

# Empowering patients and supporting patient-centered care: A spotlight on health behavior change

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# Empowering patients and supporting patient-centered care: A spotlight on health behavior change

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# Editorial: Empowering patients and supporting patient-centered care: a spotlight on health behavior change

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## KEYWORDS

empower, support, patient-centered care, health behavior (MeSH), change

## Editorial on the Research Topic

[Empowering patients and supporting patient-centered care: a spotlight on health behavior change](#)

The COVID-19 pandemic has had a major impact on both mental and physical health, with documented and ongoing effects on the health status of populations globally (1–6). Some of the drivers of these trends include the rise in risk factors and unhealthy behaviors in the population (e.g., obesity, smoking, and alcohol consumption); poor adherence to health screening, vaccination, or other preventative interventions; and increased rates of mental illness (4–13). Importantly, the greatest effects have been documented in the most vulnerable populations (3, 6, 14).

The pandemic's effects highlight the need for actions targeted toward disease prevention, with a focus on health behavior change. It is recognized that such interventions should be grounded in the principles of person-centered approaches, including patient empowerment and compassionate care provision, in order to address the complex interactions between mental and physical health and promote effective communication between healthcare professionals and patients (15–17). Sharing international learning and best practice for promoting health behavior change is key to supporting the rapid scale-up of effective intervention strategies.

This Frontiers in Medicine Research Topic “*Empowering Patients and Supporting Patient-Centered Care: A Spotlight on Health Behavior Change*” sought to collect the best and most promising empowerment-oriented strategies for supporting health behavior change. One of our key ambitions for this Research Topic was the examination of methods that address individuals, populations, and healthcare professionals and aim to reduce the risk of disease, promote healthy behaviors, or enhance adherence to healthcare interventions. The four themes that this topic aimed to include were

1. interventions and initiatives to address chronic disease risk factors including smoking cessation, alcohol use reduction, and physical exercise improvement,
2. interventions and initiatives to improve self-management and care of chronic diseases, including adherence to medicine and other therapies,

3. interventions and initiatives to prevent communicable/infectious diseases and associated behaviors, such as vaccination and other preventative interventions and policies,
4. experience and interventions focused on transferring effective interventions into complex settings and contexts focusing on multimorbidity and frailty.

We had the pleasure of communicating with many research teams and, ultimately, a collection of nine manuscripts has been published as part of this Research Topic.

Improving patient-centered mental health promotion in primary health care (PHC) to support vulnerable communities through mindfulness training was the focus of a Brazilian intervention by [Teixeira et al.](#). Their intervention was based on the Mindfulness-Based Health Promotion Model, which promotes self-care and psychological support in PHC. PHC and self-care were also the focus of a systematic review by [Rakers et al.](#), which demonstrated that population health management (PHM)-related interventions can reach many participants and are effective in reducing cardiometabolic risk factors. Self-management and self-care are among the most challenging issues that PHC and public health practitioners have to address to achieve the United Nations Sustainable Development Goal #3 “Ensuring a healthy life and promoting wellbeing for all ages” (18). The role of caregivers in achieving this target is also vital and the WHO Astana Declaration (2018) emphasizes the need to turn our attention to this group of care providers (19). [Mas-Casadesus et al.](#), in their original article, underline the need for policymakers to introduce community-based and planned interventions aimed at caregivers to improve the management of vulnerable people during periods of isolation. The findings are particularly relevant given the isolation that was experienced by a large number of people and caregivers during and after the pandemic. A perspective article by [Cipta et al.](#) reported on the impact of integrating culture-specific patient empowerment practices into healthcare settings in Indonesia. This article underscores the potential for improved health outcomes, heightened patient engagement, and the delivery of cultural services within low and middle-income countries.

This Research Topic includes two articles that address COVID-19 vaccine hesitancy, a subject that is particularly relevant given the challenges reported worldwide in achieving national vaccination program targets (3, 20, 21). [Papadakis et al.](#), reported on the development and pilot testing of an eLearning intervention for PHC practitioners and social care providers to reduce vaccination hesitancy among patients in Greece. The intervention sought to develop training on how Very Brief Advice (VBA) and motivational interviewing (MI) can be adapted to promote COVID-19 vaccine uptake and address ambivalence and resistance among patients. In a similar direction, [Lorenzo et al.](#), in their policy report, stressed the need for effective communication strategies to tackle vaccination hesitancy. They clearly underlined that trained professionals should curate communication with the public.

[Saeed et al.](#), in their original research, reported the level of satisfaction among COVID-19 survivors and discussed the challenges of healthcare affordability and the role of healthcare practitioners in Northeast India. They consider the challenges in

healthcare affordability and timeliness as important. The challenge of value-based primary care, which measures improvement in patient health outcomes relative to the cost of achieving that improvement, was the focus of a article by [Rangachari](#). This article examines how healthcare consumerism can act as a barrier or facilitate the implementation of value-based primary care.

[Fernandes et al.](#), in their study protocol, presented the key elements of a feasibility study for Parkinson’s disease. Apart from its focus on Parkinson’s as a growing health concern, this small study provided insights into the design of a community-based intervention that encompasses elements of group cognitive behavioral therapy in addition to disease management and training techniques. Such interventions in the community addressing chronic illness and disability with a focus on behavior and mental health may offer important lessons for enabling and empowering patients through health behavior support.

We hope the collection of articles featured in this Research Topic will give prominence to the importance of patient-centered approaches in improving self-care and facilitating behavior change. We are pleased to be able to share this collection of articles with the field and hope it serves to inform and inspire practitioners, policymakers, and researchers on the importance of patient-centered models to health behavior change as we continue to address the health of populations with a new perspective and insight in the post-pandemic period, with an eye to future potential health crises.

## Author contributions

CL: Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization. SP: Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization. MA: Writing – review & editing, Writing – original draft, Validation, Supervision, Project administration, Methodology, Investigation, Data curation, Conceptualization. AC: Writing – review & editing, Project administration, Investigation, Conceptualization.

