundi; CD, Democratic Republic of Congo; ET, Ethiopia; KE, Kenya; MD, Madagascar; MR, Mauritania; RW, Rwanda; TZ, Tanzania; UG, Uganda.

TABLE 3 Weighted victim decisions in spousal violence estimates among females aged 15–49 in Sub-Saharan Africa, Latest Country DHS 2003–2024, Southern Africa.

Country code	Survey year	Females 15/49	DV Module	SV	VDSV1		VDSV2		VDSV3	
					Other	Discord	Other	Discord	Other	Discord
		N	*N*	Row %	Row %	Row %	Row %	Row %	Row %	Row %
SSA	2000–24	512,269	193,232	45.5	24.0	21.5	32.3	13.2	31.7	13.8
SA	2000–24	132,144	48,215	38.0	25.5	12.5	26.8	11.2	26.5	11.6
AO	2015–16	14,379	10,519	38.3	25.0	13.3	25.7	12.6	23.4	14.9
LS	2023–24	6,413	2,490	35.5	26.7	8.8	23.7	11.8	23.7	11.8
MZ	2022–23	13,745	4,813	46.1	32.5	13.5	32.8	13.3	30.7	15.4
MW	2015–16	11,698	6,379	54.8	45.5	9.3	38.2	16.6	38.2	16.6
NM	2013	41,821	2,931	21.1	11.8	9.2	19.9	1.2	19.8	1.3
ZA	2016	18,506	4,357	18.1	15.9	2.2	13.6	4.5	14.0	4.0
ZM	2018	16,411	9,503	49.3	22.9	26.4	34.1	15.2	33.6	15.7
ZW	2015	9,171	7,223	41.3	23.9	17.4	26.9	14.4	28.5	12.8

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

SSA, Sub-Saharan Africa; DV, Domestic Violence; VDSV, Victim Decisions in Spousal Violence; Discord, Discordant Decision; Other, Unknown or Concordant Decision; SV, Spousal Violence Experience; VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Violence Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience Notwithstanding Attitudes; SA, Southern Africa; AO, Angola; LS, Lesotho; MZ, Mozambique; MW, Malawi; NM, Namibia; ZA, South Africa; ZM, Zambia; ZW, Zimbabwe.

193,232 women aged 15–49 years. A cross-sectional analytic study was carried out to compare three VDSV patterns across birth cohorts while adjusting for confounding factors (Fox, 2016; Oakes and Kaufman, 2017).

2.2 Measures

Refer to Figure 1 for the conceptualization of the primary analytical measures used and the hypothesized relationships between them.

2.2.1 Cross-system interaction measures

2.2.1.1 Dependent variable

Victim Decisions in Spousal Violence (VDSV): In line with sick-role theory (Parsons, 1975), the common-sense model of health-related decisions theory (Leventhal et al., 2016), and rational choice theory (Jasso, 2011)—which serve as interpretations of MD theory (Freidson, 1970; Toth, 2015)—I define three measures for VDSV. VDSV patterns 1, 2, and 3 are coded as 0 when respondents reported no spousal violence (0 = None). Additionally, VDSV pattern 1, coded as 2, when respondents express SV-accepting attitudes despite experiencing SV, but not otherwise (1 = Other, including Unknown and Concordant Decisions; 2 = Discordant Decision). In contrast, VDSV pattern 2, coded as 2, was observed when respondents sought help for SV despite expressing SV-accepting attitudes, but not otherwise (1 = Other, including Unknown and Concordant Decisions; 2 = Discordant Decision). VDSV pattern 3, coded as 2, when respondents sought help for SV after experiencing SV, regardless of their attitudes, but not otherwise (1 = Other, including Concordant and Unknown Decisions; 2 = Discordant Decision). Notably, Unknown And Concordant decisions were combined for VDSV patterns 1, 2, and 3 since the focus was on Discordant decisions. Moreover, VDSV patterns 1, 2, and 3 primarily derive from three underlying measures: "SV experience," "SV accepting attitudes," and "Sought help for SV." The binary variable SV experience was coded 1 when respondents experienced SV in the 12 months preceding the survey, whether emotional, sexual, or physical violence, but zero otherwise (Rutstein and Rojas, 2006; Croft et al., 2023). The binary variable SV accepting attitudes takes the value 1 when respondents felt that SV would be warranted in at least one of five hypothetical situations: if she goes out without informing him, neglects the children or argues with him, refuses to have sex with him or burns the food, but zero otherwise (Rutstein and Rojas, 2006; Arestoff and Djemai, 2016; Croft et al., 2023). Finally, the binary variable respondents sought help for SV, was coded 1 when respondents reported seeking help after the SV experience, or they did not seek help but confided in someone about it, but zero otherwise (Rutstein and Rojas, 2006; Croft et al., 2023).

2.2.1.2 Independent variable

Birth cohorts: In line with proponents of "Cohort as a Concept in the Study of Social Change" (Ryder, 1965) and "Time, Human Agency and Social Change" (Elder Jr, 1994) as interpretations of structural-functionalism theory (Dillon, 2020), I define birth cohorts. Rather than using survey-reported years of birth, I estimate these as the survey year minus the reported age at survey; this method addresses the issue of surveys spanning more than 1 year (Arestoff and Djemai, 2016). Consequently, for birth years spanning 1947 to 2005, birth cohorts ranging from 1 = 1947–1985 to 2 = 1986+ were defined. Cohort cutoff points were drawn from dates of international family planning policy change (Seltzer, 2002; Garenne, 2018), plus estimated 18-month implementation

TABLE 4 Spousal violence experience estimates among females aged 15–49 in Sub-Saharan Africa by selected predictors, Latest Country Demographic and Health Surveys, 2003–2024.

Level	Predictors	Mean	S.D.	*N*
No experience and some spousal violence experience				
Survey	Survey ethnic diversity (−10.3,1)	−1.2	4.0	31
Cluster	Cluster ethnic diversity (−10.1,1)	−0.8	2.4	18,769
	Marital instability (0,30)	0.9	1.1	18,769
	Proportion SECONDARY Plus (0,1)	0.4	0.3	18,769
Household	Household Wealth (1,5)	3.0	1.4	193,232
	Urban–rural residence (0,1)	0.4	0.5	193,232
Individual	Birth cohort (0,1)	0.6	0.5	193,232
	Time period (1,2)	2.0	0.2	193,232
	Healthcare past 12 months (1,2)	1.5	0.5	193,232
	Relationship power–differences (1,3)	2.1	0.7	193,232
	Age group (1,7)	3.5	1.8	193,232
	Residential stability (0,2)	0.7	0.7	193,232
No spousal Violence experience				
Survey	Survey ethnic diversity (−10.3,1)	−1.0	3.6	16
Cluster	Cluster ethnic diversity (−10.1,1)	−0.7	2.4	9,903
	Marital instability (0,30)	1.0	1.4	9,903
	Proportion secondary plus (0,1)	0.5	0.3	9,903
Household	Household wealth (1,5)	3.1	1.4	97,237
	Urban–rural residence (0,1)	0.4	0.5	97,237
Individual	Birth cohort (0,1)	0.7	0.5	97,237
	Time period (1,2)	2.0	0.2	97,237
	Healthcare past 12 months (1,2)	1.4	0.5	97,237
	Relationship power–differences (1,3)	2.3	0.8	97,237
	Age group (1,7)	3.1	1.9	97,237
	Residential stability (0,2)	0.6	0.7	97,237
Some spousal violence experience				
Survey	Survey ethnic diversity (−10.3,1)	−1.5	4.4	15
Cluster	Cluster ethnic diversity (−10.1,1)	−0.9	2.5	8,866
	Marital instability (0,30)	0.7	0.7	8,866
	Proportion secondary plus (0,1)	0.4	0.3	8,866
Household	Household wealth (1,5)	2.8	1.4	95,995
	Urban–rural residence (0,1)	0.3	0.5	95,995
Individual	Birth cohort (0,1)	0.5	0.5	95,995
	Time period (1,2)	2.0	0.2	95,995
	Healthcare past 12 months (1,2)	1.5	0.5	95,995
	Relationship power–differences (1,3)	1.8	0.6	95,995
	Age group (1,7)	3.9	1.7	95,995
	Residential stability (0,2)	0.7	0.7	95,995

SSA, Sub-Saharan Africa; SV, Spousal Violence; S.D., Standard Deviation; N, Number of Observations.

delays (Ayeni, 2016; Nyarko, 2016; Mutuku, 2023; Adesina, 2024), particularly the 1984 United Nations Mexico City International Conference on Population (United Nations, 1984); proxy measures for less documented national reproductive health policy changes within SSA (Seltzer, 2002; Garenne, 2018); cutoff points assumed equal outcome probability within birth cohorts.

2.2.1.3 Moderating variables

Neighborhood ethnic diversity (heterogeneity): In line with the analysis of Social Disorganization Theory (Sampson, 2012; Parks, 2013), as an interpretation of Symbolic Interactionism Theory (Goffman, 1974), I define the first moderating variable as a two-category measure coded (2) when the ethnic diversity within a survey cluster is greater than or equal to the sample grand mean ethnic diversity, and (1) otherwise. Survey clusters constitute neighborhoods. The sample grand mean ethnic diversity is estimated by dividing the total by the count of survey cluster estimates of ethnic diversity. Ethnic diversity is derived from the Entropy Index, which estimates cluster ethnicity distribution; lower scores signify low ethnic diversity, with negative scores viewed as lower than positive scores (Sampson, 2012; Parks, 2013).

Relationship power-difference: In line with sick-role theory (Parsons, 1975) as an interpretation of MD theory (Freidson, 1970; Toth, 2015), I define this second moderating variable. This is a derived measure of individual-level microsystem effects, coded (1) when respondents were in a union and were the principal decision-maker in at least one of three household decisions, (2) for respondents not currently in a union, and (0) otherwise (Rutstein and Rojas, 2006; Croft et al., 2023). Relationship power difference was used as a proxy measure for perpetrator behaviors, distinguishing between emotional, sexual, and physical violence solely and the former plus marital control issues (Rutstein and Rojas, 2006; Croft et al., 2023).

Healthcare system access: In line with macro-social policy and health inequalities theory (Solar et al., 2007; Quesnel-Vallée et al., 2021) as interpretations of Evolutionary Social Change Theory (Dietz et al., 1990), I define a proxy measure for national healthcare policy changes as the third moderating variable. Access estimates whether respondents sought family planning advice from healthcare professionals, had health insurance coverage, consulted skilled birth attendants for their most recent delivery, or delivered at a healthcare facility. The measure was coded (1) where healthcare access was reported in the 12 months preceding the survey, and (0) otherwise.

2.2.2 Control variables

First, measures to account for unaddressed mesosystem effects.

Neighborhood marital stability: Survey clusters constituted neighborhoods. Marital stability within the index survey cluster was calculated as the ratio of the proportion of divorced or separated persons amongst married persons to the proportion of single persons (Sampson, 2012; Parks, 2013).

Neighborhood residential stability: a three-category measure, was coded (0) for movers, (1) for non-movers, but (2) otherwise (Emina et al., 2011); survey clusters constituted neighborhoods.

TABLE 5 Victim decisions in spousal violence estimates in Sub-Saharan Africa among females aged 15–49, Latest Country Demographic and Health Surveys, 2003–2024.

Level	Predictors	Mean	S.D.	N	Mean	S.D.	*N*
		Discordant			Other		
VDSV3							
Survey	Survey ethnic diversity (−10.3,1)	−0.6	3.6	9	−2.7	4.8	11
Cluster	Cluster ethnic diversity (−10.1,1)	−0.9	2.3	2,340	−0.9	2.6	5,291
	Marital instability (0,30)	0.6	0.5	2,340	0.6	0.7	5,291
	Proportion secondary plus (0,1)	0.4	0.3	2,340	0.4	0.3	5,291
Household	Household wealth (1,5)	2.8	1.4	29,132	2.8	1.4	66,863
	Urban-rural residence (0,1)	0.3	0.5	29,132	0.3	0.5	66,863
Individual	Birth cohort (0,1)	0.5	0.5	29,132	0.5	0.5	66,863
	Time period (1,2)	2.0	0.2	29,132	1.9	0.2	66,863
	Healthcare past 12 months (1,2)	1.6	0.5	29,132	1.5	0.5	66,863
	Relationship power–differences (1,3)	1.8	0.6	29,132	1.8	0.6	66,863
	Age group (1,7)	3.9	1.7	29,132	3.9	1.7	66,863
	Residential stability (0,2)	0.7	0.6	29,132	0.7	0.7	66,863
VDSV2							
Survey	Survey ethnic diversity (−10.3,1)	−0.5	3.4	10	−2.9	5.0	10
Cluster	Cluster ethnic diversity (−10.1,1)	−0.8	2.2	2,252	−1.0	2.6	5,379
	Marital instability (0,30)	0.7	0.6	2,252	0.6	0.7	5,379
	Proportion secondary plus (0,1)	0.4	0.3	2,252	0.3	0.3	5,379
Household	Household wealth (1,5)	2.8	1.4	27,619	2.8	1.4	68,369
	Urban–rural residence (0,1)	0.3	0.5	27,619	0.3	0.5	68,369
Individual	Birth cohort (0,1)	0.5	0.5	27,619	0.5	0.5	68,369
	Time period (1,2)	2.0	0.2	27,619	1.9	0.2	68,369
	Healthcare past 12 months (1,2)	1.6	0.5	27,619	1.5	0.5	68,369
	Relationship power–differences (1,3)	1.8	0.7	27,619	1.8	0.6	68,369
	Age group (1,7)	4.0	1.6	27,619	3.9	1.7	68,369
	Residential stability (0,2)	0.7	0.6	27,619	0.7	0.7	68,369
VDSV1							
Survey	Survey ethnic diversity (−10.3,1)	−1.7	4.2	6	−1.7	4.5	14
Cluster	Cluster ethnic diversity (−10.1,1)	−0.9	2.5	3,510	−0.9	2.5	4,121
	Marital instability (0,30)	0.6	0.6	3,510	0.7	0.7	4,121
	Proportion secondary plus (0,1)	0.3	0.3	3,510	0.4	0.3	4,121
Household	Household wealth (1,5)	2.6	1.3	45,761	3.0	1.4	50,234
	Urban–rural residence (0,1)	0.3	0.4	45,761	0.4	0.5	50,234
Individual	Birth cohort (0,1)	0.5	0.5	45,761	0.5	0.5	50,234
	Time period (1,2)	1.9	0.2	45,761	2.0	0.2	50,234
	Healthcare past 12 months (1,2)	1.5	0.5	45,761	1.6	0.5	50,234
	Relationship power–differences (1,3)	1.8	0.6	45,761	1.8	0.7	50,234
	Age group (1,7)	3.9	1.7	45,761	4.0	1.7	50,234
	Residential stability (0,2)	0.8	0.7	45,761	0.6	0.6	50,234

S.D., Standard Deviation; N, Number of Observations; VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Violence Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience Notwithstanding Attitudes.

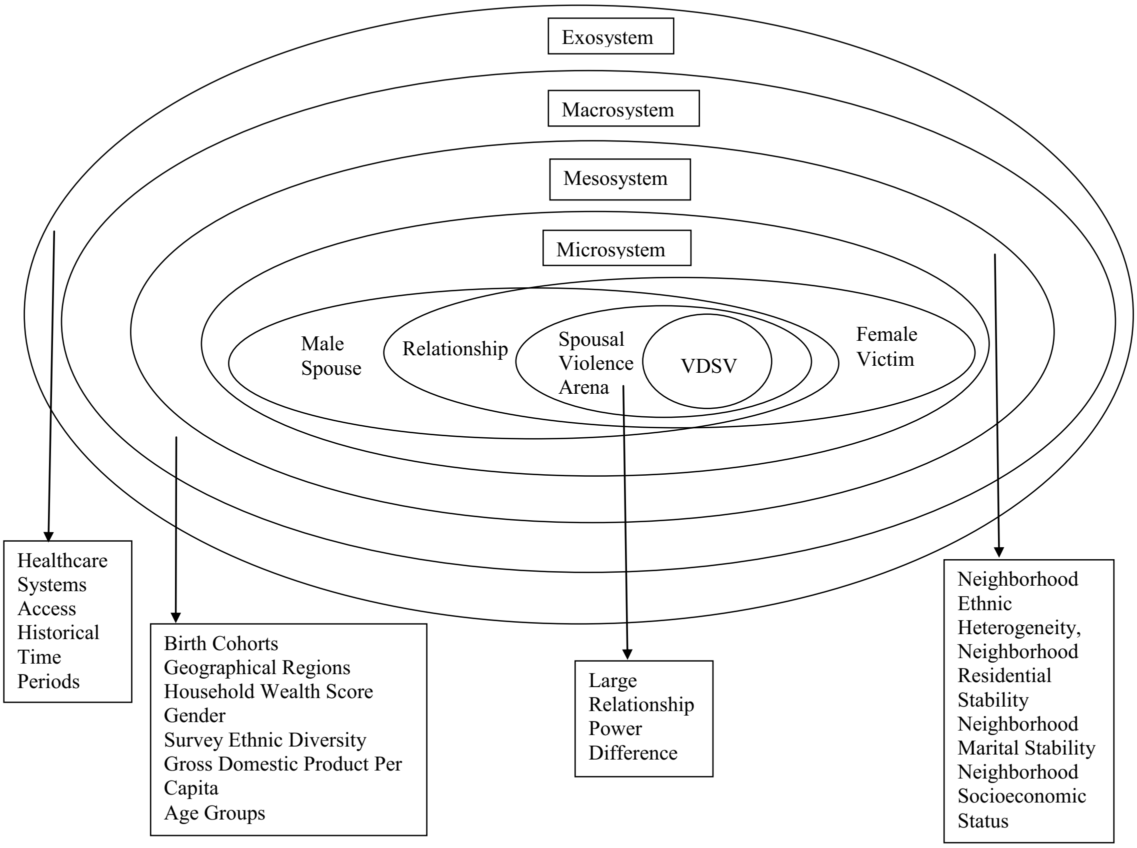

FIGURE 1
Conceptual framework for female victim decisions in spousal violence (VDSV) in Sub-Saharan Africa.