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# Does healthcare consumerism serve as a barrier or facilitator to the implementation of value-based primary care? Strategies to promote synergy and success

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**Introduction:** Value in health care is described as the measured improvement in a patient's health outcomes for the cost of achieving that improvement. In the United States, value-based care has been heralded by providers, payers, and policymakers alike, as a path to addressing the challenges facing the healthcare system and achieving the aspirational goals of the Quadruple Aim of healthcare. Primary care is often viewed as the foundational cornerstone for implementing value-based care. However, primary care is also considered as ground-zero for the rise in healthcare consumerism.

**Methods:** In essence, consumerism refers to increasing expectations from patients (consumers) to be more active participants in decisions related to their healthcare. While much of the literature has portrayed the rise in consumerism as a barrier to the implementation of value-based primary care, some have argued that it may have potential to synergize with and facilitate the implementation of value-based primary care. This paper applies an enhanced stepwise implementation framework for value-based (equitable) care, to examine the potential for conflict and synergy between consumerism and value-based care in the emerging retail model of primary care. The application is based on the potential actions of four key stakeholder groups: (1) retail healthcare entities, (2) primary-care providers, (3) consumers (patients), and (4) healthcare payers.

**Results:** The analysis helps to articulate the responsibilities of each stakeholder group in ensuring synergy between consumerism and value-based primary care. In addition, it helps to identify three drivers of synergy between consumerism and value-based care: (1) trust in the patient-provider relationship, (2) connected consumer-centric technology solutions, and (3) value-based consumer-centric payment models.

**Discussion:** Overall, the application helps to articulate a comprehensive framework for implementing value-based care that incorporates both the principles of consumerism and active consideration for health equity.

## KEYWORDS

value-based care, consumerism, primary care, retail healthcare, patient-provider trust, consumer engagement, healthcare technology, health equity



## Introduction

Leading frameworks conceptualizing healthcare systems agree that effective healthcare systems must produce better patient experience and health outcomes at a sustainable cost (1–3). Additionally, health equity, or the fair distribution of health outcomes within populations, has been embraced by the World Health Organization (WHO) as a primary aim (4, 5). Although countries around the world struggle to achieve these aims, the United States (US) is known to have the most costly and sub-specialized healthcare system, with poorer health outcomes and health equity at a population level, compared to any other industrialized peer nation (6, 7).

In recent years, value-based care has been put forth as an approach for addressing the challenges facing the US healthcare system (3, 8, 9). Value in health care has been described as the measured improvement in a patient's health outcomes for the cost of achieving that improvement (9). Since value is created only when health outcomes improve, it has been argued that value-based care cannot be defined purely in terms of cost reduction (8, 9). Notably, value-based care has been heralded by providers, payers, and policymakers alike, as a path to achieving the aspirational goals of the Quadruple Aim of healthcare, which entails improving the patient experience, improving the health of populations, and reducing the per capita cost of health care, while also improving the clinician's experience of providing care (10).

Nonetheless, formidable barriers exist to the widespread, successful implementation of value-based care, including the slow pace of change of payer reimbursement models and provider resistance to redesigning care delivery models (11–13). In recent years, the emerging trend of consumerism in healthcare has received considerable attention for its potential to serve as a barrier to value-based care, although some have argued that consumerism has the potential to synergize with and facilitate the implementation of value-based care (13, 14). In essence, consumerism refers to increasing expectations from patients (consumers) to be more active participants in decisions related to their healthcare (15, 16). Based on this interpretation, there may be no reason to view consumerism as a barrier to value-based care. If anything, it could be viewed as a facilitator, if both parties (patients and providers) have a shared goal of improving health outcomes (14). However, if consumerism is interpreted as the “commodification” of healthcare, whereby consumers expect healthcare to function like any other service (e.g., restaurants), with a focus on outcomes that may arguably be different from what providers value (e.g., convenience or speed), then consumerism could be viewed as a barrier to the implementation of value-based care (13).

## Purpose of this paper

Primary care is viewed as a foundational cornerstone for value-based care since the four primary care core functions (4Cs) of contact (access), continuity, comprehensiveness, and coordination are each associated with improved health outcomes (11). However, primary care is also viewed as ground-zero for the rise in consumerism, e.g., the “retail primary care consumer” who is willing to “shop” for primary care services within large integrated healthcare marketplaces (13).

This paper explores the potential for conflict and synergy between consumerism and value-based care in the emerging retail healthcare

model of primary care. It begins by articulating an enhanced framework for implementing value-based care that also incorporates active considerations for health equity. The framework is applied to the retail model of primary care to discuss potential avenues for conflict and synergy between consumerism and value-based care, based on the actions of four stakeholder groups: retail healthcare entities, primary care providers, consumers, and payers. The analysis helps to identify strategies for mitigating conflict and promoting synergy between consumerism and value-based care, to ensure the success of value-based care models in primary care.

## An enhanced framework for implementing value-based care that incorporates active consideration for health equity

By focusing on the outcomes that matter most to patients, value-based care aligns care with how patients experience their health. Population health only improves when the health outcomes of many individuals with shared health needs improve, which is the focus of value-based health care. Likewise, by organizing teams to care for individuals with similar needs, a value-based approach enables expertise and efficiency, to drive costs down. Measured health outcomes in turn demonstrate clinicians' ability to achieve results with patients and families and drive improvement in the results that matter most to both patients and clinicians. Correspondingly, value-based health care puts decisions about how to deliver care in the hands of the clinical team, supports their professionalism, and the power of clinician-patient relationships, to deliver effective and appropriate care.

Following years of research on value-based care, medical academic literature has articulated a five-step framework that healthcare organizations could use to implement value-based care: (1) understanding shared health needs of patients; (2) designing a comprehensive solution to improving health outcomes; (3) integrating learning teams; (4) measuring health outcomes and costs; and (5) expanding partnerships (9). It is noteworthy however, that this framework does not incorporate explicit considerations for health equity.

The COVID-19 pandemic served to both expose and exacerbate health disparities in the United States (17). Value-based care and payment models are known to have the potential to reduce health disparities (17, 18). During the pandemic, organizations that received a greater proportion of prospective (value-based) payments were protected, since their revenues were less affected by reductions in service volume. Moreover, value-based payment models encouraged organizations to develop partnerships and invest in infrastructure to address people's clinical and social needs. Correspondingly, these organizations had greater success in adapting to the public health emergency with new care models to maintain continuity of care when faced with a substantial shift to telehealth and reduction in elective services (17, 18).

At a national level however, few organizations are explicitly prioritizing health equity in their value-based care or payment models. To address this concern, health policy advocates have put forth several strategies for providers and payers to ensure consideration for equity in value-based care, including (1) the selection of equity-focused quality measures, (2) adjusting performance measures for social risk to address health disparities,

and (3) empowering healthcare organizations to address social drivers of health (18). Based on these policy recommendations, it would be reasonable to argue that each of the five steps of the framework for implementing value-based care could be enhanced to incorporate active considerations for health equity, e.g., Step 1 could be enhanced to “understanding shared health needs of patients, with active considerations for health equity,” and so on and so forth.

## Applying the framework to examine the potential for conflict and synergy between consumerism and value-based primary care

Applying the enhanced framework on value-based (equitable) care to primary care must begin with a recognition of the primary care context, including: (1) the current crisis in traditional primary care in the United States, (2) the rise of consumerism and growing threat of new retail healthcare market entrants, and (3) the urgent call for primary care providers to reclaim their territory through concerted efforts to implement value-based care.

Despite the rising momentum toward paying for value, healthcare financing continues to focus heavily on payment for transactional, visit-based care (e.g., the Medicare Relative Value Unit schedule). This leaves few options for primary care practices to provide high-value services (e.g., between-visit preventive care, care coordination, and chronic disease management) due to lack of reimbursement. However, with healthcare expenditures continuing to outpace economic growth, pressures have mounted on primary care to provide these services. The growing expectations for high-value services coupled with low revenue streams in turn, has resulted in many primary care practices struggling to maintain financial sustainability (11).

At the same time, there is evidence of rising consumerism in primary care, a trend that has resulted in growing threats to traditional primary care by new market entrants seeking to promote retail healthcare tactics in the healthcare space. Examples include nonhealthcare businesses entering healthcare (Amazon, Google, etc.), national pharmacy chains, medical device and pharmaceutical firms, information technology companies, startups, as well as existing organizations, insurance companies, integrated delivery systems (e.g., Kaiser Permanente). These market changes reflect the reality that so long as traditional primary care fails to adequately meet patients' expectations and needs, new entrants will attempt to fill this void (11, 13).

In recognition of the escalating crisis in primary care, medical leaders have called upon primary care providers to adopt new models of care delivery that reinforce the potential for improving value. These leaders have argued that redesigning care delivery and payment models based on the following principles will lead to higher value, which in turn will necessitate new approaches to workforce training: (1) reward for value, including between-visit preventive care. (2) focus on building relationships with patients (consumers) through teams and technology, with non-physicians assuming an increasing role in healthcare. (3) focus on high complexity presentations by generalist physicians, and (4) focus on whole-person care that addresses health behaviors and provides vision, hearing, dental, and social services (11).

The urgent need for concerted efforts from primary care providers to implement value-based care in turn helps to underscore

the need for effective strategies to mitigate conflict and promote synergy between consumerism and value-based primary care. Notably, the actions of four stakeholder groups involved, (1) retail healthcare entities, (2) primary care providers, (3) consumers, and (4) payers, have potential to affect the interplay between consumerism and value-based care. In the sections below, the framework for implementing value-based (equitable) care is applied to examine the potential for conflict and synergy between consumerism and value-based primary care, arising from actions of each stakeholder group. The application helps to identify strategies for promoting synergy between consumerism and value-based primary care.

## Retail healthcare entities

Retail healthcare entities could engage in a variety of activities that foster conflict between consumerism and value-based care (13, 14).

1. They could allow consumers (patients) to comparison-shop by delivering greater price transparency, which in turn has the effect of creating price competition, pressuring sellers to lower the prices for their services.
2. They could also engage in “volume selling” or getting consumers to access lower-cost, health services (e.g., wellness services, fitness monitoring, walk-in clinics) on a frequent basis, thereby emphasizing the purely transactional aspects of healthcare delivery.
3. They may also engage in market segmentation, i.e., grouping patients with similar needs and preferences to target certain services, a tactic that allows the retail entity to undercut the provider and approach the patient directly to market products or services, e.g., wearable devices, that the patient may not need, but may in fact place greater demand on the provider's time with uncertain reimbursement.

In summary, a consistent theme in retail healthcare tactics is the introduction of intermediaries between the buyer (consumer/patient) and seller (provider) to shape decisions about which products consumers should buy, thereby undermining providers' ability to build meaningful relationships with the patient (13, 14) (Table 1).

## Primary care providers

Primary care providers who do not embrace value-based care and continue to espouse fee-for-service may view retail clinics as a source of competition. These providers may see retail clinics as skimming easier cases and leaving the more complex and time-consuming patients for the primary care providers, thereby adding new challenges to their workflow in the broader context of lack of reimbursement for care coordination and other high-value services (13, 14). In this scenario, some primary care providers may respond by establishing “direct primary care” models, i.e., stand-alone practices that no longer deal with insurance and instead require a smaller panel of patients to pay monthly subscription fees to receive more on-demand care (14) (Table 2).

TABLE 1 Potential for conflict and synergy between consumerism and value-based care arising from actions of retail primary care companies.