Within index households, stay duration was defined as the reported length of stay in years for those coded "96" or "visitor," but completed age in years for those coded "since birth" or "always."

Neighborhood socioeconomic status: Survey clusters constituted neighborhoods. Cluster Socioeconomic Status was indirectly estimated by calculating the proportion of women aged 15 to 49 years who have attained secondary education or higher (African Population and Health Research Center, 2002).

Furthermore, measures accounting for unaddressed macrosystem effects. Age groups, a derived measure of completed age in years at the time of the interview, categorized into 5-year intervals, ranging from 1 = 15–19 years to 7 = 45–49 years. Household Wealth Score, a derived measure of reported household assets and living conditions, was coded from 1 to 5, with 1 representing the poorest and 5 denoting the wealthiest households (Rutstein and Rojas, 2006; Croft et al., 2023). Gross Domestic Product (GDP) Per Capita was derived by country from International Monetary Fund estimates (IMF, 2024) to capture between-country socioeconomic differences (Magadi, 2017; Goodson and Hayes, 2021; IMF, 2024).

Survey ethnic diversity: In line with Social Disorganization Theory (Sampson, 2012; Parks, 2013), as an interpretation of Symbolic Interactionism Theory (Goffman, 1974), I define *Survey Ethnic Diversity* which is derived from the Entropy Index. It estimates various ethnic distributions within each country survey; lower scores indicate less ethnic diversity, with negative scores perceived as lower than positive scores (Sampson, 2012; Parks, 2013).

Moreover, measures adjusting for unaddressed exosystem effects. *Historical Time Periods*, a derived three-category variable, was coded (1) for surveys conducted between 1990 and 2000, (2) for 2001 to 2010, and (3) for 2011 to 2024, aligned with the 'Time, Human Agency and Social Change' Theory (Elder Jr, 1994), providing interpretations of structural-functionalism theory (Dillon, 2020), and serving as a proxy measure for changes across DHS Data Collection Phases (Rutstein and Rojas, 2006; Croft et al., 2023).

Finally, measures to address unexamined structural-level macrosystem effects. *Geographical Regions*, a classification derived from the countries where interviews were conducted, coded 1 for East, 2 for South, and 3 for West Africa.

2.3 Empirical analysis

2.3.1 Descriptive analysis

Each categorical variable was assessed for zero cell values, and recategorizations were implemented where necessary (Lewis-Beck, 1995). For every variable, central tendency and dispersion were estimated using means and standard deviations, respectively (Lewis-Beck, 1995; Lewis-Beck and Lewis-Beck, 2016). For continuous variables, histograms and skewness statistics were employed to evaluate the normality of the variable distribution (Lewis-Beck, 1995; Fox, 2016; Lewis-Beck and Lewis-Beck, 2016); normality implied that means were equal to modes and medians. Regarding skewness statistics, results with p-value ≥ 0.05 indicated normality assumptions could be rejected and suitable transformations could be applied (Lewis-Beck, 1995); all such continuous variables were converted into categorical variables (Lee and Forthofer, 2006). All descriptive analyses were conducted using STATA 16.0; see Tables 1–5.

2.3.2 Multivariate analysis

The multivariate analysis sample was restricted to the most recent 2001–2024 country DHS data, focusing on 193,232 women aged 15–49 years. Unadjusted Odds Ratios (ORs) were employed to evaluate the strength of the bivariate association between the dependent variables, VDSV patterns 1–3, and the primary explanatory variable, birth cohorts (Liebetrau, 1983; Lewis-Beck and Lewis-Beck, 2016). The moderating effects of neighborhood ethnic heterogeneity, relationship power difference, and healthcare systems accessibility were subsequently evaluated through interaction terms added to the base models. Control measures, such as household wealth and age groups, were also included in the models to account for potential confounding effects. Analyses were based on cross-sectional data; thus, the results reflect neither a causal association nor the direction of the association (Liebetrau, 1983).

A two-level hierarchical multinomial logistic regression model (Gelman and Hill, 2007; Luke, 2020; Rabe-Hesketh and Skrondal, 2022) was fitted to assess VDSV variation across birth cohorts while controlling for potential confounding effects from social-theory-derived determinants at the individual, cluster, and household levels as fixed effects (level 1), and for country effects as random effects (level 2). Within countries, household-level clustering was comparably limited within the sample (Tables 4, 5), but spatial interpolation was employed to account for clustering at the geographical cluster level (Galster, 2012; Duncan and Kawachi, 2018). Across countries, cluster-level and household-level effects helped to account for the hierarchical structure and clustering within DHS datasets (ICF International, 2012; Greenwell and Salentine, 2018). At the country level, random effects accommodate the possibility that, given the average values of all other independent variables, the probability of the outcome varies due to clustering (Gelman and Hill, 2007; Luke, 2020; Rabe-Hesketh and Skrondal, 2022). However, spatial interpolation effects account for the possibility that even within countries, the likelihood of the outcome additionally varies across geographical clusters (Galster, 2012; Duncan and Kawachi, 2018). All multivariate analyses were performed using the mblogit function in the mclogit package (Elff, 2022) of the R programming language version 4.4.0 (R Development Core Team, 2025), which adjusts for survey weights and design by incorporating sampling weights in the likelihood function (Elff, 2022).

Sample weight use is occasionally debated (Winship and Radbill, 1994; Lee and Forthofer, 2006); however, sampling weights were applied to adjust for non-response and oversampling. P-values of ≤ 0.05 were considered statistically significant. Independent variables' standard error (SE) precision and likelihood ratio test-based parameter testing were employed. Ultimately, the reported results utilized adjusted odds ratios (ORs) with 95% confidence intervals (CIs). Maximum likelihood estimation (MLE) was sought at 100 iterations to achieve convergence Ors (Andersen, 2008). In addition to ORs, post-estimation tests were performed to confirm that multivariate models fitted the data better than null models (prtest ≤ 0.05) (Hoffmann, 2004; Fox, 2016), including predicted marginal probabilities (Curtis et al., 1993; Fox, 2016), Wald tests (Hoffmann, 2004; Fox, 2016), Akaike Information Criterion (AIC), and Bayesian Information Criterion (BIC) scores (Hoffmann, 2004), alongside model log-likelihood tests (Hoffmann, 2004). Statistical conclusion validity, evaluating the plausibility of study findings, was assessed through external validity measures (Trochim, 2005). The Relative Index of Inequality (RII) estimates (Sergeant and Firth, 2006; O'Donnell and Wagstaff, 2008; Moreno-Betancur et al., 2015) were used to evaluate final models against relevant social theories (Trochim, 2005), particularly those addressing socioeconomic disparities in healthcare access. Some limitations in the validity assessments were noted (Fleck and Kuhn, 1979; Trochim, 2005; White, 2015).

3 Results

3.1 Descriptive analysis results

Tables 1–3 highlight regional variations in SV Experience and VDSV rates across Sub-Saharan Africa (SSA). Compared to SV experience rates in SSA (45.5%), SV experience rates are highest in Western Africa (50.3%), followed by Eastern Africa (44.8%) and Southern Africa (38.0%). For VDSV, the highest rates are seen for Other type VDSV2 (31.6%), Other type VDSV3 (31.0%), and Other type VDSV1 (23.6%). Lower rates occur for Discordant VDSV1 (20.7%), Discordant VDSV3 (13.5%), and Discordant VDSV2 (12.8%). Specifically, for the most reported VDSV types, the highest Other type VDSV2 rates are observed in Western Africa (37.2%), Eastern Africa (30.8%), and Southern Africa (26.9%), conversely the highest Discordant VDSV1 rates are observed in Eastern Africa (26.4%), Western Africa (23.3%), and Southern Africa (12.5%). Additionally, regional estimates of women's spousal violence against partners (calculations not shown) reveal the highest rates in Southern Africa (3.82%), followed by Western Africa (3.69%) and Eastern Africa (2.97%), compared to SSA (3.52%).

Table 4 indicates that in the final analytical sample, spousal violence was more commonly reported in survey years characterized by comparatively lower survey ethnic entropy/diversity, lower cluster ethnic entropy/diversity, lower cluster marital instability, and lower cluster proportions of women with secondary education or higher. Additionally, spousal violence victims were of lower socioeconomic status, lower urbanicity, younger birth cohorts, slightly better healthcare system accessibility, less women's final say in household decision-making, and higher residential stability when compared to women not reporting spousal violence.

TABLE 6 Multivariate multinomial logistic regression model selection for birth cohort differences in victim decisions in spousal violence in Sub-Saharan Africa demographic health surveys 2003–2024.

		df	AIC	BIC	Log-lik. (Full)	LRTest	Deviance
By VDSV1							
M1	Birth cohorts + other predictors (Mean Values)	43	331,511.7	331,949.6	−165,712.9	97,889.2	331,425.7
M2	Birth cohorts * cluster ethnic diversity + other predictors (mean values)	47	331,414.3	331,892.8	−165,660.1	97,994.6	331,320.3
M3	Birth cohorts * cluster ethnic diversity * relationship power-difference + other predictors (mean values)	63	312,073.8	312,715.3	−155,973.9	117,367.1	311,947.8
M4	Birth cohorts * cluster ethnic diversity * relationship power-difference * healthcare systems access + other predictors (mean values)	87	310,666	311,551.9	−155,246	118,822.9	310,492
N	Sample size (weighted)						195,389.6
By VDSV2							
M1	Birth cohorts + other predictors (mean values)	43	325,990.7	326,428.5	−162,952.3	103,410.2	325,904.7
M2	Birth cohorts * cluster ethnic diversity + other predictors (mean values)	47	325,923.3	326,401.9	−162,914.7	103,485.6	325,829.3
M3	Birth cohorts * cluster ethnic diversity * relationship power-difference + other predictors (mean values)	63	306,449	307,090.5	−153,161.5	122,991.9	306,323
M4	Birth cohorts * cluster ethnic diversity * relationship power-difference * healthcare systems access + other predictors (mean values)	87	305,127.7	306,013.6	−152,476.8	124,361.2	304,953.7
N	Sample size (weighted)						195,389.6
By VDSV3							
M1	Birth cohorts + other predictors (mean values)	43	328,560.9	328,998.8	−164,237.5	100,839.9	328,474.9
M2	Birth cohorts * cluster ethnic diversity + other predictors (mean values)	47	328,494	328,972.6	−164,200	100,914.9	328,400
M3	Birth cohorts * cluster ethnic diversity * relationship power-difference + other predictors (mean values)	63	309,142	309,783.5	−154,508	120,298.9	309,016
M4	Birth cohorts * cluster ethnic diversity * relationship power-difference * healthcare systems access + other predictors (mean values)	87	307,806.9	308,692.8	−153,816.5	121,682	307,632.9
N	Sample size (weighted)						195,389.6

Author calculations using Demographic and Health Survey Data, 2003–2024.

VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help For Spousal Violence Despite Spousal Violence Accepting Attitudes; VDSV3, Sought Help For Spousal Violence After Spousal Violence Experience Notwithstanding Attitudes; AIC, Aikake Criteria: lower values are better for prediction; BIC, Bayesian Information Criteria: smaller positive BIC is better and indicates a better model fit; Log lik. , Log Likelihood Full. Model: higher positive and lower negative values indicate better fit; df, Degrees of freedom: higher values are best fitted for predictions and generally mean larger sample sizes. Higher degrees of freedom also mean more power to reject a false null hypothesis and find a statistically significant result. Deviance: Lower deviance values indicate a better model fit. LRTest: The larger the difference between the null model (a constant-only model) and the current model, including predictors, the stronger the evidence that the model is significant.

Table 5 shows that among those reporting spousal violence, notwithstanding VDSV type, Discordant VDSV and Other type VDSV are evenly distributed across pre-1986 and post-1986 birth cohorts. Discordant VDSV1 and VDSV2 typically occur in areas with lower ethnic diversity, while Other VDSV1 and VDSV2 types were found in higher diversity areas; however, both Discordant and Other type VDSV appear equally in VDSV3 contexts. Across relationship power differences, not much variability is observed when comparing Discordant VDSV against Other type VDSV. Regarding healthcare system access, while Discordant VDSV1 and Discordant VDSV2 were more common among women with better access, Discordant VDSV3 is more prevalent among those with less healthcare access.

3.2 Multivariate model selection

Table 6 presents potential regression models of cohort disparities in VDSV in SSA. Based on the reviewed MD literature, four models were evaluated (M1–M4); centered on the lowest AICs, lowest BICs, highest positive and lowest negative log-likelihoods, highest degrees of freedom, lowest deviance, and largest difference between the null model (constant-only model) and the current model, M4 was selected. Typically, the best models were selected based on AIC and BIC measures, but other information criteria, such as log-likelihoods and degrees of freedom, deviance, and likelihood ratio tests (LR tests), helped resolve discrepancies among models. While AIC determines the best predictive models and BIC helps select the "true" model amongst multiple possible

TABLE 7 Estimated odds ratios (or) and confidence intervals (ci) for spousal violence accepting attitudes despite spousal violence experience across birth cohort differences in Sub-Saharan Africa, Latest Country DHS 2003–2024.

Predictors	Categories	Discordant VDSV1		Other type VDSV1	
		OR	CI	OR	CI
	(Intercept)	1.17	0.55–2.47	2.32	0.94–5.75
Birth cohort	BC2 (*Ref*:BC1)	1.10	0.86–1.42	1.09	0.83–1.43
Cluster ethnic diversity	NE2 (*Ref*:NE1)	0.82	0.74–0.90	0.90	0.81–1.00
Relationship power-difference	PD2 (*Ref*:PD1)	0.72	0.59–0.88	0.95	0.77–1.18
	PD3	0.82	0.66–1.03	0.75	0.58–0.97
Healthcare systems access	HC2 (*Ref*:HC1)	0.89	0.70–1.12	1.40	1.08–1.81
Urban residence	Rural (*Ref*:Urban)	1.10	1.07–1.14	1.03	0.99–1.07
Wealth quintile	Poorer (*Ref*.Poorest)	0.99	0.95–1.03	0.90	0.86–0.94
	Middle	0.95	0.91–0.99	0.80	0.77–0.83
	Richer	0.83	0.79–0.87	0.62	0.59–0.65
	Richest	0.66	0.62–0.69	0.38	0.36–0.40
Historical time period	2013–2024 (*Ref*:2003–2012)	0.36	0.18–0.74	0.34	0.14–0.82
Cluster residential stability	Non–Movers (*Ref*:Movers)	1.13	1.10–1.17	1.13	1.10–1.17
	Others	0.64	0.38–1.07	1.43	0.76–2.68
Age group	20–24(*Ref*:15–19)	2.86	2.70–3.03	2.06	1.95–2.18
	25–29	3.85	3.63–4.08	2.56	2.41–2.70
	30–34	4.38	4.11–4.67	2.85	2.67–3.03
	35–39	4.66	4.32–5.03	3.16	2.92–3.41
	40–44	4.66	4.30–5.05	3.05	2.81–3.32
	45–49	4.97	4.57–5.40	3.18	2.92–3.47
Survey ethnic diversity		1.02	0.98–1.07	1.02	0.96–1.08
GDP per capita		1.00	1.00–1.00	1.00	1.00–1.00
Cluster secondary plus proportion		0.88	0.82–0.95	0.46	0.42–0.50
Cluster marital instability		0.90	0.88–0.92	0.84	0.82–0.87
Interaction term 1	BC2*NE2	1.09	0.94–1.26	1.07	0.91–1.25
Interaction term 2	BC2*NE2*PD2	0.96	0.80–1.15	0.96	0.79–1.16
	BC2*NE2*PD3	1.59	1.30–1.95	1.68	1.33–2.12
Interaction term 3	BC2*NE2*PD2*HC2	0.91	0.71–1.16	0.74	0.57–0.96
	BC2*NE2*PD3*HC2	0.78	0.58–1.06	0.43	0.31–0.61
Observations		195,389			

Demographic and Health Surveys(DHS), 2003–2024.