Framework for implementing value-based (equitable) care	Potential for conflict through stakeholder actions	Potential for synergy through stakeholder actions
(1) Understanding shared health needs of patients, with active consideration for health equity.	Comparison-shopping (price competition), volume-selling, and market segmentation are all retail tactics that can be detrimental to the provision of value-based care by pitting the consumer against the provider and by introducing the retail entity as an intermediary in the provider-patient relationship (13), which in turn can prevent providers from being able to develop an understanding of shared health needs of patients.	Some retail healthcare entities have chosen to serve as low-cost extensions to primary care as opposed to substitutes. They are staffed by nurse practitioners to manage acute conditions and return patients to their primary care physician (14). This approach enables primary care providers to take the lead in understanding shared health needs of patients and relying on retail entities to maintain continuity of care through efficient use of resources.
(2) Designing a comprehensive solution to improving health outcomes, with active consideration for health equity.	Volume-selling shifts the focus to transactional excellence, whereas designing a comprehensive solution to address health needs requires relational excellence between providers and patients (13) to craft a solution that fits within the patient's life context, addresses medical and social needs, and is efficient in the use of resources.	By partnering with providers (instead of competing with them), retail healthcare entities can help to maintain continuity of care and be part of a comprehensive solution for addressing patients' medical and social needs.
(3) Integrating learning teams, with active consideration for health equity.	By competing, instead of collaborating with providers to address patients' needs, retail entities hinder providers' ability to establish co-located learning teams to coordinate care and improve outcomes with efficient use of resources.	Some retail care entities are also committed to sharing data about patient care encounters with primary care physicians, and some are committed to helping patients without primary care find a medical home (14). Such approaches enable service integration to ensure effective and efficient care. They also enable retail entities to work as a team with primary care providers, to integrate learning and improve health outcomes.
(4) Measuring health outcomes and costs, with active consideration for health equity.	Market segmentation undermines providers' ability to work in the best interests of the patient by allowing the retail entity to target products and services to patients that the provider may deem as inappropriate or deviating from evidence-based guidelines for treatment. This in turn may hinder the development of health outcome and equity measures that are valued by providers.	Studies indicate that care provided at retail clinics for common acute illnesses, e.g., respiratory infection, urinary tract infection, is as good if not better than care delivered in ambulatory or emergency room settings (22, 23). Also, many of these entities are committed to strict evidence-based guideline adherence, which in turn is directly aligned with the value-based care goals of measuring and improving outcomes (14, 22).
(5) Expanding partnerships, with active consideration for health equity.	Pitting consumers against providers through volume selling and market segmentation hinders the development of a collaborative spirit among providers, which in turn is essential for expanding partnerships within the profession and the community, to improve health outcomes of people with similar needs and promote population health.	Retail strategies of serving as a low-cost extension of primary care, using a team-based approach to data sharing, and implementing evidence-based guidelines to improve outcomes, can enable primary care providers to expand partnerships to address needs of groups of patients, to promote population health and achieve the goals of value-based care.

## Healthcare consumers

Ultimately, health outcomes need to improve for value-based care to succeed, and consumers can derail success through no-shows or non-adherence resulting from lack of trust and engagement. The concept of “Patient” implies responsibility on the part of providers, and a historical hierarchy based on the premise that providers act or decide on behalf of patients. The concept of “Consumers,” on the other hand, is founded on the principle of choice and preferences (19). Consumers make decisions that affect their health based on information they choose to pay attention to. Therefore, blind faith in providers' actions may no longer be the norm, which in turn forms the root of trust issues that are increasingly being recognized as a disruptive force in the US healthcare system (20). Value-based

care is critically dependent on “patient engagement.” Patients must desire to improve their conditions while using resources responsibly (9). Therefore, providers need to factor in holistic information related to people's lives, needs, preferences, technology use, and constraints into care plans to build trust and ensure patient engagement (Table 3).

## Healthcare payers

Public and private healthcare payers have a key role to play in regulating the interplay between consumerism and value-based care. Until recently, value-based payment models focused exclusively on influencing providers to reduce costs, which in turn had the effect of creating perverse incentives among providers to cherry pick healthier

TABLE 2 Potential for conflict and synergy between consumerism and value-based care arising from actions of primary care providers.

Framework for implementing value-based (equitable) care	Potential for conflict through stakeholder actions	Potential for synergy through stakeholder actions
(1) Understanding shared health needs of patients, with active consideration for health equity.	Direct primary care models are exclusive practices that have potential to limit access to primary care for those without the means to contract directly. This in turn greatly limits the ability to understand shared health needs of patients within a population (14). Correspondingly, this model has potential to exacerbate disparities, as the most vulnerable would face the greatest challenges for access.	Primary care providers who embrace value-based care principles are likely to view retail sites as valuable low-cost extensions of primary care that could be leveraged as partners for improving outcomes at a sustainable cost. Such providers are also likely to invest efforts in building trusting relationships with their patients (consumers) to understand the full spectrum of their medical and social needs for developing holistic and effective care plans.
(2) Designing a comprehensive solution to improving health outcomes, with active consideration for health equity.	By making their practices exclusive and competing with retail care models and other primary care providers, direct primary care providers can greatly limit the ability to design a comprehensive solution for improving health outcomes and promote population health.	Embracing value-based care, establishing partnerships with retail care sites, and investing in consumer-centric technology like telehealth and remote (home-based) diagnostics and monitoring, can engage and empower consumers to be stewards of their own health, while also catering to the growing consumer demand for convenience and efficiency (15, 16). The increasing potential for connectivity between remote technology and physicians' offices, moreover, helps to design a comprehensive solution for improving health outcomes. Moreover, remote care can reduce the need for office visits and alleviate transportation barriers and costs, thereby helping to promote equity in healthcare access and outcomes.
(3) Integrating learning teams, with active consideration for health equity.	Direct primary care models can have the effect of propagating silos by creating exclusive practices and mitigating the potential for learning, collaboration, and care coordination needed to improve health outcomes at a sustainable cost.	Partnering with retail care sites that serve as low-cost extensions of primary care and sharing data on patient care encounters can help to integrate learning teams and improve care coordination. Similarly, increasing connectivity between remote (home-based) care technology and physicians' offices helps to integrate learning teams and remain continuously responsive to patients' evolving needs.
(4) Measuring health outcomes and costs, with active consideration for health equity.	Direct contracting creates silos (exclusive patient panels) and limits the potential for data sharing with other primary care providers, which hinders the ability to measure health outcomes and costs and reduce health disparities.	Primary care providers that espouse value-based care principles, can initiate meaningful partnerships with retail care sites, patients/families, and community partners (11, 14), to implement evidence-based guidelines, and ensure data sharing and connectivity, to measure and improve health outcomes and promote health equity.
(5) Expanding partnerships, with active consideration for health equity.	Direct primary care models could adversely impact primary care providers who do not engage in direct contracting, by forcing them to care for a sicker and more vulnerable population (14), thereby limiting their ability to improve outcomes, manage population health, and expand partnerships.	Primary care providers who strive to redesign care to maintain continuity, establish retail care partnerships, invest in telehealth services, and leverage the potential of connected remote care technology, will be better poised to expand partnerships for improving health outcomes for the populations they serve, at a sustainable cost.