Ref., Reference Category; BC1, Pre-1986, BC2, 1986+; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity, NE2, Sample Grand Mean and Greater; PD1, Final Say in Household Decisions, PD2, No Final Say, PD3, Never Married; HC1, No Healthcare Access, HC2, Healthcare Access in Past 12 Months; VDSV1, Spousal Violence Accepting Attitudes Despite Spousal Violence Experience; GDP, Gross Domestic Product; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions.

models, higher degrees of freedom suggest larger sample sizes and, subsequently, better false null hypotheses rejection; typically, the lowest AICs and highest log-likelihoods also went together (Hoffmann, 2004; Fox, 2016).

3.3 Multivariate analysis results

Tables 7–9 present odds ratios for VDSV1, VDSV2, and VDSV3 across birth cohorts (BCs), neighborhood ethnic heterogeneity (NE), relationship power differences (PDs), and healthcare systems access (HC), adjusted for other related predictors. Conversely, Tables 10–14 present changes in predicted marginal probabilities for VDSV1, VDSV2, and VDSV3 across birth cohorts (before and after 1986) adjusted for similar factors with other predictors held constant at mean values.

Do birth cohorts explain VDSV in SSA? To what extent? (Hypothesis 1). Table 10 reveals that when holding other predictors constant at mean values, a 1-unit increase in BCs was associated

TABLE 8 Estimated odds ratios (OR) and confidence intervals (CI) for sought help for spousal violence despite accepting attitudes across birth cohort differences in Sub-Saharan Africa, Latest Country DHS 2003–2024.

Predictors	Categories	Discordant VDSV2		Other type VDSV2	
		OR	CI	OR	CI
	(Intercept)	3.00	1.66–5.45	0.67	0.27–1.64
Birth cohort	BC2 (*Ref*:BC1)	1.13	0.89–1.44	1.06	0.79–1.42
Cluster ethnic Diversity	NE2 (*Ref*:NE1)	0.87	0.80–0.96	0.84	0.75–0.94
Relationship Power-Difference	PD2 (*Ref*:PD1)	0.89	0.74–1.07	0.67	0.53–0.85
	PD3	0.82	0.66–1.02	0.74	0.56–0.97
Healthcare Systems Access	HC2 (*Ref*:HC1)	1.10	0.88–1.38	0.98	0.74–1.28
Urban Residence	Rural (*Ref*:Urban)	1.06	1.02–1.09	1.09	1.04–1.14
Wealth Quintile	Poorer (*Ref*.Poorest)	0.95	0.91–0.98	0.92	0.88–0.97
	Middle	0.87	0.84–0.91	0.85	0.81–0.90
	Richer	0.73	0.70–0.77	0.70	0.66–0.73
	Richest	0.54	0.51–0.56	0.47	0.44–0.50
Historical Time Period	2013–2024 (*Ref*:2003–2012)	0.29	0.16–0.50	0.52	0.22–1.21
Cluster Residential Stability	Non-movers (*Ref*:Movers)	1.09	1.06–1.12	1.28	1.23–1.32
	Others	1.07	0.71–1.60	0.68	0.36–1.26
Age Group	20–24 (*Ref*:15–19)	2.29	2.18–2.41	2.78	2.59–2.99
	25–29	2.89	2.75–3.04	3.86	3.59–4.15
	30–34	3.27	3.09–3.45	4.39	4.05–4.76
	35–39	3.54	3.30–3.78	4.79	4.36–5.26
	40–44	3.57	3.32–3.84	4.46	4.03–4.92
	45–49	3.82	3.54–4.12	4.55	4.10–5.04
Survey Ethnic Diversity		1.02	0.98–1.05	1.04	0.98–1.09
GDP Per Capita		1.00	1.00–1.00	1.00	1.00–1.00
Cluster Secondary Plus Proportion		0.64	0.59–0.68	0.80	0.73–0.88
Cluster Marital Instability		0.87	0.86–0.89	0.89	0.86–0.91
Interaction Term 1	BC2*NE2	1.07	0.93–1.23	1.08	0.91–1.28
Interaction Term 2	BC2*NE2*PD2	0.97	0.82–1.14	0.94	0.76–1.17
	BC2*NE2*PD3	1.62	1.34–1.97	1.60	1.24–2.07
Interaction term 3	BC2*NE2*PD2*HC2	0.83	0.66–1.04	0.86	0.65–1.15
	BC2*NE2*PD3*HC2	0.64	0.48–0.86	0.60	0.41–0.87
Observations		195389			

Demographic and Health Surveys(DHS), 2003–2024.

Ref., Reference Category; BC1, Pre-1986, BC2, 1986+; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity, NE2, Sample Grand Mean and Greater; PD1, Final Say in Household Decisions, PD2, No Final Say, PD3, Never Married; HC1, No Healthcare Access, HC2, Healthcare Access in Past 12 Months; VDSV2, Sought Help for Spousal Violence despite Accepting Attitudes; GDP, Gross Domestic Product; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions.

with changes of 0.55%, minus 0.11%, and 0.71% in predicted marginal probabilities of Discordant VDSV1, VDSV2, and VDSV3, respectively; furthermore, changes of 4.86%, 5.14%, and 5.14%, respectively, in Other VDSV1, VDSV2, and VDSV3 types.

Does neighborhood ethnic heterogeneity moderate birth cohort differences in VDSV? To what extent? (Hypothesis 1). In sub-Saharan Africa, Table 10 indicates, while holding other predictors constant at mean values, with every 1-unit increase in BCs and corresponding 1-unit increase in cluster ethnic diversity, 1.45%, 0.86%, and 2.02% changes in predicted marginal probabilities of Discordant VDSV1, VDSV2, and VDSV3 in neighborhoods with ethnic heterogeneity less than sample grand mean, compared to minus 0.01%, minus 0.70%, and minus 0.10% changes in neighborhoods with ethnic heterogeneity equal to or greater than sample grand mean, respectively. Additionally, Table 10 indicates that under similar conditions, neighborhoods with below sample grand mean ethnic heterogeneity experience 2.07%, 2.13%, and 2.13% changes in predicted marginal probabilities

TABLE 9 Estimated odds ratios (OR) and confidence intervals (CI) for sought help for spousal violence after spousal violence experience notwithstanding attitudes across birth cohort differences in Sub-Saharan Africa, Latest Country DHS 2003–2024.

Predictors	Categories	Discordant VDSV3		Other type VDSV3	
		OR	CI	OR	CI
	(Intercept)	2.75	1.47–5.18	0.87	0.37–2.03
Birth Cohort	BC2 (*Ref*:BC1)	1.09	0.86–1.38	1.19	0.88–1.61
Cluster Ethnic Diversity	NE2 (*Ref*:NE1)	0.85	0.78–0.93	0.89	0.80–1.00
Relationship Power-Difference	PD2 (*Ref*:PD1)	0.82	0.68–0.98	0.83	0.66–1.05
	PD3	0.85	0.69–1.06	0.65	0.49–0.87
Healthcare Systems Access	HC2 (*Ref*:HC1)	1.02	0.81–1.28	1.16	0.88–1.52
Urban Residence	Rural (*Ref*:Urban)	1.06	1.03–1.10	1.07	1.03–1.12
Wealth Quintile	Poorer (*Ref*.Poorest)	0.94	0.91–0.98	0.93	0.89–0.97
	Middle	0.86	0.83–0.90	0.87	0.83–0.91
	Richer	0.72	0.69–0.75	0.73	0.69–0.77
	Richest	0.53	0.50–0.55	0.50	0.47–0.53
Historical Time Period	2013–2024 (*Ref*:2003–2012)	0.30	0.16–0.54	0.46	0.20–1.03
Cluster Residential Stability	Non–Movers (*Ref*:Movers)	1.13	1.10–1.16	1.17	1.13–1.21
	Others	1.11	0.72–1.71	0.62	0.35–1.12
Age Group	20–24 (*Ref*:15–19)	2.42	2.31–2.55	2.40	2.24–2.56
	25–29	3.16	3.01–3.32	3.06	2.86–3.28
	30–34	3.61	3.41–3.81	3.40	3.16–3.67
	35–39	3.93	3.67–4.21	3.66	3.34–4.00
	40–44	3.94	3.67–4.24	3.47	3.15–3.82
	45–49	4.06	3.76–4.38	3.89	3.52–4.29
Survey Ethnic Diversity		1.02	0.98–1.06	1.03	0.97–1.08
GDP Per Capita		1.00	1.00–1.00	1.00	1.00–1.00
Cluster Secondary Plus Proportion		0.65	0.60–0.70	0.76	0.69–0.84
Cluster Marital Instability		0.88	0.86–0.89	0.88	0.85–0.91
Interaction Term 1	BC2*NE2	1.09	0.95–1.26	1.02	0.86–1.21
Interaction Term 2	BC2*NE2*PD2	0.95	0.80–1.12	1.00	0.81–1.24
	BC2*NE2*PD3	1.69	1.39–2.05	1.46	1.12–1.91
Interaction Term 3	BC2*NE2*PD2*HC2	0.86	0.68–1.08	0.78	0.58–1.03
	BC2*NE2*PD3*HC2	0.63	0.48–0.84	0.62	0.42–0.91
Observations		195389			

Demographic and Health Surveys(DHS), 2003–2024.

Ref., Reference Category; BC1, Pre-1986, BC2, 1986+; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity, NE2, Sample Grand Mean and Greater; PD1, Final Say in Household Decisions, PD2, No Final Say, PD3, Never Married; HC1, No Healthcare Access, HC2, Healthcare Access in Past 12 Months; VDSV3 , Sought Help for Spousal Violence after Spousal Violence Experience; GDP, Gross Domestic Product; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions.

of Other VDSV1, VDSV2, and VDSV3 types, compared to 6.73%, 7.13%, and 7.13% changes in neighborhoods with greater ethnic heterogeneity.

Do relationship power difference and neighborhood ethnic heterogeneity moderate birth cohort differences in VDSV? To what extent? (Hypothesis 2). In SSA, Table 11 indicates, while holding

TABLE 10 Effects of neighborhood ethnic heterogeneity (NE) on percent change across birth cohorts (BC) in predicted probabilities of victim decisions in spousal violence (VDSV) in Sub-Saharan Africa, Latest Country DHS 2003–2024.

VDSV	Region	BC	BC/NE1	BC/NE2
Discord VDSV1	Sub-Saharan Africa	0.55	1.45	(0.01)
	Eastern Africa	0.81	1.50	0.36
	Southern Africa	0.53	1.44	(0.06)
	Western Africa	0.29	1.40	(0.33)
Discord VDSV2	Sub-Saharan Africa	(0.11)	0.86	(0.70)
	Eastern Africa	0.04	0.92	(0.50)
	Southern Africa	(0.08)	0.84	(0.67)
	Western Africa	(0.30)	0.83	(0.93)
Discord VDSV3	Sub-Saharan Africa	0.71	2.02	(0.10)
	Eastern Africa	0.83	2.04	0.06
	Southern Africa	0.79	2.02	0.00
	Western Africa	0.51	2.01	(0.36)
Other VDSV1	Sub-Saharan Africa	4.86	2.07	6.73
	Eastern Africa	5.14	2.13	7.13
	Southern Africa	4.85	2.07	6.67
	Western Africa	4.60	2.02	6.38
Other VDSV2	Sub-Saharan Africa	5.14	2.13	7.13
	Eastern Africa	4.03	1.81	5.52
	Southern Africa	3.91	1.74	5.34
	Western Africa	3.68	1.72	5.06
Other VDSV3	Sub-Saharan Africa	5.14	2.13	7.13
	Eastern Africa	3.75	1.42	5.29
	Southern Africa	3.71	1.40	5.23
	Western Africa	3.42	1.39	4.85

Author calculations using Demographic and Health Survey (DHS), 2003–2024.
VDSV1, Spousal Violence Accepting Attitudes despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence despite Accepting Attitudes; VDSV3, Sought Help for Spousal Violence after Spousal Violence Experience; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity; NE2, Sample Grand Mean and Greater; Discord=Discordant Decisions; Other, No Decision or Concordant Decisions.

other predictors at mean values, with every 1-unit increase in BCs, average changes in Discordant VDSV1 probabilities of 46.2%, 3.7%, and minus 46.9% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in cluster ethnic diversity below sample grand mean. In contrast, average changes in Discordant VDSV1 probabilities of 46.1%, 3.4%, and minus 46.6% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to the sample grand mean. Additionally, Other VDSV1 probabilities reflect changes of 40.4%, 7.6%, and minus 40.5% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity below sample grand mean, compared to average changes in Other VDSV1 probabilities of 37.9%, 7.3%, and minus 39.1% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to sample grand mean.

In SSA, Table 11 indicates, while holding other predictors at mean values, with every 1-unit increase in BCs, average changes in Discordant VDSV2 probabilities of 43.3%, 4.7%, and minus 48.2% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in cluster ethnic diversity below sample grand mean. In contrast, average changes in Discordant VDSV2 probabilities of 37.6%, 2.7%, and minus 44.5% across relationship power-differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to the sample grand mean. Additionally, Other VDSV2 probabilities reflect changes of 47.9%, 5.8%, and minus 48.8% across relationship power-differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity below sample grand mean, compared to average changes in Other VDSV2 probabilities of 45.4%, 8.9%, and minus 41.0% across relationship power-differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to sample grand mean.

In SSA, Table 11 indicates, while holding other predictors at mean values, with every 1-unit increase in BCs, average changes in Discordant VDSV3 probabilities of 43.1%, 5.8%, and minus 47.1% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in cluster ethnic diversity below sample grand mean. In contrast, average changes in Discordant VDSV3 probabilities of 40.4%, 3.4%, and minus 44.7% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to the sample grand mean. Additionally, other VDSV3 probabilities reflect changes of 48.1%, 5.5%, and minus 49.3% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity below sample grand mean, compared to average changes in Other VDSV3 probabilities of 44.4%, 8.7%, and minus 40.8% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity greater than or equal to sample grand mean.

Do birth cohorts on VDSV effects, varying across relationship power difference and neighborhood ethnic heterogeneity, also differ with healthcare systems' accessibility? To what extent? (Hypothesis 3).

3.3.1 Discordant VDSV1, VDSV2, and VSDV3

In SSA, Table 12 shows, across HC1, with other predictors held constant at mean values, for each 1-unit increase in BCs, Discordant VDSV1 probabilities change by 51.9%, minus 4.1%, and minus 63.3% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, where cluster ethnic diversity is below the sample grand mean. In contrast, with cluster ethnic diversity at or above the grand mean, the changes were 47.4%, minus 4.7%, and minus 60.9%. Additionally, under similar conditions, across HC2, Discordant VDSV1 probabilities change by 41.1%, 11.8%, and minus 25.1% across relationship power differences, small (PD1), large (PD2),

TABLE 11 Effects of neighborhood ethnic heterogeneity (NE) and relationship power difference (PD) on percent change across birth cohorts (BC) in predicted probabilities of victim decisions in spousal violence (VDSV) in Sub-Saharan Africa, Latest Country DHS 2003–2024.

VDSV	Region	BC /NE1 /PD1	BC /NE1 /PD2	BC /NE1 /PD3	BC /NE2 /PD1	BC /NE2 /PD2	BC /NE2 /PD3
Discord VDSV1	Sub-Saharan Africa	46.18	3.74	(46.93)	46.11	3.41	(46.59)
	Eastern Africa	45.52	3.96	(46.84)	47.19	3.71	(47.00)
	Southern Africa	47.59	3.65	(47.20)	48.43	3.48	(47.27)
	Western Africa	45.44	3.61	(46.73)	42.72	3.02	(45.50)
Discord VDSV2	Sub-Saharan Africa	43.31	4.71	(48.23)	37.56	2.69	(44.49)
	Eastern Africa	44.97	4.85	(48.70)	39.87	3.01	(45.11)
	Southern Africa	42.77	4.67	(48.18)	39.09	2.82	(45.17)
	Western Africa	42.17	4.61	(47.82)	33.72	2.23	(43.19)
Discord VSDV3	Sub-Saharan Africa	43.07	5.83	(47.12)	39.95	3.39	(44.70)
	Eastern Africa	44.51	5.93	(47.63)	41.87	3.67	(45.32)
	Southern Africa	42.61	5.80	(47.07)	41.84	3.60	(45.36)
	Western Africa	42.10	5.75	(46.67)	36.14	2.91	(43.42)
Other VDSV1	Sub-Saharan Africa	40.37	7.61	(40.52)	37.88	7.29	(39.07)
	Eastern Africa	39.73	7.84	(40.43)	38.89	7.61	(39.54)
	Southern Africa	41.71	7.52	(40.84)	40.06	7.36	(39.85)
	Western Africa	39.65	7.48	(40.30)	34.67	6.89	(37.83)
Other VDSV2	Sub-Saharan Africa	47.91	5.80	(48.80)	45.39	8.88	(40.95)
	Eastern Africa	49.63	5.94	(49.26)	47.83	9.23	(41.61)
	Southern Africa	47.36	5.76	(48.75)	47.00	9.02	(41.67)
	Western Africa	46.74	5.70	(48.39)	41.33	8.40	(39.57)
Other VDSV3	Sub-Saharan Africa	48.07	5.47	(49.25)	44.41	8.65	(40.81)
	Eastern Africa	49.56	5.58	(49.73)	46.40	8.94	(41.48)
	Southern Africa	47.59	5.45	(49.20)	46.37	8.88	(41.52)
	Western Africa	47.06	5.39	(48.81)	40.48	8.14	(39.44)

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

VDSV1, Spousal Violence Accepting Attitudes Despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience; NE1, Less than Sample Grand Cluster Mean Ethnic Diversity; NE2, Sample Grand Mean and Greater Neighborhood Ethnic Diversity; PD1, Final Say in Household Decisions; PD2, No Final Say; PD3, Never Married; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions.

and never-married (PD3) where cluster ethnic diversity is below sample grand mean, compared to changes of 45.8%, 11.8%, and minus 28.3% where cluster ethnic diversity at or above the sample grand mean.