patients to demonstrate outcomes improvement at reduced costs (21). The increasing priority on health equity, however, has potential to facilitate a more holistic approach to value-based care by encouraging providers and consumers to work together to improve outcomes and reduce disparities, with efficient use of resources (17, 22). When payers' efforts focus exclusively on inducing providers to make cost-effective clinical decisions or on influencing consumers' healthcare purchasing behavior, the goals of value-based care could become difficult to achieve. For value-based care to succeed, providers and consumers need to share the responsibility for effective health care, i.e., improving health outcomes, and promoting health equity at a sustainable cost (Table 4).

## Discussion

The Health Care Transformation Task Force has articulated the primary goal of consumerism as: "supporting a person's ability to receive high-quality healthcare that best aligns with their goals, expectations, and preferences for services in a culturally relevant way. Reduction in cost, while important, should be considered a secondary benefit (15)." The analysis in this paper helps to identify the responsibilities of four key stakeholder groups in enabling the principles of consumerism to be synergistically incorporated into value-based care models.

TABLE 3 Potential for conflict and synergy between consumerism and value-based care arising from actions of consumers.

Framework for implementing value-based (equitable) care	Potential for conflict through stakeholder actions	Potential for synergy through stakeholder actions
(1) Understanding shared health needs of patients, with active consideration for health equity.	When consumers do not trust their healthcare providers and decide to use the system infrequently or only for sick care, it could become challenging for providers to understand patients' medical and social needs (19, 20).	Value-based care is critically dependent on patient trust and engagement. Correspondingly, providers need to invest considerable effort in understanding patients' shared medical and social needs to develop holistic care plans to engage and empower patients to improve outcomes at a sustainable cost.
(2) Designing a comprehensive solution to improving health outcomes, with active consideration for health equity.	Consumer health illiteracy, and lack of trust in the healthcare system could prompt consumers to seek information for self-care from social media or private data platforms elsewhere (19) and only access the healthcare systems minimally, which could greatly hinder the ability to design a comprehensive solution	Adoption of consumer health technology is growing fast. Wellness is a growing priority in people's lives and the use of mobile health apps and consumer wearables is advancing rapidly (19). Developing effective channels of communication with patients to gain a broad understanding of consumers' use of health information and technology can help to design a comprehensive solution for improving outcomes in partnership with patients.
(3) Integrating learning teams, with active consideration for health equity.	If providers remain unaware of consumers' use of technology for self-care, they may find it challenging to remain connected with their patients and to integrate learning teams for improving outcomes.	Earning patients' trust will enable better information and data sharing from patients to facilitate a clearer understanding of patients' needs which in turn will help to integrate learning teams. Building trust with patients and families in turn will require providers to convince people that they are placing the patients' best interests above any self-interest of their own.
(4) Measuring health outcomes and costs, with active consideration for health equity.	Poor provider-patient communication resulting from mistrust and misinformation hinders the ability to capture meaningful data about patient needs and health behaviors which in turn limits the capacity to measure health outcomes and costs.	Providers must factor in information about people's medical needs and living conditions (social health) into care plans and strategies. This type of holistic approach to patient care will help to build trust and facilitate information-sharing regarding consumers' use of healthcare technology that providers in turn could leverage to measure and improve outcomes at a sustainable cost.
(5) Expanding partnerships, with active consideration for health equity.	Ineffective patient-provider communication can create misinformation related to a patient's health needs making it a challenge to achieve the goals of value-based care of improving health outcomes at a sustainable cost. Since expansion of partnerships is contingent on improving outcomes, this step is hindered by the absence of trusting relationships between providers and patients.	An engaged and empowered consumer base can serve as a strong foundation for effective information sharing about patients' health and social needs to integrate learning teams and measure and improve outcomes which in turn will enable the expansion of partnerships to widen the base and influence of value-based care.

Retail healthcare entities must partner with primary care providers to serve as low-cost, convenient, and effective extensions of primary care, and ensure a high degree of data sharing and connectivity with primary care practices to promote synergy between consumerism and value-based care. Primary care providers in turn, must embrace the principles of value-based care, and partner with retail care sites to offer consumer-centric options for acute care. Concurrently, they must strive to build strong, trusting relationships with patients, to create a foundation for designing comprehensive solutions to address patients' health needs, to improve health outcomes and equity at a sustainable cost. Consumers can derail the success of value-based care by not showing up for appointments, not sharing information, using disconnected healthcare technology, and not adhering to care plans, owing to lack of trust and engagement. Correspondingly, payers must design payment models that reward consumer-centric value-based (equitable) care options to promote trusting relationships

between providers and patients and facilitate a shared responsibility for improving health outcome and equity at a sustainable cost, to ensure the success of value-based primary care.