Furthermore, in SSA, Table 12 indicates, across HC1, while holding other predictors constant at mean values, for each 1-unit increase in BCs, average changes in Discordant VDSV2 probabilities are 54.8%, minus 6.0%, and minus 72.1% across relationship power-differences, small (PD1), large (PD2), and never-married (PD3) respectively, in clusters ethnic diversity below the sample grand mean. In contrast, for cluster ethnic diversity at or above the grand mean, the changes are 51.1%, minus 3.3%, and minus 62.6%. Additionally, across HC2, under similar conditions, the average changes in Discordant VDSV2 probabilities were 30.9%, 16.3%, and minus 9.1% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in cluster ethnic diversity below the sample grand mean, compared to 25.1%, 8.5%, and minus 19.6% for cluster ethnic diversity at or above the sample grand mean.

Finally, in SSA, Table 12 indicates, across HC1, with other predictors held constant at mean values, for each 1-unit increase in BCs, average changes in Discordant VDSV3 probabilities are 58.9%, minus 3.9%, and minus 71.7% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in clusters ethnic diversity below the sample grand mean. In contrast, for cluster ethnic diversity at or above the grand mean, the changes are 50.9%, minus 5.8%, and minus 64.5%. Additionally, across HC2, under similar conditions, the average changes in Discordant VDSV3 probabilities were 27.0%, 16.1%, and minus 6.6% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in cluster ethnic diversity below sample grand mean, compared to 30.0%, 13.2%, and minus 15.7% for cluster ethnic diversity at or above the sample grand mean.

TABLE 12 Effect of healthcare systems accessibility (HC) on percent change across birth cohorts (BC) in predicted probabilities of discordant victim decisions in spousal violence (VDSV) in Sub-Saharan Africa adjusted for neighborhood ethnic heterogeneity (NE), relationship power difference (PD), Latest Country DHS 2003–2024.

VDSV	Region	HC	BC/NE1/ PD1	BC/NE1/ PD2	BC/NE1/ PD3	BC/NE2/PD1	BC/NE2/ PD2	BC/NE2/ PD3
Discord VDSV1	Sub-Saharan Africa	HC1	51.90	(4.14)	(63.26)	47.41	(4.72)	(60.90)
	Eastern Africa	HC1	51.87	(3.76)	(63.31)	49.46	(4.45)	(61.41)
	Southern Africa	HC1	53.07	(4.41)	(63.43)	49.66	(4.89)	(61.50)
	Western Africa	HC1	50.76	(4.25)	(63.03)	43.10	(4.82)	(59.80)
	Sub-Saharan Africa	HC2	41.14	11.81	(25.10)	45.82	11.78	(28.32)
	Eastern Africa	HC2	39.71	11.78	(24.76)	45.75	12.09	(28.36)
	Southern Africa	HC2	42.89	11.98	(25.48)	48.29	12.17	(28.94)
	Western Africa	HC2	40.84	11.66	(25.05)	43.43	11.06	(27.67)
Discord VDSV2	Sub-Saharan Africa	HC1	54.82	(5.96)	(72.14)	51.13	(3.27)	(62.62)
	Eastern Africa	HC1	57.59	(5.77)	(72.45)	54.24	(3.11)	(63.21)
	Southern Africa	HC1	53.85	(6.09)	(72.16)	53.21	(3.29)	(63.25)
	Western Africa	HC1	53.02	(6.04)	(71.83)	45.94	(3.40)	(61.41)
	Sub-Saharan Africa	HC2	30.93	16.34	(9.12)	25.05	8.47	(19.63)
	Eastern Africa	HC2	31.59	16.37	(9.60)	26.65	8.97	(20.01)
	Southern Africa	HC2	30.79	16.41	(8.94)	26.07	8.78	(20.07)
	Western Africa	HC2	30.41	16.22	(8.81)	22.42	7.65	(18.82)
Discord VDSV3	Sub-Saharan Africa	HC1	58.86	(3.85)	(71.72)	50.86	(5.78)	(64.51)
	Eastern Africa	HC1	61.06	(3.77)	(72.08)	53.45	(5.61)	(65.05)
	Southern Africa	HC1	58.13	(3.85)	(71.70)	53.36	(5.73)	(65.10)
	Western Africa	HC1	57.40	(3.93)	(71.39)	45.76	(5.99)	(63.38)
	Sub-Saharan Africa	HC2	26.97	16.11	(6.59)	29.86	13.18	(15.69)
	Eastern Africa	HC2	27.73	16.22	(7.04)	31.14	13.56	(16.15)
	Southern Africa	HC2	26.73	16.05	(6.55)	31.18	13.59	(16.12)
	Western Africa	HC2	26.45	16.05	(6.18)	27.26	12.39	(14.80)

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

VDSV1, Spousal Violence Accepting Attitudes Despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Spousal Violence Experience; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity; NE2, ; Sample Grand Mean and Greater Neighborhood Ethnic Diversity; na, Not Applicable; HC1, No Healthcare Access; HC2, Healthcare Access in Past 12 Months; PD1, Final Say in Household Decisions; PD2, No Final Say; PD3, Never Married; Discord, Discordant Decision; Other, Unknown or Concordant Decisions.

3.3.2 Other type VDSV1, VDSV2, and VSDV3

In SSA, Table 13 shows, with other predictors held constant at mean values, for every 1-unit increase in BCs, average changes in Other VDSV1 type probabilities across HC1 are 59.1%, minus 3.7%, and minus 59.0% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, in clusters ethnic diversity below the sample grand mean. In contrast, for cluster ethnic diversity at or above the grand mean, the changes are 56.0%, minus 3.2%, and minus 56.7%. Similarly, for HC2, average changes in Other VDSV1 type probabilities are 23.4%, 10.9%, and minus 15.7% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity below the sample grand mean, compared to 21.7%, 10.8%, and minus 15.7% for cluster ethnic diversity at or above the sample grand mean.

Furthermore, In SSA, Table 13 indicates, with other predictors held constant at mean values, for each 1-unit increase in BCs, average changes in Other VDSV2 type probabilities across HC1 are 69.7%, 2.1%, and minus 70.0% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, with cluster ethnic diversity below the sample grand mean. In contrast, for cluster ethnic diversity at or above the grand mean, the changes are 60.2%, 4.2%, and minus 59.1%. Similarly, across HC2, average changes of 26.7%, 8.8%, and minus 17.8% in Other VDSV2 type probabilities are observed across relationship power differences, small (PD1), large (PD2), and never-married (PD3), for cluster ethnic diversity below sample grand mean, compared to 31.8%, 13.1%, and minus 17.1% for cluster ethnic diversity at or above the sample grand mean.

Finally, in SSA, Table 13 indicates, with other predictors held constant at mean values, for each 1-unit increase in BCs, average

TABLE 13 Effect of healthcare systems accessibility (HC) on percent change across birth cohorts (BC), in predicted probabilities of other victim decisions in spousal violence (VDSV) in Sub-Saharan Africa adjusted for neighborhood ethnic heterogeneity (NE), and relationship power difference (PD), Latest Country DHS 2003–2024.

VDSV	Region	HC	BC/NE1/PD1	BC/NE1/PD2	BC/NE1/PD3	BC/NE2/PD1	BC/NE2/PD2	BC/NE2/PD3
OtherVDSV1	Sub-Saharan Africa	HC1	59.12	3.67	(58.97)	55.97	3.19	(56.66)
	Eastern Africa	HC1	59.09	4.09	(59.03)	58.14	3.48	(57.23)
	Southern Africa	HC1	60.35	3.38	(59.16)	58.35	3.00	(57.32)
	Western Africa	HC1	57.93	3.55	(58.72)	51.41	3.09	(55.44)
	Sub Saharan Africa	HC2	23.42	10.89	(15.73)	21.68	10.75	(15.67)
	Eastern Africa	HC2	22.16	10.87	(15.36)	21.62	11.06	(15.72)
	Southern Africa	HC2	24.95	11.06	(16.16)	23.74	11.14	(16.40)
	Western Africa	HC2	23.15	10.75	(15.68)	19.68	10.04	(14.91)
OtherVDSV2	Sub-Saharan Africa	HC1	69.65	2.08	(70.04)	60.17	4.20	(59.08)
	Eastern Africa	HC1	72.68	2.29	(70.37)	63.46	4.37	(59.73)
	Southern Africa	HC1	68.59	1.95	(70.06)	62.38	4.17	(59.77)
	Western Africa	HC1	67.68	2.00	(69.70)	54.67	4.05	(57.75)
	Sub-Saharan Africa	HC2	26.72	8.82	(17.83)	31.77	13.07	(17.12)
	Eastern Africa	HC2	27.36	8.85	(18.27)	33.46	13.60	(17.51)
	Southern Africa	HC2	26.59	8.90	(17.67)	32.85	13.40	(17.56)
	Western Africa	HC2	26.22	8.72	(17.55)	29.01	12.22	(16.28)
OtherVDSV3	Sub-Saharan Africa	HC1	67.95	1.59	(70.14)	60.68	5.70	(58.07)
	Eastern Africa	HC1	70.27	1.67	(70.52)	63.45	5.89	(58.71)
	Southern Africa	HC1	67.18	1.59	(70.11)	63.35	5.76	(58.77)
	Western Africa	HC1	66.41	1.50	(69.79)	55.25	5.46	(56.73)
	Sub-Saharan Africa	HC2	28.43	8.68	(19.08)	29.52	10.88	(18.87)
	Eastern Africa	HC2	29.20	8.79	(19.47)	30.79	11.25	(19.31)
	Southern Africa	HC2	28.19	8.63	(19.05)	30.83	11.28	(19.29)
	Western Africa	HC2	27.90	8.63	(18.73)	26.92	10.10	(18.01)

Author Calculations using Demographic and Health Surveys (DHS), 2003–2024.

VDSV1, Spousal Violence Accepting Attitudes Despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Violence Experience; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity; NE2, Sample Grand Mean and Greater; na, Not Applicable; HC1, No Access; HC2, Access in Past 12 Months; PD1, Final Say in Household Decisions; PD2, No Final Say; PD3, Never Married; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions.

changes in Other VDSV3 type probabilities across HC1 are 68.0%, 1.6%, and minus 70.1% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), respectively, with cluster ethnic diversity below the sample grand mean. When cluster ethnic diversity is at or above the grand mean, the changes are 60.7%, 5.7%, and minus 58.1%. Furthermore, across HC2, under similar conditions, average changes in Other VDSV3 types probabilities are 28.4%, 8.7%, and minus 19.1% across relationship power differences, small (PD1), large (PD2), and never-married (PD3), in cluster ethnic diversity below sample grand mean, compared to 29.5%, 10.9% and minus 18.9% at or above the sample grand mean.

3.3.3 Statistical conclusion validity assessment

Table 14 presents results of the external validity assessment, including the relative index of inequality (RII) estimates comparing predicted marginal probabilities from final models for the poorest and richest groups (SES1 and SES5). The final model probabilities were those adjusted for BCs, NE, PD, and HC (discussed above). The RII estimates confirm that healthcare access contributes to cohort disparities in VDSV in SSA; smaller poor-rich ratios of Discordant VDSV1, VDSV2, and VDSV3 probabilities for each 1-unit increase in BCs among women reporting healthcare systems access in the 12 months preceding the survey compared to those reporting no access. The above-observed patterns are further supported by smaller poor-rich ratios of Other type VDSV1, VDSV2, and VDSV3 probabilities for each 1-unit increase in BCs changes among women reporting healthcare systems access in the 12 months preceding the survey.

4 Discussion and conclusion

Contradictory evidence exists on whether medicine may explain social disparities in health perceptions. This study examines whether medicine could explicate social differences, particularly

TABLE 14 Socioeconomic differences (SES) in healthcare systems access (HC) effects on percent change across birth cohorts (BC) in predicted probabilities of victim decisions in spousal violence (VDSV) in Sub-Saharan Africa, adjusted for neighborhood ethnic heterogeneity (NE) and relationship power differences (PD), Latest Country DHS 2003–2024.

VDSV	HC	RII	NE1	NE1	NE1	NE2	NE2	NE2
			PD1	PD2	PD3	PD1	PD2	PD3
Discord VDSV1	HC1	SES1	0.61	0.90	0.93	0.62	1.05	0.92
		/SES5						
	HC2	SES1	0.62	0.74	0.63	0.69	0.72	0.87
		/SES5						
Discord VDSV2	HC1	SES1	0.58	0.97	0.93	0.60	1.13	0.92
		/SES5						
	HC2	SES1	0.68	0.78	0.68	0.61	0.65	0.83
		/SES5						
Discord VDSV3	HC1	SES1	0.59	0.98	0.93	0.60	1.08	0.92
		/SES5						
	HC2	SES1	0.65	0.78	0.54	0.65	0.75	0.79
		/SES5						
Other VDSV1	HC1	SES1	0.61	1.14	0.92	0.64	0.98	0.90
		/SES5						
	HC2	SES1	0.71	0.66	0.88	0.57	0.76	0.70
		/SES5						
Other VDSV2	HC1	SES1	0.62	1.10	0.92	0.63	0.90	0.91
		/SES5						
	HC2	SES1	0.64	0.65	0.84	0.67	0.75	0.80
		/SES5						
Other VDSV3	HC1	SES1	0.62	1.04	0.92	0.63	0.92	0.90
		/SES5						
	HC2	SES1	0.66	0.65	0.84	0.65	0.71	0.82
		/SES5						

Author calculations using Demographic and Health Surveys (DHS), 2003–2024.

VDSV1, Spousal Violence Accepting Attitudes Despite Spousal Violence Experience; VDSV2, Sought Help for Spousal Violence Despite Spousal Accepting Attitudes; VDSV3, Sought Help for Spousal Violence After Violence Experience; NE1, Less than Sample Grand Mean Cluster Ethnic Diversity; NE2, Sample Grand Mean and Greater; na, Not Applicable; HC1, No Access; HC2, Access in Past 12 Months; SES5, Richest Wealth Quintile; SES1, Poorest Wealth Quintile; PD1, Final Say in Household Decisions; PD2, No Final Say; PD3, Never Married; Discord, Discordant Decisions; Other, Unknown or Concordant Decisions; RII, Relative Index of Inequality Estimates (SES5/SES1).

cohort differences in victim decisions in spousal violence (VDSV) in sub-Saharan Africa (SSA); herein, "medicine" serves as a controlled environment or "mesocosm" for observing natural behaviors (Odum, 1984), while VDSV represents spousal violence (SV) perceptions.

Across BCs, a greater percentage change in predicted marginal probabilities for other type VDSV compared to discordant VDSV was observed at mean values. When analyzing neighborhood ethnic heterogeneity, a smaller increase across BCs in predicted marginal probabilities was observed for discordant VDSV compared to other type VDSV in higher cluster ethnic diversity areas (NE2) compared to lower cluster ethnic diversity areas (NE1); observed differences diminished after adjusting for relationship power differences and healthcare system access.

Regarding the overall direction of change across BCs, the findings suggest that across large power difference (PD1), both Discordant and Other type VDSV probabilities increase across BCs; younger cohorts exhibit higher VDSV rates. Across never-married women (PD3), both Discordant and Other type VDSV probabilities decrease across BCs; younger cohorts demonstrate lower VDSV rates. However, across small power difference (PD2), mixed patterns emerged: among those with recent healthcare access (HC2), both Discordant and Other type VDSV predicted marginal probabilities increase across BCs; younger cohorts exhibit greater VDSV rates. However, among those without recent healthcare access (HC1), the probabilities decrease across BCs, which means younger cohorts show lower VDSV rates.

Specifically concerning healthcare access, the following patterns were observed. For large power difference (PD1), for example, women with recent healthcare access (HC2) show about half the percentage change across BCs in Discordant and Other type VDSV-predicted marginal probabilities compared to those without. Similarly, for never-married women (PD3), the change is about a quarter. In contrast, for small power difference (PD2), women with recent healthcare access (HC2) experience a threefold change in Discordant and Other type VDSV-predicted marginal probabilities compared to those without.