The analysis and discussion in this paper also help to identify three key themes among the drivers of synergy between consumerism and value-based care:

- (1) Trust in the provider-patient relationship. To build trust, primary care providers must convince patients that they are placing their best interests above their own self-interest; and demonstrate respect for differing patient beliefs and perspectives by engaging in dialogue to provide alternate information and recommendations (20).
- (2) Connected consumer-centric healthcare technology solutions. Consumer-centric remote (home-based) diagnostics and monitoring technology (14, 16) that are connected to primary care practices can serve the dual purpose of incorporating



TABLE 4 Potential for conflict and synergy between consumerism and value-based care arising from actions of payers.

Framework for implementing value-based (equitable) care	Potential for conflict through stakeholder actions	Potential for synergy through stakeholder actions
(1) Understanding shared health needs of patients, with active consideration for health equity.	Payment models designed exclusively to influence providers to reduce costs can create perverse incentives to cherry-pick (21) healthier patients which can serve as a barrier to understanding the shared health needs of patients to improve outcomes and promote population health.	Designing value-based payment models with a focus on improving outcomes and health equity at a sustainable cost, has the potential to motivate providers to understand shared health needs of groups of patients with a view to improving outcomes and health equity at a sustainable cost.
(2) Designing a comprehensive solution to improving health outcomes, with active consideration for health equity.	Payment models that are focused on influencing consumers' healthcare purchasing behavior (e.g., incentives to purchase wellness services or wearables) without provider buy-in, can adversely impact the provider-patient relationship (19) and hinder provider engagement in seeking comprehensive solutions to improve health outcomes.	Value-based payment models that support consumer-centric care options like low-cost, convenient, retail care (14), and connected, remote (home-based) care technology (16), can empower providers to address both medical and social drivers of health to design a comprehensive solution for addressing shared health needs of patients to improve health outcomes and health equity.
(3) Integrating learning teams, with active consideration for health equity.	Payment models that are designed to reward cost reduction as opposed to the intended goals of value-based care (16), have the potential to induce providers to focus on cost cutting (at the expense of outcomes improvement), which in turn could impede with the integration of learning teams for improving outcomes.	Payment models that focus on improving outcomes and reducing health disparities, have the potential to unite providers and patients in seeking a comprehensive solution to address health needs through data sharing and remote technology-connectivity, to integrate learning teams for success.
(4) Measuring health outcomes and costs, with active consideration for health equity.	Payment models that focus on cost reduction may result in little or no attention to measuring and improving outcomes, thereby hindering the ability to achieve the goal of value-based care.	Payment models that stay true to the philosophy value-based care of improving outcomes can enable data sharing across collaborating entities, effective integration of learning teams and measurement of outcomes, costs, and health equity to ensure attainment of the goals of value-based care.
(5) Expanding partnerships, with active consideration for health equity.	Payment models focused on cost reduction or on influencing consumers' purchasing behavior, may pit providers against patients, and prevent the development of a provider-patient partnership for improving outcomes, which in turn could hinder the ability to expand partnerships without a sufficient evidence base on improved outcomes to appeal to diverse pool of stakeholders.	Payment models that incentivize demonstration of improved health outcomes at a sustainable cost, could enable providers to be successful in expanding partnerships to improve outcomes for groups of people with similar needs, and promote population health and equity, to achieve the goals of value-based care.

both principles of consumerism (e.g., convenience and efficiency) and consideration for health equity (e.g., elimination of transportation barriers) to achieve the goals of value-based primary care.

- (3) Value-based consumer-centric payment models. These type of payment models may be indispensable in promoting trusting relationships between patients and providers and facilitating a shared responsibility for designing comprehensive solutions to address health needs of groups of patients, and improving health outcomes and equity, at a sustainable cost, to achieve the goals of value-based care (16, 19).

Overall, the analysis helps to articulate an enhanced, comprehensive framework for implementing value-based care that incorporates both the principles of consumerism and consideration for health equity. In other words, each step of the five-step framework for implementing value-based care (discussed earlier) (9), can be enhanced to incorporate both principles of consumerism and consideration for health equity. For example, Step 1 could be modified to “understanding shared health needs of patients, with

active consideration for the principles of consumerism and health equity.”

## Conclusion

This paper applies a stepwise framework for implementing value-based (equitable) care to examine the potential for both conflict and synergy between consumerism and value-based care in the retail model of primary care. The analysis helps to articulate the responsibilities of four stakeholder groups and underscore the importance of (1) trust in the patient-provider relationship, (2) connected consumer-centric technology solutions, and (3) value-based consumer-centric payment models in promoting synergy between consumerism and value-based primary care.

As the healthcare industry continues to shift to value-based care, and consumerism rises, strong, trusting provider-patient relationships that foster a shared responsibility for designing comprehensive solutions to address health needs, will hold the key to success. Concurrently, a convergence between payers and providers will



be required to deliver on the expectations of value-based, consumer-centric payment models. In this scenario, investments in consumer-centric technology that facilitates connectivity across the four stakeholder groups (retail healthcare entities, providers, consumers, and payers), has potential to serve as a foundational cornerstone for attaining the goals of consumer-centric value-based primary care with active considerations for health equity.

## 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.

## Author contributions

PR: Conceptualization, Investigation, Validation, Writing – original draft, Writing – review and editing.