Finally, the statistical conclusion validity assessment (Trochim, 2005) using Relative Index of Inequality (RII) estimates (Sergeant and Firth, 2006; O'Donnell and Wagstaff, 2008; Moreno-Betancur et al., 2015) confirms that healthcare systems access modifies socioeconomic health inequalities in the study sample, though some limitations were noted in the validity assessments (Fleck and Kuhn, 1979; White, 2015).

Household-level findings support the medical dominance (MD) theory, which examines social interactions within healthcare systems through the lens of relationship power asymmetry and its effects (Freidson, 1970; Starr, 1982). First, evidence concurs that power-asymmetry relationships, such as those in spouse–partner relationships, identical to physician–patient relationships, are biased across specific social factors (Abbott, 1988; Dillon, 2020); statistical significance for selected social determinants, relationship power differences, and healthcare system accessibility were observed. Moreover, findings challenge the value-free perspective of the sick-role theory (Parsons, 1975; Dillon, 2020), and reveal statistically significant cross-system interaction modification effects for spouse–partner relationships, similar to those in physician–patient relationships; power-asymmetry relationships may be value-influenced (Conrad and Schneider, 1992; Dillon, 2020).

Furthermore, observed cross-systemic interaction effects corroborate macro-societal socio-ecological theories (Bronfenbrenner, 2005; Mackie et al., 2015) by illustrating how structure-constrained human agency can affect VDSV (Archer, 2000; Davidson, 2015); discordant decision-making has been associated with constrained individual agency (Davidson, 2015; Kabiru et al., 2017). Moreover, statistically significant healthcare systems access effects partially support medical mesocosms (Odum, 1984), which suggests that medical dominance (MD) theory via pattern-matching (Trochim, 2005; Punch, 2014) may illuminate socio-behavioral patterns within spousal violence in households in SSA. Finally, healthcare access effects on cohort differences in VDSV highlight the broad positive social impacts of adequate healthcare, including reducing socioeconomic inequalities in health (Phelan et al., 2010; Quesnel-Vallée et al., 2021), despite known limitations (Great Britain Working Group on Inequalities in Health et al., 1982; Lutfey and Freese, 2005; Frohlich and Abel, 2014).

The increase in predicted marginal probabilities for Other type VDSV across BCs concurs with lower acceptance of SV amongst younger age groups in SSA (ICF, 2012b), despite higher SV incidence potentially confounding the results (UN-WOMEN, 2024).

Research on healthcare systems access and spousal violence in SSA suggests that variations in VDSV may relate to differing exposure to anti-violence interventions at healthcare facilities (Sprague et al., 2016; Hatcher et al., 2019). Similarly, the power difference measure reflects differing women's autonomy in healthcare decisions (Rutstein and Rojas, 2006; Croft et al., 2023); going from pre-1986 to post-1986 birth cohorts, observed VDSV predicted marginal probabilities change across both healthcare systems access and relationship power differences (small, large, and never-married). Additionally, study results emphasize the moderating effect of relationship power difference (UN-WOMEN, 2024).

Despite limitations, research in SSA also concurs that medicine can help reduce social health inequalities, for instance, among the urban poor facing poor health outcomes and limited healthcare access (African Population and Health Research Center, 2002, 2014). First, medical research has increased awareness of social health disparities related to urban–rural and within-urban area differences (Ezeh et al., 2017; Lilford et al., 2017). Moreover, access to maternal healthcare, such as the Output-Based Aid (OBA) Voucher Program, has resulted in fewer home deliveries (Bellows et al., 2012) and lower infant mortality risks (Amendah et al., 2013). However, it correlates with higher spousal violence (Izugbara and Ngilangwa, 2010; Njuki et al., 2012) and increased maternal mortality risks due to inadequate healthcare resources (Ziraba et al., 2009b), as well as the threat of catastrophic healthcare costs (Buigut et al., 2015). Additionally, immunization interventions have not fully resolved inequities in access (Ettarh et al., 2012; Egondi et al., 2015).

Still, interpretations must acknowledge several study limitations. First, household surveys pose several challenges. Spatial interpolation of self-reported data for neighborhood-level measures may exacerbate inaccuracies, underestimating highs and overestimating lows (Van Ham and Manley, 2012; Duncan and Kawachi, 2018). Sampling errors can occur (McNabb, 2020; Olson, 2020) due to the underrepresentation of wealthier households (Wolff, 1987) and imprecision at smaller sub-national levels (ICF International, 2012; Greenwell and Salentine, 2018). Additionally, other errors (McNabb, 2020; Olson, 2020), such as non-response and underreporting (Wolff, 1987; Morelli et al., 2015) and their subsequent effects, such as selection, reporting, and recall biases (Wolff, 1987; O'Donnell and Wagstaff, 2008). To address these issues, the results were adjusted for socioeconomic disparities (Trochim, 2005), and sample weights were applied to account for non-response and underreporting (Lee and Forthofer, 2006). Recent surveys helped mitigate recall and reporting biases (Magadi and Desta, 2011), and control groups of unaffected women were included to reduce selection bias (Lee and Forthofer, 2006). Nationally representative household surveys remain crucial in countries with limited vital statistics (Joubert et al., 2012; Ye et al., 2012). However, implementation challenges, such as poor weather and limited resource availability (Iburg et al., 2001; Greenwell and Salentine, 2018), can cause delays between surveys, impacting pooled analyses (Iburg et al., 2001; Croft et al., 2023); predefined data collection periods, DHS Phase Identifiers, were established to help manage these delays (UNICEF, 2015; Greenwell and Salentine, 2018).

Second, outside low-and-middle-income countries, SV interventions target both public health and legal redress systems (Rizo and Macy, 2011; Prosman et al., 2014; Huntley et al., 2019; Satyen et al., 2019), within SSA; however, policy-makers, partly due to reported SV-accepting social norm barriers in legal redress systems (Odero et al., 2014; Mannell et al., 2016; Gillum et al., 2018), primarily advance public health SV interventions (Joyner, 2013), which may bias study findings (Shadish et al., 2001; Trochim, 2005). During the Coronavirus disease (COVID-19) lockdowns, for instance, SV victims increased, but healthcare systems worldwide prioritized COVID-19 (Akudolu et al., 2023; UN-WOMEN, 2024). Some post-pandemic studies suggested roles for alternative SV support from informal neighborhood social networks, multi-sectoral government support, and non-governmental organizations (Kibe et al., 2020; Wood et al., 2022a; Engdawork et al., 2024). Other studies, however, advocated for healthcare systems support, recommending health caregiver re-training (Wood et al., 2022b) and expanded allied health professionals' involvement, such as including radiologists (Matoori et al., 2021).

Third, to mitigate the risk of social desirability bias in discussions about marriage and sexuality (Ezenweke, 2016; Mannell et al., 2016), a behavioral measure was employed to capture SV perceptions (Mackie et al., 2015). Additionally, to mitigate survey data limitations, several constructed or proxy measures, such as healthcare systems access, were incorporated (Croft et al., 2023). Moreover, the measurement framework used, drawn from macro-meso-micro analogy (Mackie et al., 2015), constitutes multiple social theories but limited accounting for between-theory mediation effects (Ransome, 2010); predictive margins estimated socio-ecological theory hypothesized macro, mezzo, micro, and exosystem interaction effects (Wright, 1997; Bronfenbrenner, 2005), achieving reproducibility (Trochim, 2005; Punch, 2014) but compromising other conditional interaction possibilities (Ransome, 2010; Galster, 2012; Dahlgren and Whitehead, 2021). Moreover, pattern-matching Leventhal's "common-sense-model" theory, which utilizes cyclic illness perception measures (Leventhal et al., 2016), VDSV1, VDSV2, and VDSV3, was derived from related measures, SV experience, help-seeking for SV, and SV accepting attitudes, a suboptimal approach due to internal validity risks (Shadish et al., 2001; Trochim, 2005). Overall, non-standardized measures can undermine plausibility testing, aka. related research evidence comparability (Pearlin, 1989; Cohen et al., 1995; Wright, 1997), a critical factor for establishing strong causal associations (Bonita et al., 2006; Oakes and Kaufman, 2017); evidence on challenges associated with different conceptualizations of stress (Pearlin, 1989; Cohen et al., 1995) and social class (Wright, 1997) corroborate this. Nonetheless, differing trends in VDSV patterns 1 and 2 counter VDSV 3, suggesting that alternative measures may provide valuable insights, augmenting existing survey practices, specifically concerning VDSV pattern 3 (Croft et al., 2023).

Furthermore, the question arises, why, despite known limitations (Odum, 1984; Carpenter, 1996), interrogate esoteric human behavior through mesocosms of equivalent better-understood human behavior? For theory and practice, partially significant healthcare system access modification results imply fragmentary multi-contextual importance of healthcare mesocosms. A contra-mesocosm argument of Parsons' teacher–student and physician–patient interactions' mesocosms (Dillon, 2020) maybe that, while current social systemic influence, including systemic interactions influence, is assumed, unique preceding social system influence is ignored, such as across gender, race, and social class (Zgourides and Zgourides, 2000). System stativity and stability are also incorrectly assumed, and person-to-person differences are ignored (Zgourides and Zgourides, 2000). Moreover, a contra-mesocosm argument of the physician–patient and spouse–partner relationships' mesocosm may be that, while spouse–partner power-asymmetry is primarily personal, physician–patient power-asymmetry is mainly professional (Dillon, 2020), as such, equal power asymmetry may be inconsonant.

Contra-mesocosm debates also incorporate pro-microcosm and pro-macrocosm analogy debates. Pro-microcosm analogy debates suggest using smaller social context studies to explicate larger contexts or single-case studies to explicate multi-person case studies. Specifically, pro-microcosm debates include bridging social process expectations and reality (Auyero, 1999) and transcending social attitudes to illustrate the social phenomenon under study (LaPiere, 1934), such as through participatory observation (Hochschild, 1997; Olson, 2020). Pro-macrocosm analogy debates postulate using larger social contexts to explicate smaller contexts or many to explain one, such as multi-country studies. Specifically, pro-macrocosm debates include relatively low costs for comprehensive large-number studies (Lamont and Swidler, 2014) and within-study error correction methods (Jerolmack and Khan, 2014; Lamont and Swidler, 2014) for misreporting (Jerolmack and Khan, 2014) or bias (Lamont and Swidler, 2014), cross-disciplinary transference (Lamont and Swidler, 2014).

Pro-mesocosm debates encompass contra-microcosm and contra-macrocosm analogy debates. Contra-microcosm analogy debates include limited generalizability of study findings (Weiss, 2004; Small, 2009), positionality bias (McCorkel and Myers, 2003; Takacs, 2003), and overdependence on master narratives (McCorkel and Myers, 2003) for unique stories (Katz, 1997). Contra-macrocosm analogy debates include objectivity rather than subjectivity, implying limited in-depth subject study (Lamont and Swidler, 2014), outlier exclusion (Lamont and Swidler, 2014), and methodological individualism (Heath, 2005), as opposed to collectivism, where social groups and structures primarily explain individuals. However, results illustrate mesocosm applicability, MD, to understanding social systems' influence on VDSV within households in SSA, which also endures across different VDSV estimation methods, postulating strong mesocosm effects.

Study results advocate healthcare systems' approaches to social problems (Conrad and Schneider, 1992; Ityo, 2010; UN-WOMEN, 2024) in SSA, specifically healthcare systems' theory-based approaches. Healthcare system access effects indicate VDSV sensitivity to macro-societal changes, suggesting roles for macro-societal policy (UN-WOMEN, 2024). Notably, the data indicate shifts in cohort differences correspond with significant reproductive health policy milestones, such as the 1984 Mexico International Conference on Population Development (United Nations, 1984). Findings emphasize comprehensive yet localized adoption of macro-societal policies, such as supporting evidence-based best practices in the ongoing implementation of The Maputo Protocol of 1995 (Ayeni, 2016; Nyarko, 2016; Mutuku, 2023; Adesina, 2024). Future research may explore the implications of such findings today, particularly in light of donor healthcare funding cuts in developing countries (Bosire, 2025; World Health Organization, 2025).

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://dhsprogram.com/data/available-datasets.cfm.

Ethics statement

Ethical approval was not required for the study involving human data in accordance with the local legislation and institutional requirements. Written informed consent to participate in this study was not required in accordance with the national legislation and the institutional requirements.

Author contributions

PE: Writing – original draft, Writing – review & editing, Formal analysis.

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Conflict of interest

The author declares that the research was conducted in the absence of any commercial or financial relationships that could be construed as a potential conflict of interest.

Publisher's note

References

Abbott, A. D. (1988). *The System of Professions: An Essay on the Division of Expert Labor*. Chicago: University of Chicago Press. doi: 10.7208/chicago/9780226189666.001.0001

Abramsky, T., Devries, K., Kiss, L., Nakuti, J., Kyegombe, N., Starmann, E., et al. (2014). Findings from the SASA! Study: a cluster randomized controlled trial to assess the impact of a community mobilization intervention to prevent violence against women and reduce HIV risk in Kampala, Uganda. *BMC Med.* 12:122. doi: 10.1186/s12916-014-0122-5

Adesina, O. (2024). Article 9 of The Maputo Protocol and The Advancement of Political Rights for Women in Nigeria. *Afr. J. Psychol. Stud. Soc. Issues* 27, 146–162. doi: 10.6084/m9.figshare.25249972

African Population and Health Research Center (2002). *Population and Health Dynamics in Nairobi's Informal Settlements.* Nairobi: APHRC.

African Population and Health Research Center (2014). *Population and Health Dynamics in Nairobi's Informal Settlements: Report of the Nairobi Cross-Sectional Slums Survey (NCSS) 2012.* Nairobi: APHRC.

Africapractice (2024). Femicide in Kenya and the resounding call for accountability. Available online at: https://africapractice.com/insights/ (Accessed August 1, 2024).

Ahmad, F., Driver, N., McNally, M. J., and Stewart, D. E. (2009). "Why doesn't she seek help for partner abuse?" An exploratory study with South Asian immigrant women. *Soc. Sci. Med.* 69, 613–622. doi: 10.1016/j.socscimed.2009.06.011

Akudolu, L. O., Okolie, C. N., Okoro, E. A., Nwamuo, B. E., Okeke, I., Aigbonoga, S., et al. (2023). Global rise in gender-based violence against women and girls during COVID-19 lockdown: An insight from Africa. *Cogent Arts Humanit.* 10:2188772. doi: 10.1080/23311983.2023.2188772

Alexander, G. R., Kogan, M. D., and Nabukera, S. (2002). Racial differences in prenatal care use in the United States: are disparities decreasing? *Am. J. Public Health* 92, 1970–1975. doi: 10.2105/AJPH.92.12.1970

Allen, M., and Devitt, C. (2012). Intimate Partner Violence and Belief Systems in Liberia. *J. Interpers. Violence* 27, 3514–3531. doi: 10.1177/0886260512445382

Alubo, O., and Hunduh, V. (2017). Medical dominance and resistance in Nigeria's health care system. *Int. J. Health Serv.* 47, 778–794. doi: 10.1177/0020731416675981

Amendah, D. D., Mutua, M. K., Kyobutungi, C., Buliva, E., and Bellows, B. (2013). Reproductive health voucher program and facility based delivery in informal settlements in Nairobi: a longitudinal analysis. *PLoS ONE* 8:e80582. doi: 10.1371/journal.pone.0080582

Ananth, C. V., Misra, D. P., Demissie, K., and Smulian, J. C. (2001). Rates of preterm delivery among Black women and White women in the United States over two decades: an age-period-cohort analysis. *Am. J. Epidemiol.* 154, 657–665. doi: 10.1093/aje/154.7.657

Andersen, R. (2008). *Modern Methods for Robust Regression*. Los Angeles: Sage Publications. doi: 10.4135/9781412985109

Archer, M. S. (2000). *Being Human: the Problem of Agency*. Cambridge, U.K. ; New York: Cambridge University Press. doi: 10.1017/CBO9780511488733

Arestoff, F., and Djemai, E. (2016). Women's empowerment across the life cycle and generations: evidence from Sub-Saharan Africa. *World Dev.* 87, 70–87. doi: 10.1016/j.worlddev.2016.06.002

Armstrong, D. (1995). The rise of surveillance medicine. *Sociol. Health Illn.* 17, 393–404. doi: 10.1111/1467-9566.ep10933329

Assari, S. (2013). Multilevel approach to intimate partner violence research and prevention. *Int. J. Prev. Med.* 4, 616–617.

Auyero, J. (1999). "From the client's point (s) of view": how poor people perceive and evaluate political clientelism. *Theory Soc.* 28, 297–334. doi: 10.1023/A:1006905214896

Ayeni, V. (2016). "The Impact of the African Charter and the Maputo Protocol in Nigeria," in *The Impact of the African Charter and Maputo Protocol in Selected African States*, ed. V. Ayeni (South Africa: Pretoria University Law Press), 183–202.

Balogun, M. O., and John-Akinola, Y. O. (2015). A qualitative study of intimate partner violence among women in Nigeria. *J. Interpers. Violence* 30, 2410–2427. doi: 10.1177/0886260514553112

Bellows, B., Kyobutungi, C., Mutua, M. K., Warren, C., and Ezeh, A. (2012). Increase in facility-based deliveries associated with a maternal health voucher programme in informal settlements in Nairobi, Kenya. *Health Policy Plan.* 28, 134–142. doi: 10.1093/heapol/czs030

Berhanie, E., Gebregziabher, D., Berihu, H., Gerezgiher, A., and Kidane, G. (2019). Intimate partner violence during pregnancy and adverse birth outcomes: a case-control study. *Reprod. Health* 16:22. doi: 10.1186/s12978-019-0670-4

Bernstein, M., Phillips, T., Zerbe, A., McIntyre, J. A., Brittain, K., Petro, G., et al. (2016). Intimate partner violence experienced by HIV-infected pregnant women in South Africa: a cross-sectional study. *BMJ Open* 6:e011999. doi: 10.1136/bmjopen-2016-011999

Bhuwania, P., and Heymann, J. (2022). Tuition-free secondary education and women's attitudes toward intimate partner violence: evidence from Sub-Saharan Africa. *SSM - Popul. Health* 17:101046. doi: 10.1016/j.ssmph.2022.101046

Bonita, R., Beaglehole, R., and Kjellström, T. (2006). *Basic Epidemiology*. Geneva: World Health Organization.

Bosire, N. (2025). *Health funding cuts: We must stop weeping and start building.* Dly. Nation. Available online at: https://nation.africa/kenya/health/health-funding-cuts-we-must-stop-weeping-and-start-building-4919350 (Accessed May 10, 2025).

Bronfenbrenner, U. (2005). *Making Human Beings Human: Bioecological Perspectives On Human Development*. Thousand Oaks: Sage Publications.

Buigut, S., Ettarh, R., and Amendah, D. D. (2015). Catastrophic health expenditure and its determinants in Kenya slum communities. *Int. J. EQUITY Health* 14. doi: 10.1186/s12939-015-0168-9

Carpenter, S. R. (1996). Microcosm experiments have limited relevance for community and ecosystem ecology. *Ecology* 77, 677–680. doi: 10.2307/2265490

Christofides, N., and Jewkes, R. (2010). Acceptability of universal screening for intimate partner violence in voluntary HIV testing and counseling services in South Africa and service implications. *AIDS Care* 22, 279–285. doi: 10.1080/09540120903193617

Coburn, D. (1993). State authority, medical dominance, and trends in the regulation of the health-professions - the ontario case. *Soc. Sci. Med.* 37, 841–850. doi: 10.1016/0277-9536(93)90137-S

Coburn, D. (1999). Phases of capitalism, welfare states, medical dominance, and health care in Ontario. *Int. J. Health Serv.* 29, 833–851. doi: 10.2190/57WB-A3D1-GE4V-B437

Coggon, D., Barker, D., and Rose, G. (2009). *Epidemiology for the Uninitiated*. New York: John Wiley and Sons.

Cohen, S., Kessler, R. C., and Gordon, L. U. (1995). "Strategies for measuring stress in studies of psychiatric and physical disorders," in *Measuring stress: A guide for health and social scientists*, eds. R. C. Kessler and L. U. Gordon (Oxford: Oxford University Press), 3–26. doi: 10.1093/oso/9780195086416.003.0001

Colombini, M., Dockerty, C., and Mayhew, S. H. (2017). Barriers and facilitators to integrating health service responses to intimate partner violence in low- and middle-income countries: a comparative health systems and service analysis. *Stud. Fam. Plann.* 48, 179–200. doi: 10.1111/sifp.12021

Colombini, M., Mayhew, S., and Watts, C. (2008). Health-sector responses to intimate partner violence in low- and middle-income settings: a review of current models, challenges and opportunities. *Bull. World Health Organ.* 86, 635–642. doi: 10.2471/BLT.07.045906

Conrad, P. (1992). Medicalization and social control. *Annu. Rev. Sociol.* 18, 209–232. doi: 10.1146/annurev.so.18.080192.001233

Conrad, P. (2005). The shifting engines of medicalization. *J. Health Soc. Behav.* 46, 3–14. doi: 10.1177/002214650504600102

Conrad, P. (2007). *The Medicalization of Society: on the Transformation of Human Conditions into Treatable Disorders*. Baltimore: Johns Hopkins University Press. doi: 10.56021/9780801885846

Conrad, P., and Schneider, J. W. (1992). *Deviance and Medicalization : From Badness To Sickness : With a New Afterword by the Authors*. Philadelphia: Temple University Press.

Cooper, R. J., Bissell, P., Ward, P., Murphy, E., Anderson, C., Avery, T., et al. (2012). Further challenges to medical dominance? The case of nurse and pharmacist supplementary prescribing. *Health* 16, 115–133. doi: 10.1177/1363459310364159

Corburn, J., and Hildebrand, C. (2015). Slum sanitation and the social determinants of women's health in Nairobi, Kenya. *J. Environ. Public Health* 2015:209505. doi: 10.1155/2015/209505

Corburn, J., and Sverdlik, A. (2017). Slum upgrading and health equity. *Int. J. Environ. Res. Public. Health* 14:342. doi: 10.3390/ijerph14040342

Croft, T. N., Allen, C. K., and Zachary, B. W. (2023). *Guide to DHS Statistics*. Calverton, MD: ORC Macro.

Curtis, S. L., Diamond, I., and McDonald, J. W. (1993). Birth interval and family effects on postneonatal mortality in Brazil. *Demography* 30, 33–43. doi: 10.2307/2061861

Dahlgren, G., and Whitehead, M. (2021). The Dahlgren-Whitehead model of health determinants: 30 years on and still chasing rainbows. *Public Health* 199, 20–24. doi: 10.1016/j.puhe.2021.08.009

Davidson, A. (2015). *Social Determinants of Health: A Comparative Approach.* Oxford: Oxford University Press.

Decker, M. R., Nair, S., Saggurti, N., Sabri, B., Jethva, M., Raj, A., et al. (2013). Violence-related coping, help-seeking and health care-based intervention preferences among perinatal women in Mumbai, India. *J. Interpers. Violence* 28, 1924–1947. doi: 10.1177/0886260512469105

Delamou, A., Samandari, G., Camara, B. S., Traore, P., Diallo, F. G., Millimono, S., et al. (2015). Prevalence and correlates of intimate partner violence among family planning clients in Conakry, Guinea. *BMC Res. Notes* 8, 814–814. doi: 10.1186/s13104-015-1811-7

Dietz, T., Burns, T. R., and Buttel, F. H. (1990). Evolutionary theory in sociology: an examination of current thinking. *Sociol. Forum* 5, 155–171. doi: 10.1007/BF01112590

Dillon, M. (2020). *Introduction to Sociological Theory: Theorists, Concepts, and Their Applicability to the Twenty-First Century.* New York: John Wiley and Sons.

Duncan, D. T., and Kawachi, I. (2018). *Neighborhoods and Health*. New York: Oxford University Press. doi: 10.1093/oso/9780190843496.003.0001

Egondi, T., Oyolola, M., Mutua, M. K., and Elung'ata, P. (2015). Determinants of immunization inequality among urban poor children: evidence from Nairobi's informal settlements. *Int. J. Equity Health* 14:24. doi: 10.1186/s12939-015-0154-2

Elder Jr, G. H. (1994). Time, human agency, and social change: perspectives on the life course. *Soc. Psychol. Q.* 4:15. doi: 10.2307/2786971

Elff, M. (2022). *mclogit: Multinomial Logit Models, with or without Random Effects or Overdispersion.* Available online at: https://CRAN.R-project.org/package=mclogit (Accessed April 25, 2025).

Emina, J., Beguy, D., Zulu, E. M., Ezeh, A. C., Muindi, K., Elung'ata, P., et al. (2011). Monitoring of health and demographic outcomes in poor urban settlements: evidence from the Nairobi Urban Health and Demographic Surveillance System. *J. Urban Health* 88, 200–218. doi: 10.1007/s11524-011-9594-1

Engdawork, K., Amdework, E., Assefa, S., Ayode, D., and Tadele, G. (2024). Experiences and lessons from structural interventions against COVID-19 in Addis Ababa, Ethiopia. *Front. Sociol.* 9:1305549. doi: 10.3389/fsoc.2024.1305549

Essendi, H., Mills, S., and Fotso, J.-C. (2011). Barriers to formal emergency obstetric care services' utilization. *J. URBAN Health-Bull. N. Y. Acad. Med.* 88, 356–369. doi: 10.1007/s11524-010-9481-1

Ettarh, R. R., Mutua, M. K., and Kyobutungi, C. (2012). Ethnicity and delay in measles vaccination in a Nairobi slum. *Trop. Med. Health* 40:59. doi: 10.2149/tmh.2012-09s

Evans, R. G., Barer, M. L., and Marmor, T. R. (1994). *Why are Some People Healthy and Others Not? The Determinants of Health of Populations.* New York: A. de Gruyter. doi: 10.1515/9783112421628

Ezeanochie, M. C., Olagbuji, B. N., Ande, A. B., Kubeyinje, W. E., and Okonofua, F. E. (2011). Prevalence and correlates of intimate partner violence against HIV-seropositive pregnant women in a Nigerian population. *Acta Obstet. Gynecol. Scand.* 90, 535–539. doi: 10.1111/j.1600-0412.2011.01083.x

Ezeh, A., Oyebode, O., Satterthwaite, D., Chen, Y.-F., Ndugwa, R., Sartori, J., et al. (2017). The history, geography, and sociology of slums and the health problems of people who live in slums. *LANCET* 389, 547–558. doi: 10.1016/S0140-6736(16)31650-6

Ezenweke, E. O. (2016). Rites of passage and sustainable development in traditional Africa: reflections for contemporary society. *J. Relig. Hum. Relat.* 8, 19–34.

Fleck, L., and Kuhn, T. S. (1979). *Genesis and Development of a Scientific Fact.* Chicago: University of Chicago Press.

Fogel, R. W., and Costa, D. L. (1997). A theory of technophysio evolution, with some implications for forecasting population, health care costs, and pension costs. *Demography* 34, 49–66. doi: 10.2307/2061659

Foucault, M. (1975). *The Birth of the Clinic: An Archaeology of Medical Perception.* New York: Vintage Books.

Fox, J. (2016). *Applied Regression Analysis and Generalized Linear Models. Third Edition*. Los Angeles: SAGE.

Freidson, E. (1970). *Profession of Medicine : A Study of the Sociology of Applied Knowledge.* New York: Dodd, Mead.

Frohlich, K. L., and Abel, T. (2014). Environmental justice and health practices: understanding how health inequities arise at the local level. *Sociol. Health Illn.* 36, 199–212. doi: 10.1111/1467-9566.12126

Galster, G. C. (2012). "The mechanism (s) of neighbourhood effects: theory, evidence, and policy implications," in *Neighbourhood effects research: New perspectives* (Springer), 23–56. doi: 10.1007/978-94-007-2309-2_2

Gamble, V. (1997). Under the shadow of Tuskegee: African Americans and health care. *Am. J. PUBLIC Health* 87, 1773–1778. doi: 10.2105/AJPH.87.11.1773

Garenne, M. (2018). "Family planning and fertility decline in Africa: from 1950 to 2010," in *Family Planning*, ed. Z. O. Amarin (Rijeka: IntechOpen), Ch. 7. doi: 10.5772/intechopen.71029

Gelman, A., and Hill, J. (2007). *Data analysis using regression and multilevel/hierarchical models*. Cambridge: Cambridge University Press. doi: 10.32614/CRAN.package.arm

Gerhardt, U. (1989). *Ideas About Illness : An Intellectual and Political History Of Medical Sociology*. New York: New York University Press. doi: 10.1007/978-1-349-20016-0

Ghasi, N. C., Ogbuabor, D. C., and Onodugo, V. A. (2020). Perceptions and predictors of organizational justice among healthcare professionals in academic hospitals in South-Eastern Nigeria. *BMC Health Serv. Res.* 20:155. doi: 10.1186/s12913-020-05187-5

Gibbs, A., Carpenter, B., Crankshaw, T., Hannass-Hancock, J., Smit, J., Tomlinson, M., et al. (2017). Prevalence and factors associated with recent intimate partner violence and relationships between disability and depression in postpartum women in one clinic in eThekwini Municipality, South Africa. *PLoS ONE* 12:e0181236. doi: 10.1371/journal.pone.0181236

Gillum, T. L., Doucette, M., Mwanza, M., and Munala, L. (2018). Exploring kenyan women's perceptions of intimate partner violence. *J. Interpers. Violence* 33, 2130–2154. doi: 10.1177/0886260515622842

Goffman, E. (1974). *Stigma: notes on the management of spoiled identity*. New York: J. Aronson.

Goldman, J., Reeves, S., Wu, R., Silver, I., MacMillan, K., and Kitto, S. (2016). A sociological exploration of the tensions related to interprofessional collaboration in acute-care discharge planning. *J. Interprof. Care* 30, 217–225. doi: 10.3109/13561820.2015.1072803

Goodson, A., and Hayes, B. (2021). Help-seeking behaviors of intimate partner violence victims: a cross-national analysis in developing nations. *J. Interpers. Violence* 36, NP4705–NP4727. doi: 10.1177/0886260518794508

Great Britain Working Group on Inequalities in Health, Black, D., Townsend, P., and Davidson, N. (1982). *Inequalities in health : the Black report*. Harmondsworth, Middlesex, England: Penguin Books.

Greenwell, F., and Salentine, S. (2018). "Population-Based Surveys," in *Health Information Systems Strengthening: Standards and Best Practices for Data Sources.* (Washington, D.C., United States: Measure Evaluation, USAID). Available online at: https://www.measureevaluation.org/resources/hisdatasourcesguide/module-8-population-based-surveys (Accessed April 25, 2025).

Hampanda, K. (2016a). Intimate partner violence against HIV-positive women is associated with sub-optimal infant feeding practices in Lusaka, Zambia. *Matern. Child Health J.* 20, 2599–2606. doi: 10.1007/s10995-016-2087-9

Hampanda, K., Ybarra, M., and Bull, S. (2014). Perceptions of health care services and HIV-related health-seeking behavior among Uganda adolescents. *AIDS Care-Psychol. Socio-Med. Asp. AIDSHIV* 26, 1209–1217. doi: 10.1080/09540121.2014.894612

Hampanda, K. M. (2016b). Intimate partner violence and HIV-positive women's non-adherence to antiretroviral medication for the purpose of prevention of mother-to-child transmission in Lusaka, Zambia. *Soc. Sci. Med.* 153, 123–130. doi: 10.1016/j.socscimed.2016.02.011

Harvey, S., Lees, S., Mshana, G., Pilger, D., Hansen, C., Kapiga, S., et al. (2018). A cluster randomized controlled trial to assess the impact on intimate partner violence of a 10-session participatory gender training curriculum delivered to women taking part in a group-based microfinance loan scheme in Tanzania (MAISHA CRT01): study protocol. *BMC Womens Health* 18:55. doi: 10.1186/s12905-018-0546-8

Hatcher, A. M., Mkhize, S. P., Parker, A., and de Kadt, J. (2022). Depressive symptoms and violence exposure in a population-based sample of adult women in South Africa. *PLoS Glob. Public Health* 2:e0001079. doi: 10.1371/journal.pgph.0001079

Hatcher, A. M., Smout, E. M., Turan, J. M., Christofides, N., and Stöckl, H. (2015). Intimate partner violence and engagement in HIV care and treatment among women: a systematic review and meta-analysis. *Aids* 29, 2183–2194. doi: 10.1097/QAD.0000000000000842

Hatcher, A. M., Woollett, N., Pallitto, C. C., Mokoatle, K., Stöckl, H., and Garcia-Moreno, C. (2019). Willing but not able: Patient and provider receptiveness to addressing intimate partner violence in Johannesburg antenatal clinics. *J. Interpers. Violence* 34, 1331–1356. doi: 10.1177/0886260516651094

Heath, J. (2005). Methodological individualism. *Stanf. Encycl. Philos. 2008 Ed.* Available online at: https://plato.stanford.edu/archives/win2008/entries/methodological-individualism/ (Accessed April 24, 2025).

Hochschild, A. R. (1997). *The Time Bind: When Work Becomes Home and Home Becomes Work. 1st ed.* New York: Metropolitan Books. doi: 10.2307/41165911

Hoffmann, J. P. (2004). *Generalized Linear Models: An Applied Approach*. Boston: Pearson A and B.

Hollingshead, A. B., and Redlich, F. C. (1953). Social stratification and psychiatric disorders. *Am. Sociol. Rev.* 18, 163–169. doi: 10.2307/2087725

Horn, R., Puffer, E. S., Roesch, E., and Lehmann, H. (2016). "I don't need an eye for an eye": Women's responses to intimate partner violence in Sierra Leone and Liberia. *Glob. Public Health* 11, 108–121. doi: 10.1080/17441692.2015.1032320

Huntley, A. L., Potter, L., Williamson, E., Malpass, A., Szilassy, E., and Feder, G. (2019). Help-seeking by male victims of domestic violence and abuse (DVA): a systematic review and qualitative evidence synthesis. *BMJ OPEN* 9:21960. doi: 10.1136/bmjopen-2018-021960

Iburg, K. M., Murray, C. J. L., Sadana, R., Mathers, C. D., Lopez, A. D., and World Health, Organization Global Programme on Evidence for Health Policy (2001). *Comparative analyses of more than 50 household surveys on health status/Ritu Sadana... [et al.]*. Available online at: https://apps.who.int/iris/handle/10665/67777 (Accessed April 25, 2025).