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# Landing wise program: feasibility study protocol for Parkinson's disease

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Regardless of the benefits of fall prevention programs, people with Parkinson's disease (PD) will still fall. Therefore, it is crucial to explore novel therapeutic approaches that are well-accepted and effective for addressing fall risk and the fear of falls among this population. The present study aims to assess the feasibility of the Landing Wise program as a therapeutic intervention for reducing the fear of falling in people with PD. A mixed-methods study will be conducted using convenience sampling to recruit 20 people with PD with a moderate concern of falling from a Parkinson's Patients Association. In addition to usual care, participants will attend 2 days per week, 90 min group sessions for 8 weeks. The intervention combines group cognitive behavioral intervention with the training of safe landing strategies. Feasibility will be assessed by six key domains (recruitment strategy and rates, enrollment, retention, acceptability, reasons for decline/withdrawal, and adverse events). Quantitative data will be analyzed using descriptive statistics to characterize the sample, followed by inferential statistics to evaluate differences in the Short Falls Efficacy Scale-International Scale, Movement Disorder Society Unified Parkinson's Disease Rating Scale, Timed Up Go, 6-Minutes Walking Distance, and fall frequency and severity scores between baseline and final assessment. Qualitative data will be analyzed using an inductive thematic analysis process. There is a growing interest in developing new effective therapeutic approaches for people with PD. If proven program feasibility, this study precedes a randomized controlled trial to establish the effectiveness of the Landing Wise program.

## KEYWORDS

Parkinson's disease, accidental falls, accident prevention, exercise movement techniques, cognitive behavioral therapy, safe landing, rehabilitation, physiotherapy

## 1. Introduction

Parkinson's disease (PD) is a chronic degenerative disorder of the central nervous system that primarily affects the motor system, triggering involuntary or uncontrollable movements, like tremors, rigidity, bradykinesia, and difficulty with balance and coordination (1, 2). However, PD can also cause non-motor complications such as cognitive impairment, sleep disorders, mental health disorders, pain, and sensory disturbances (2). In the last two decades, PD prevalence has doubled, and it is estimated that in 2019 affected over 8.5 million individuals (1, 3). Progression of PD symptoms leads to restrictions in many life areas, ultimately resulting in high rates of disability and care requirements (4).

In 2019, the WHO (1) estimated that PD resulted in 329,000 deaths, showing an increase of over 100% in the last two decades, and was responsible for 5.8 million disability-adjusted life years, resulting in a rise of 81% over the same period, escalating faster than for any other neurological disorder worldwide.

Falls are common among people with PD (5, 6), and, notably, the fall rate in this population is often higher than that observed in older adults without PD (5, 7). Consequently, they can experience fearful anticipation of falls, developing a fear of falling (FOF) (8, 9). The FOF can ultimately reduce balance performance and limit the person's activity levels (8, 10), compromising one's quality of life (11). Fall prevention programs mainly targeted intrinsic (e.g., muscle weakness, balance problem) or extrinsic (e.g., environmental hazards) fall risk factors (9, 12). Despite the benefits of these programs, it is crucial to highlight that participants within these programs are still at risk of falling (13).

It is vital to develop novel therapeutic approaches that are technically feasible, economically valuable, and culturally, ethically, and socially accepted for addressing fall risk and the FOF among this population (14–16).

Recent studies show that it is possible to reduce the fear of falling among older adults (17, 18). In addition, there is evidence that cognitive behavioral therapy (CBT) can effectively reduce the fear of falling, with significant immediate retention effects for up to 12 months (19–21). CBT is a psychotherapeutic skills-based, non-pharmacological treatment aimed at modifying individuals' thoughts and behavior by teaching practical strategies to support the individual more effectively in navigating daily challenges (22). In the Landing Wise program context, CBT principles and techniques are seamlessly integrated to address the physical aspects, such as safe landing strategies, and the psychological aspects, including FOF and anxiety, commonly experienced by individuals with PD.

The Landing Wise program takes a comprehensive approach that goes beyond physical training. It delves into the cognitive and emotional dimensions of FOF and anxiety, helping participants explore the intricate connections between their thoughts, feelings, and behaviors. Doing so empowers them with practical strategies to navigate daily challenges more effectively and adjust thought patterns—particularly those marked by negativity or behaviors like social isolation and withdrawal (23).

Previous studies have shown that CBT is a feasible treatment for anxiety and depressive symptoms in people with PD (24–27). More importantly, when applied to address FOF, CBT may yield broader positive outcomes, potentially reducing falls and enhancing overall

activities of daily living (28, 29). The versatility of CBT allows for deploying a wide range of strategies that can be used in CBT, such as cognitive restructuring, training of coping skills, or practicing new skills that can be used in real-world situations to help people with PD to overcome these patterns. For instance, as part of the Landing Wise program's integration of CBT, individuals grappling with FOF may actively practice safe landing strategies. Not only do these strategies provide tools for safe fall management, but they also reduce the impact load of a fall. A systematic review by Moon and Sosnoff (13) synthesized findings from 13 studies on safe landing strategies, demonstrating their potential to reduce the risk of injury during falls significantly. The authors concluded that landing strategies significantly decrease the impact load during a fall and might effectively reduce the impact load of falling.

Considering that previous studies have shown the positive effects of CBT and practice safe landing strategies on people at risk of falling, here, we combine the two approaches in a program. Therefore, in this study, our primary aim is to assess the feasibility of the Landing Wise program as a therapeutic intervention for reducing FOF in people with PD. Secondary objectives include assessing the program's preliminary effects on the people with PD.

## 2. Materials and methods

### 2.1. Study design

This study is a mixed methods study using quantitative and qualitative assessments. To ensure the quality of the research protocol report, we will use The Good Reporting of A Mixed Methods Study (GRAMMS) checklist (30).

### 2.2. Study setting

The intervention will be delivered in a gymnasium of a Day Care Unit from a Private Institution of Social Solidarity in the region of Lisbon and Tagus Valley in Portugal that caters to a population of over 80,000 people.

### 2.3. Sampling and recruitment

The study population consists of people with PD recruited from the Parkinson Patients Association and the outpatient neurology units from two hospital centers in Lisbon and Tagus Valley. The sampling method selection will be non-probabilistic by convenience. All eligible candidates will be invited to join the program.