ICF (2012a). *Survey Organization Manual for Demographic and Health Surveys.* Rockville, MD, USA: ICF.

ICF (2012b). *The DHS Program STATCompiler. Funded by USAID.* Available online at: https://www.statcompiler.com/en/ (Accessed August 1, 2024).

ICF (2020). *Demographic and Health Survey Interviewer's Manual.* Rockville, MD, USA: ICF.

ICF International (2012). *DHS Sampling and Household Listing Manual*. Calverton, MD, USA: ICF International.

Illich, I. (1976). *Medical Nemesis*. New York: Bantam Books.

IMF (2024). *World Economic Outlook, October 2024.* Washington, D.C., United States: International Monetary Fund. Available online at: (Accessed December 31, 2024).

Itimi, K., Dienye, P. O., and Gbeneol, P. K. (2014). Intimate partner violence and associated coping strategies among women in a primary care clinic in Port Harcourt, Nigeria. *J. Fam. Med. Prim. Care* 3:193. doi: 10.4103/2249-4863.141601

Ityo, A. K. (2010). *The medical professionals: a microcosm.* Niger. J. Med. 19. Available online at: https://journals.lww.com/njom/Fulltext/2010/19040/The_Medical_Professionals__a_Microcosm.1.aspx (Accessed May 8, 2025).

Izugbara, C. O., and Ngilangwa, D. P. (2010). Women, poverty and adverse maternal outcomes in Nairobi, Kenya. *BMC Womens Health* 10:33. doi: 10.1186/1472-6874-10-33

Jacobs, T., and Jewkes, R. (2002). Vezimfilho: a model for health sector response to gender violence in South Africa. *Int. J. Gynecol. Obstet.* 78, S51–S56. doi: 10.1016/S0020-7292(02)00044-9

Jasso, G. (2011). "James S. Coleman," in *The Wiley-Blackwell companion to major social theorists* (Malden, MA: Wiley-Blackwell), 219–239. doi: 10.1002/9781444396621.ch28

Jefferies, H. M. (2016). *A comparative, ecological analysis of male-to-female intimate partner violence in the United States and Marlboro County, South Carolina.*

Jerolmack, C., and Khan, S. (2014). Talk is cheap ethnography and the attitudinal fallacy. *Sociol. Methods Res.* 43, 178–209. doi: 10.1177/0049124114523396

Joubert, J., Rao, C., Bradshaw, D., Dorrington, R. E., Vos, T., and Lopez, A. D. (2012). Characteristics, availability and uses of vital registration and other mortality data sources in post-democracy South Africa. *Glob. Health Action* 5, 1–19. doi: 10.3402/gha.v5i0.19263

Joyner, K. (2013). Correspondence: Relevance and feasibility of WHO recommendations for intimate partner violence care in South African primary health settings. *Afr. Saf. Promot. J. Inj. Violence Prev.* 11, 21–27.

Joyner, K., and Mash, B. (2012a). A comprehensive model for intimate partner violence in South African primary care: action research. *BMC Health Serv. Res.* 12, 1–10. doi: 10.1186/1472-6963-12-399

Joyner, K., and Mash, B. (2014). Quality of care for intimate partner violence in South African primary care: a qualitative study. *Violence Vict.* 29, 652–669. doi: 10.1891/0886-6708.VV-D-13-00005

Joyner, K., and Mash, R. (2012b). Recognizing intimate partner violence in primary care: Western Cape, South Africa. *PLoS ONE* 7:e29540. doi: 10.1371/journal.pone.0029540

Joyner, K., and Mash, R. J. (2011). The value of intervening for intimate partner violence in South African primary care: project evaluation. *BMJ Open* 1:254. doi: 10.1136/bmjopen-2011-000254

Kabiru, C. W., Mumah, J. N., Maina, B. W., and Abuya, B. A. (2017). Violence victimisation and aspirations–expectations disjunction among adolescent girls in urban Kenya. *Int. J. Adolesc. Youth* 2017, 1–10. doi: 10.1080/02673843.2017.1345769

Kanagaratnam, P., Mason, R., Hyman, I., Manuel, L., Berman, H., and Toner, B. (2012). Burden of womanhood: tamil women's perceptions of coping with intimate partner violence. *J. Fam. Violence* 27, 647–658. doi: 10.1007/s10896-012-9461-1

Kapiga, S., Harvey, S., Mshana, G., Hansen, C. H., Mtolela, G. J., Madaha, F., et al. (2019). A social empowerment intervention to prevent intimate partner violence against women in a microfinance scheme in Tanzania: findings from the MAISHA cluster randomised controlled trial. *Lancet Glob. Health* 7, e1423–e1434. doi: 10.1016/S2214-109X(19)30316-X

Katz, J. (1997). Ethnography's warrants. *Sociol. Methods Res.* 25, 391–423. doi: 10.1177/0049124197025004002

Kaye, D. K., Ekstroem, A. M., Johansson, A., Bantebya, G., and Mirembe, F. M. (2007). Escaping the triple trap: coping strategies of pregnant adolescent survivors of domestic violence in Mulago hospital, Uganda. *Scand. J. Public Health* 35, 180–186. doi: 10.1080/14034940600858490

Kenya National Bureau of Statistics, Ministry of Health/Kenya, National AIDS, Control Council/Kenya, Kenya Medical Research Institute, and National Council for Population and Development/Kenya (2015). *Kenya Demographic and Health Survey 2014*. Rockville, MD, USA.

Kibe, P. M., Kisia, L., and Bakibinga, P. (2020). COVID-19 and community healthcare: perspectives from Nairobi's informal settlements. *Pan Afr. Med. J.* 35:106. doi: 10.11604/pamj.supp.2020.35.2.24532

Kohli, A., Perrin, N., Mpanano, R. M., Banywesize, L., Mirindi, A. B., Banywesize, J. H., et al. (2015). Family and community driven response to intimate partner violence in post-conflict settings. *Soc. Sci. Med.* 146, 276–284. doi: 10.1016/j.socscimed.2015.10.011

Lamont, M., and Swidler, A. (2014). Methodological pluralism and the possibilities and limits of interviewing. *Qual. Sociol.* 37, 153–171. doi: 10.1007/s11133-014-9274-z

LaPiere, R. T. (1934). Attitudes vs. actions. *Soc. Forces* 13, 230–237. doi: 10.2307/2570339

Lee, E. S., and Forthofer, R. N. (2006). *Analyzing Complex Survey Data. 2nd ed.* Thousand Oaks, CA: Sage Publications. doi: 10.4135/9781412983341

Lennan, E. (2014). Non-medical prescribing of chemotherapy: engaging stakeholders to maximise success? *Ecancermedicalscience* 8:417. doi: 10.3332/ecancer.2014.417

Leventhal, H., Phillips, L. A., and Burns, E. (2016). The common-sense model of self-regulation (CSM): a dynamic framework for understanding illness self-management. *J. Behav. Med.* 39, 935–946. doi: 10.1007/s10865-016-9782-2

Lewis-Beck, M. S. (1995). *Data Analysis: An Introduction*. Thousand Oaks: Sage Publications. doi: 10.4135/9781412983846

Lewis-Beck, M. S., and Lewis-Beck, C. (2016). *Applied regression: An introduction. Second Edition*. Thousand Oaks, CA: Sage publications. doi: 10.4135/9781483396774

Liebetrau, A. M. (1983). *Measures of Association*. Beverly Hills: Sage Publications. doi: 10.4135/9781412984942

Lilford, R. J., Oyebode, O., Satterthwaite, D., Melendez-Torres, G. J., Chen, Y.-F., Mberu, B., et al. (2017). Improving the health and welfare of people who live in slums. *LANCET* 389, 559–570. doi: 10.1016/S0140-6736(16)31848-7

Luke, D. A. (2020). *Multilevel Modeling. Second edition*. Thousand Oaks, CA: SAGE Publications, Inc. doi: 10.4135/9781544310305

Luker, K. (2008). *Salsa Dancing Into The Social Sciences: Research in an Age of Info-Glut*. Cambridge, MS: Harvard University Press.

Lutfey, K., and Freese, J. (2005). Toward some fundamentals of fundamental causality: socioeconomic status and health in the routine clinic visit for diabetes1. *Am. J. Sociol.* 110, 1326–1372. doi: 10.1086/428914

Mackenbach, J. P., Kunst, A. E., Cavelaars, A. E., Groenhof, F., Geurts, J. J., and Health, E. W. G., on S. I. in (1997). Socioeconomic inequalities in morbidity and mortality in western Europe. *LANCET* 349, 1655–1659. doi: 10.1016/S0140-6736(96)07226-1

Mackie, G., Moneti, F., Shakya, H., and Denny, E. (2015). *What Are Social Norms? How are they Measured?* California: University of California at San Diego.

Magadi, M., and Desta, M. (2011). A multilevel analysis of the determinants and cross-national variations of HIV seropositivity in sub-Saharan Africa: Evidence from the DHS. *Health Place* 17, 1067–1083. doi: 10.1016/j.healthplace.2011.06.004

Magadi, M. A. (2017). Multilevel determinants of teenage childbearing in sub-Saharan Africa in the context of HIV/AIDS. *Health Place* 46, 37–48. doi: 10.1016/j.healthplace.2017.04.006

Mahenge, B., Stoeckl, H., Abubakari, A., Mbwambo, J., and Jahn, A. (2016). Physical, sexual, emotional and economic intimate partner violence and controlling behaviors during pregnancy and postpartum among women in dares Salaam, Tanzania. *PLoS ONE* 11:e0164376. doi: 10.1371/journal.pone.0164376

Mannell, J., Jackson, S., and Umutoni, A. (2016). Women's responses to intimate partner violence in Rwanda: Rethinking agency in constrained social contexts. *Glob. Public Health* 11, 65–81. doi: 10.1080/17441692.2015.1013050

Marcotte, D. E. (2004). *The Economics of Gender and Mental Illness*. Emerald Group Publishing Limited. doi: 10.1016/S0194-3960(2004)15

Marmot, M., and Wilkinson, R. G. (2006). *Social Determinants of Health.* Oup Oxford. doi: 10.1093/acprof:oso/9780198565895.001.0001

Matoori, S., Khurana, B., Balcom, M. C., Froehlich, J. M., Janssen, S., Forstner, R., et al. (2021). Addressing intimate partner violence during the COVID-19 pandemic and beyond: how radiologists can make a difference. *Eur. Radiol.* 31, 2126–2131. doi: 10.1007/s00330-020-07332-4

McCleary-Sills, J., Namy, S., Nyoni, J., Rweyemamu, D., Salvatory, A., and Steven, E. (2016). Stigma, shame and women's limited agency in help-seeking for intimate partner violence. *Glob. Public Health* 11, 224–235. doi: 10.1080/17441692.2015.1047391

McCorkel, J. A., and Myers, K. (2003). What difference does difference make? Position and privilege in the field. *Qual. Sociol.* 26, 199–231. doi: 10.1023/A:1022967012774

McKeown, T. (1979). *The role of Medicine: Dream, Mirage, or Nemesis?* Princeton, NJ: Princeton University Press. doi: 10.1515/9781400854622

McNabb, D. E. (2020). *Nonsampling Error*. London, England: SAGE Publications Limited.

Measure DHS/ICF International (2013). *ICF International, Demographic and Health Surveys Methodology: Standard Recode Manual for DHS 6. Demogr. Health Surv. Toolkit Methodol. Meas. DHS Phase III 2008-2013 Meas.* DHSICF Int. Wash. DC USA.

Menard, S. W. (2002). *Longitudinal Research. 2nd ed.* Thousand Oaks, Calif: Sage Publications. doi: 10.4135/9781412984867

Metheny, N., Mkhize, S. P., Scott, D., and Hatcher, A. (2024). Violence victimization and depressive symptoms among a sub-sample of sexual and gender minority adults in a population-based South African study. *J. Interpers. Violence* 2024:08862605241243348. doi: 10.1177/08862605241243348

Metheny, N., and Stephenson, R. (2019). Help seeking behavior among women who report intimate partner violence in afghanistan: an analysis of the 2015 Afghanistan demographic and health survey. *J. Fam. Violence* 34, 69–79. doi: 10.1007/s10896-018-0024-y

Mohammed, B. H., Johnston, J. M., Harwell, J. I., Yi, H., Tsang, K. W., and Haidar, J. A. (2017). Intimate partner violence and utilization of maternal health care services in Addis Ababa, Ethiopia. *Bmc Health Serv. Res.* 17:178. doi: 10.1186/s12913-017-2121-7

Morelli, S., Smeeding, T., and Thompson, J. (2015). Post-1970 trends in within-country inequality and poverty: rich and middle-income countries. *Handb. Income Distrib.* 2, 593–696. doi: 10.1016/B978-0-444-59428-0.00009-6

Moreno-Betancur, M., Latouche, A., Menvielle, G., Kunst, A. E., and Rey, G. (2015). Relative index of inequality and slope index of inequality: a structured regression framework for estimation. *Epidemiology* 26:12. doi: 10.1097/EDE.0000000000000311

Morgensten, J. (2018). *Bias in Medical Research*. Available online at: https://first10em.com/bias/ (Accessed April 24, 2025). doi: 10.51684/FIRS.5988

Mutuku, I. (2023). *Taking Stock: Maputo Protocol in Advancing Women's Rights*. Available online at: http://www.aphrc.org (Accessed August 12, 2024).

National Research Council (U.S.), Weinstein, M., Vaupel, J. W., Wachter, K. W., and National Research Council (U.S.) (2008). *Biosocial Surveys*. Washington, DC: National Academies Press.

Naved, R. T., Al Mamun, M., Mourin, S. A., and Parvin, K. (2018). A cluster randomized controlled trial to assess the impact of SAFE on spousal violence against women and girls in slums of Dhaka, Bangladesh. *PLoS ONE* 13:e0198926. doi: 10.1371/journal.pone.0198926

Njuki, R., Okal, J., Warren, C. E., Obare, F., Abuya, T., Kanya, L., et al. (2012). Exploring the effectiveness of the output-based aid voucher program to increase uptake of gender-based violence recovery services in Kenya: a qualitative evaluation. *BMC Public Health* 12:426. doi: 10.1186/1471-2458-12-426

Nyarko, M. G. (2016). "The impact of the African Charter and Maputo Protocol in Ghana," in *The Impact of the African Charter and Maputo Protocol in Selected African States.* ed. V. Ayeni (South Africa: Pretoria University Law Press), 95–113.

Oakes, J. M., and Kaufman, J. S. (2017). *Methods in Social Epidemiology*. Second edition. San Francisco, CA: Jossey-Bass, A Wiley Brand.

Odero, M., Hatcher, A. M., Bryant, C., Onono, M., Romito, P., Bukusi, E. A., et al. (2014). Responses to and resources for intimate partner violence: qualitative findings from women, men, and service providers in Rural Kenya. *J. Interpers. Violence* 29, 783–805. doi: 10.1177/0886260513505706

O'Donnell, O. A., and Wagstaff, A. (2008). *Analyzing Health Equity Using Household Survey Data: a Guide to Techniques and Their Implementation.* World Bank Publications. doi: 10.1596/978-0-8213-6933-3

Odum, E. P. (1984). The mesocosm. *BioScience* 34, 558–562. doi: 10.2307/1309598

Olson, K. (2020). *Interviewer Effects From a Total Survey Error Perspective. 1st ed.* Boca Raton: CRC Press. doi: 10.1201/9781003020219

Onoh, R. C., Umeora, O. U. J., Ezeonu, P. O., Onyebuchi, A. K., Lawani, O. L., and Agwu, U. M. (2013). Prevalence, pattern and consequences of intimate partner violence during pregnancy at abakaliki southeast Nigeria. *Ann. Med. Health Sci. Res.* 3, 484–491. doi: 10.4103/2141-9248.122048

Pannucci, C. J., and Wilkins, E. G. (2010). Identifying and avoiding bias in research. *Plast. Reconstr. Surg.* 126, 619–625. doi: 10.1097/PRS.0b013e3181de24bc

Parks, M. J. (2013). Urban poverty traps: neighbourhoods and violent victimisation and offending in Nairobi, Kenya. *Urban Stud.* 51, 1812–1832. doi: 10.1177/0042098013504144

Parsons, T. (1975). The sick role and the role of the physician reconsidered. *Milbank Mem. Fund Q. Health Soc.* 53, 257–278. doi: 10.2307/3349493

Patwardhan, V., Flor, L., and Gakidou, E. (2023). Gender differences in global Disability-Adjusted Life Years (DALYs): a descriptive Analysis of the global burden of disease study 2021. *Popul. Med.* 5:163644. doi: 10.18332/popmed/163644

Pearlin, L. I. (1989). The sociological study of stress. *J. Health Soc. Behav.* 241–256. doi: 10.2307/2136956

Phelan, J. C., Link, B. G., and Tehranifar, P. (2010). Social conditions as fundamental causes of health inequalities: theory, evidence, and policy implications. *J. Health Soc. Behav.* 51, S28–S40. doi: 10.1177/0022146510383498

Porter, R. (1985). *Patients and Practitioners: Lay Perceptions of Medicine in Pre-Industrial Society*. Cambridge ; New York: Cambridge University Press. doi: 10.1017/CBO9780511563690

Prabhu, M., Mchome, B., Ostermann, J., Itemba, D., Njau, B., and Thielman, N. (2011). Prevalence and correlates of intimate partner violence among women attending HIV voluntary counseling and testing in northern Tanzania, 2005-2008. *Int. J. Gynecol. Obstet.* 113, 63–67. doi: 10.1016/j.ijgo.2010.10.019

Prosman, G.-J., Wong, S. H. L. F., and Lagro-Janssen, A. L. M. (2014). Why abused women do not seek professional help: a qualitative study. *Scand. J. CARING Sci.* 28, 3–11. doi: 10.1111/scs.12025

Punch, K. (2014). *Introduction to Social Research: Quantitative and Qualitative Approaches. Third edition*. Los Angeles, California: SAGE.

Quesnel-Vallee, A. (2004). Is it really worse to have public health insurance than to have no insurance at all? Health insurance and adult health in the United States. *J. Health Soc. Behav.* 45, 376–392. doi: 10.1177/002214650404500402

Quesnel-Vallée, A., Bilodeau, J., and Conway, K. (2021). "Social policies and health inequalities," in *The Wiley Blackwell Companion to Medical Sociology*, ed. W. Cockerham (Hoboken, NJ: John Wiley and Sons), 322. doi: 10.1002/9781119633808.ch16

R Development Core Team (2025). *R: A Language and Environment for Statistical Computing*. R Found. Stat. Comput. Vienna Austria.

Rabe-Hesketh, S., and Skrondal, A. (2022). *Multilevel and Longitudinal Modeling Using Stata*. Fourth edition. College Station, Texas: Stata Press. Available online at: http://www.mcgill.ca/library/ (Accessed April 1, 2025).

Ransome, P. (2010). *Social Theory for Beginners. 1st Edn*. Bristol: Bristol University Press. doi: 10.56687/9781447314387

Rees, K., Zweigenthal, V., and Joyner, K. (2014a). Health sector responses to intimate partner violence: a literature review. *Afr. J. Prim. Health Care Fam. Med.* 6, 1–8. doi: 10.4102/phcfm.v6i1.712

Rees, K., Zweigenthal, V., and Joyner, K. (2014b). Implementing intimate partner violence care in a rural sub-district of South Africa: a qualitative evaluation. *Glob. Health Action* 7:24588. doi: 10.3402/gha.v7.24588

Rittenhouse, D. R., Braveman, P., and Marchi, K. (2003). Improvements in prenatal insurance coverage and utilization of care in California: an unsung public health victory. *Matern. Child Health J.* 7, 75–86. doi: 10.1023/A:1023812009298

Ritzer, G. (2005). *Encyclopedia of Social Theory*. Thousand Oaks, CA: Sage Publications. doi: 10.4135/9781412952552

Ritzer, G., and Ryan, J. M. (2011). *The Concise Encyclopedia of Sociology*. Chichester, West Sussex, U.K.; Malden, MA: Wiley-Blackwell. doi: 10.1002/9781444392654

Rizo, C. F., and Macy, R. J. (2011). Help seeking and barriers of Hispanic partner violence survivors: a systematic review of the literature. *Aggress. Violent Behav.* 16, 250–264. doi: 10.1016/j.avb.2011.03.004

Rose, N. (2001). The politics of life itself. *Theory Cult. Soc.* 18, 1–30. doi: 10.1177/02632760122052020

Rutstein, S. O., and Rojas, G. (2006). *Guide to DHS Statistics*. Calverton MD: ORC Macro.

R. Williams, D., and Williams-Morris, R. (2000). Racism and mental health: the African American experience. *Ethn. Health* 5, 243–268. doi: 10.1080/713667453

Ryder, N. B. (1965). The cohort as a concept in the study of social change. *Am. Sociol. Rev.* 30, 843–861. doi: 10.2307/2090964

Sampson, R. J. (2012). *Great American City: Chicago and the Enduring Neighborhood Effect*. Chicago: University of Chicago Press. doi: 10.7208/chicago/9780226733883.001.0001

Sandstrom, K., and Kleinman, S. (2004). *Encyclopedia of Social Theory*. Thousand Oaks, CA: SAGE Publications, Inc.

Sandstrom, R. W. (2007). The meanings of autonomy for physical therapy. *Phys. Ther.* 87, 98–106. doi: 10.2522/ptj.20050245

Satyen, L., Rogic, A. C., and Supol, M. (2019). Intimate partner violence and help-seeking behaviour: a systematic review of cross-cultural differences. *J. Immigr. Minor. Health* 21, 879–892. doi: 10.1007/s10903-018-0803-9

Sauro, J. (2015). *7 ways to handle missing data. MeasuringU*. Available online at: https://measuringu.com/handle-missing-data/ (Accessed March 16, 2021).

Seltzer, J. R. (2002). *The Origins and Evolution of Family Planning Programs in Developing Countries*. London: Rand Corporation.

Sergeant, J. C., and Firth, D. (2006). Relative index of inequality: definition, estimation, and inference. *Biostatistics* 7, 213–224. doi: 10.1093/biostatistics/kxj002

Shadish, W. R., Cook, T. D., and Campbell, D. T. (2001). *Experimental and Quasi-Experimental Designs For Generalized Causal Inference*. Boston: Houghton Mifflin.

Shryock, H. S., Siegel, J. S., and Larmon, E. A. (1975). *The methods and materials of demography*. 3rd print., rev. Washington: U.S. Dept. of Commerce, Bureau of the Census : for sale by the Supt. of Docs. U.S. Govt. Print. Off.

Sica, G. T. (2006). Bias in research studies. *Radiology* 238, 780–789. doi: 10.1148/radiol.2383041109

Silverman, D. (1981). The child as a social object: Down's Syndrome children in a paediatric cardiology clinic. *Sociol. Health Illn.* 3, 254–274. doi: 10.1111/1467-9566.ep10486744

Silverman, D. (1983). The clinical subject: adolescents in a cleft-palate clinic. *Sociol. Health Illn.* 5, 253–274. doi: 10.1111/j.1467-9566.1983.tb00435.x

Simister, J. G. (2010). Domestic violence and female genital mutilation in Kenya: effects of ethnicity and education. *J. Fam. Violence* 25, 247–257. doi: 10.1007/s10896-009-9288-6

Small, M. L. (2009). How many cases do I need? On science and the logic of case selection in field-based research. *Ethnography* 10, 5–38. doi: 10.1177/1466138108099586

Small, M. L., and Newman, K. (2001). Urban poverty after the truly disadvantaged: the rediscovery of the family, the Neighborhood, and Culture. *Annu. Rev. Sociol.* 27:23. doi: 10.1146/annurev.soc.27.1.23

Solar, O., and Irwin, A. (2010). *A Conceptual Framework for Action on the Social Determinants of Health*. Geneva: World Health Organization (WHO). Available online at: https://iris.who.int/handle/10665/44489 (Accessed April 25 2025).

Solar, O., Irwin, A., and WHO Commission on Social Determinants of Health (2007). *A Conceptual Framework on the Social Determinants of Health*. Geneva: World Health Organization (WHO).

Sprague, C., Hatcher, A. M., Woollett, N., Sommers, T., and Black, V. (2016). 'They can't report abuse, they can't move out. They are at the mercy of these men': exploring connections between intimate partner violence, gender and HIV in South African clinical settings. *Cult. Health Sex.* 18, 567–581. doi: 10.1080/13691058.2015.1096420

Sprague, S., McKay, P., Madden, K., Scott, T., Tikasz, D., Slobogean, G. P., et al. (2017). Outcome measures for evaluating intimate partner violence programs within clinical settings: a systematic review of the literature. *Trauma Violence Abuse* 18, 508–522. doi: 10.1177/1524838016641667

Starr, P. (1982). *The Social Transformation of American Medicine*. New York: Basic Books.

Swart, E. (2013). Doing survival: strategies for coping with gender-based violence in kenya's kibera slum. *Affil. - J. Women Soc. Work* 28, 40–50. doi: 10.1177/0886109912470111

Takacs, D. (2003). How does your positionality bias your epistemology? *Thought Action* 19, 27–38.

The Africa Health Agenda International Conference Commission, Edwine, B., Pokuaa, F. A., Francis, O., Shabir, M., Karim, B., et al. (2021). *The State of Universal Health Coverage in Africa. Kenya: Amref Health Africa.* Available online at: https://ahaic.org/download/the-state-of-universal-health-coverage-in-africa/ (Accessed April 24, 2025).

Thomas, S. B., and Quinn, S. C. (1991). The Tuskegee Syphilis Study, 1932 to 1972: implications for HIV education and AIDS risk education programs in the black community. *Am. J. Public Health* 81, 1498–1505. doi: 10.2105/AJPH.81.11.1498

Timmermans, S., and Oh, H. (2010). The continued social transformation of the medical profession. *J. Health Soc. Behav.* 51, S94–S106. doi: 10.1177/0022146510383500

Toth, F. (2015). Sovereigns under Siege. How the medical profession is changing in Italy. *Soc. Sci. Med.* 136, 128–134. doi: 10.1016/j.socscimed.2015.05.024

Trochim, W. M. K. (2005). *Research Methods: the Concise Knowledge Base*. Cincinnati, OH: Atomic Dog Pub.

Tusiime, S., Musinguzi, G., Tinkitina, B., Mwebaza, N., Kisa, R., Anguzu, R., et al. (2015). Prevalence of sexual coercion and its association with unwanted pregnancies among young pregnant females in Kampala, Uganda: a facility based cross-sectional study. *BMC Womens Health* 15:79. doi: 10.1186/s12905-015-0235-9

Umeora, O. U. J., Dimejesi, B. I., Ejikeme, B. N., and Egwuatu, V. E. (2008). Pattern and determinants of domestic violence among prenatal clinic attendees in a referral centre, South-east Nigeria. *J. Obstet. Gynaecol.* 28, 769–774. doi: 10.1080/01443610802463819

UNICEF (2015). *Monitoring the situation of children and women for 20 years: The Multiple Indicator Cluster Surveys (MICS) 1995–2015*. New York, NY: United Nations Children's Fund (UNICEF).

United Nations (1984). *Report of the International Conference on Population, 1984, Mexico City, 6-14 August*. New York: United Nations (UN). Available online at: http://digitallibrary.un.org/record/74631/files/E_CONF.76_19-EN.pdf (Accessed April 25, 2025).

UN-WOMEN (2024). *Facts and figures: Ending violence against women*. Available online at: https://www.unwomen.org/en/articles/facts-and-figures/facts-and-figures-ending-violence-against-women (Accessed April 25, 2025).

Van Ham, M., and Manley, D. (2012). Neighbourhood effects research at a crossroads. ten challenges for future research introduction. *Environ. Plan. A* 44, 2787–2793. doi: 10.1068/a45439

Weiss, M. C., and Sutton, J. (2009). The changing nature of prescribing: pharmacists as prescribers and challenges to medical dominance. *Sociol. Health Illn.* 31, 406–421. doi: 10.1111/j.1467-9566.2008.01142.x

Weiss, R. S. (2004). In their own words: making the most of qualitative interviews. *Contexts* 3, 44–51. doi: 10.1525/ctx.2004.3.4.44

White, K. (2015). "Ludwik fleck: thought collectives and the sociology of medical knowledge," in *The Palgrave Handbook of Social Theory in Health, Illness and Medicine*, ed. F. Collyer (London: Palgrave Macmillan UK), 141–157. doi: 10.1057/9781137355621_9

Wilson, P. M., Kendall, S., and Brooks, F. (2007). The expert patients programme: a paradox of patient empowerment and medical dominance. *Health Soc. Care Commun.* 15, 426–438. doi: 10.1111/j.1365-2524.2007.00701.x

Wilson, W. J. (1987). *The Truly Disadvantaged Chicago*. IL Univ. Chic.

Winship, C., and Radbill, L. (1994). Sampling weights and regression analysis. *Sociol. Methods Res.* 23, 230–257. doi: 10.1177/0049124194023002004

Wolff, E. N. (1987). *International Comparisons of the Distribution of Household Wealth*. Oxford : New York: Clarendon Press; Oxford University Press.

Wood, L., Baumler, E., Schrag, R. V., Guillot-Wright, S., Hairston, D., Temple, J., et al. (2022a). "Don't know where to go for help": safety and economic needs among violence survivors during the COVID-19 pandemic. *J. Fam. Violence* 37, 959–967. doi: 10.1007/s10896-020-00240-7

Wood, L., Schrag, R. V., Baumler, E., Hairston, D., Guillot-Wright, S., Torres, E., et al. (2022b). On the front lines of the COVID-19 pandemic: occupational experiences of the intimate partner violence and sexual assault workforce. *J. Interpers. Violence* 37, NP9345–NP9366. doi: 10.1177/0886260520983304

World Health Organization (2013). *Global and Regional Estimates of Violence Against Women: Prevalence and Health Effects of Intimate Partner Violence and Non-Partner Sexual Violence.* Geneva: World Health Organization (WHO).

World Health Organization (2025). *WHO warns of severe disruptions to health services amid funding cuts.* United NationsUN News Glob. Perspect. Hum. Ser. Available online at: https://news.un.org/en/story/2025/04/1162091 (Accessed May 10, 2025).

Wright, E. O. (1997). *Class Counts: Comparative Studies in Class Analysis*. Cambridge ; New York : Paris: Cambridge University Press ; Maison des sciences de l'homme.

Ye, Y., Wamukoya, M., Ezeh, A., Emina, J. B., and Sankoh, O. (2012). Health and demographic surveillance systems: a step towards full civil registration and vital statistics system in sub-Sahara Africa? *BMC Public Health* 12, 1–11. doi: 10.1186/1471-2458-12-741

Zedelius, C. M., Müller, B. C. N., and Schooler, J. W. (2017). *The Science of Lay Theories : How Beliefs Shape our Cognition, Behavior, and Health.* Cham: Springer. doi: 10.1007/978-3-319-57306-9

Zgourides, G. D., and Zgourides, C. S. (2000). "Social change and movements," in *CliffsQuickReview Sociology* (Foster City, CA: IDG Books Worldwide, Inc.).

Zhou, M., Desborough, J., Parkinson, A., Douglas, K., McDonald, D., and Boom, K. (2019). Barriers to pharmacist prescribing: a scoping review comparing the UK, New Zealand, Canadian and Australian experiences. *Int. J. Pharm. Pract.* 27, 479–489. doi: 10.1111/ijpp.12557

Ziraba, A. K., Madise, N., Mills, S., Kyobutungi, C., and Ezeh, A. (2009a). Maternal mortality in the informal settlements of Nairobi city: what do we know. *Reprod Health* 6, 4755–4756. doi: 10.1186/1742-4755-6-6

Ziraba, A. K., Mills, S., Madise, N., Saliku, T., and Fotso, J.-C. (2009b). The state of emergency obstetric care services in Nairobi informal settlements and environs: results from a maternity health facility survey. *BMC Health Serv. Res.* 9:46. doi: 10.1186/1472-6963-9-46

Zola, I. K. (1972). Medicine as an institution of social control. *Sociol. Rev.* 20, 487–504. doi: 10.1111/j.1467-954X.1972.tb00220.x

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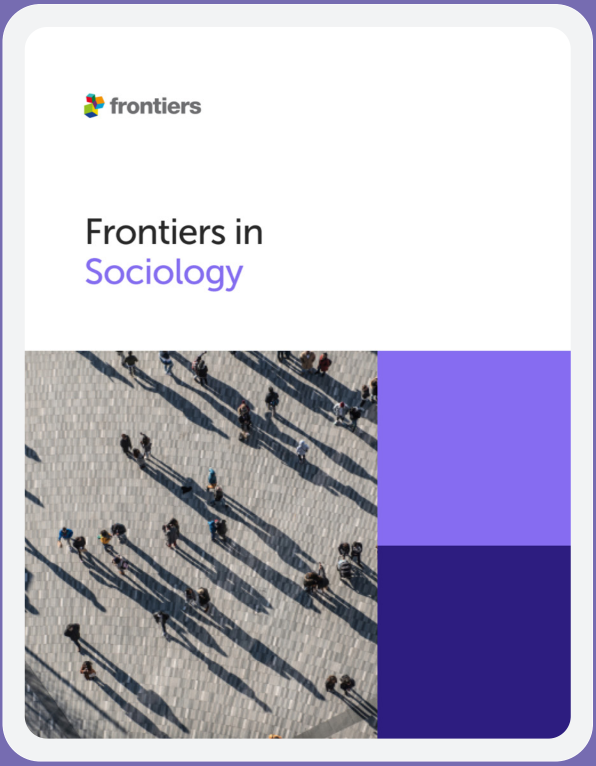

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