Participants will be included if they fulfill the inclusion criteria:

- Diagnosis of idiopathic PD (Movement Disorder Society PD criteria) (31);
- Hoehn and Yahr stages II–IV (32);
- Age above 18;
- Moderate concern of falling with the Short Falls Efficacy Scale International (Short FES-I) >9 (33);
- A Montreal Cognitive Assessment (MoCA) score >25 (Normal cognition) (34);

- f. Able to tolerate a minimum of 45 min of exercise (Following recommendations from PD guidelines) (35);
- g. Able to communicate with the investigator, to understand and comply with the study procedures;
- h. Willing and able to provide written informed consent to participate and understand the right to withdraw their consent at any time without prejudice to future medical care.

Participants will be excluded if they have any of the following:

- a. A MDS-UDPRS Part III item 3.12 score > 3 (Severe postural instability: very unstable, tends to lose balance spontaneously or with just a gentle pull on the shoulders);
- b. Severe cognitive difficulties and significant active psychiatric problems that aggravate when exercising;
- c. Severe hearing or visual impairment;
- d. Missed two consecutive sessions.

Our study aims to recruit 20 participants in total. This sample size was calculated using G\*Power (36), taking into account a large effect size ( $d_z = 0.8$ ), an alpha level ( $\alpha$ ) of 0.05, and a statistical power ( $1 - \beta$ ) of 0.8. These calculations were performed for both the two-tailed matched pairs t-test and the two-tailed matched pairs Wilcoxon signed-rank test, which will be employed in the quantitative data analysis. Further details about these analyses are provided in the data analysis section below. Both tests indicated a required sample size of 15 participants. To account for a possible dropout rate of 25%, we increased the sample size to 20 participants.

In the first stage of recruitment, healthcare professionals (nurses, physiotherapists, and physicians) will be responsible for screening and identifying suitable participants based on the data in the patient's clinical file (diagnosis, staging of the functional disability associated with PD, and clinical data). These professionals will introduce the study to potential participants and provide an information sheet containing the study aims and procedures. A research team member will contact potential participants who have applied for the recruitment process via telephone to present comprehensive information regarding the study procedures and verify their willingness to participate. We recommend taking a minimum of 24 h to consider the advantages and disadvantages of participating in the study and formulate questions before deciding on participating. Once all questions have been answered, potential participants will be asked to sign an informed consent. Access to patient clinical data will only be granted to the researcher at this stage. Figure 1 shows a flow diagram for participants.

## 2.4. Intervention

The intervention consists of an 8-week program with 90-min group sessions held twice a week. The program combines group CBT with training in safe landing strategies, thus ensuring each component receives dedicated 45-min sessions (35, 37, 38). This intervention will supplement the usual care.

The intervention will be delivered by a rehabilitation nurse with PhDs in Nursing Sciences and Psychology, trained in Cognitive behavioral therapy, and experienced in motor and cognitive exercise programs. Following European Parkinson's guidelines (35), we will

consider eight people with PD as the optimum number of participants per group.

Assistance to the instructor will be provided by two nurses that are receiving their master's training in rehabilitation nursing. In addition, the students will receive 8 h of CBT training conducted by a cognitive-behavioral therapist.

To keep the program challenging and engaging, the instructor will gradually raise the complexity of the exercise session accordingly to the participants' willingness and improved condition. The instructor will use the Borg Effort Perception Scale to assess the participants' perceived effort through sessions (39). Participants can achieve an intensity rating between 14 (Somewhat Hard) and 17 (Very Hard) on a 20-point Borg scale, indicating a range from somewhat challenging to very hard perceived exertion during exercise (40).

The CBT will be based on the FOF management model (41) that illustrates how community-dwelling older adults think, feel, and act when facing FOF. According to this model, the FOF arises when the person believes falling is an inevitable part of aging. These misconceptions may lead older adults to withdraw from social activities instead of focusing on strategies to manage the problem. The FOF model indicates that older adults may embrace different strategies: display psychosomatic symptoms, adopt an attitude of risk prevention, pay attention to environmental safety, and modify their own's behavior. The FOF will be relieved when the person is satisfied with the outcomes (41).

The program syllabus will be designed based on prior research (42, 43), aiming to restructure misconceptions to foster a positive view of fall risk management, increase self-confidence and physical wellness concerning falling, and a sense of control over falling. The sessions will cover the following themes: (1) introduction; (2) associations with falls and fear of falling; (3) participant's view of FOF; (4) cognitive restructuring; (5) strategies to manage fall risk; (6) strategies to manage FOF; (7) application of strategies in daily life; and (8) problem-solving (learning how to fall, stand up and call for help).

Each session will be carefully planned by a team composed of a cognitive-behavioral therapist, a rehabilitation nurse, a physiotherapist, and an exercise physiologist, experts in PD, who will develop a guide to help manage each session. Then, a panel of experts in CBT will assess the guide's appropriateness and contents. The structure of the CBT sessions is described in Table 1.

After completing the CBT, the initial stage of safe landing training commences with a 10-min physical warm-up session aimed at reducing the risk of injury. This is followed by a 10-min improvisation phase, wherein participants will have the freedom to move in accordance with specific instructions (such as bilateral movements, large and big movements, movements that are not usually carried out in everyday life activities, as getting up and down from the floor, etc.).

All participants will be equipped with protective gear for the second stage, including a wrist guard and neck protector. The intervention methods consist of 20 min of safe landing training exercises aiming to teach participants how to fall in such a manner to alleviate the impact severity and minimize the risk of injury.

We have chosen the three safe landing techniques that have proven to be effective in reducing the impact severity of various falls (13) (Figure 2), namely:

- a. Backward squatting (flex the knees and hips while contracting the muscles spanning these joints);

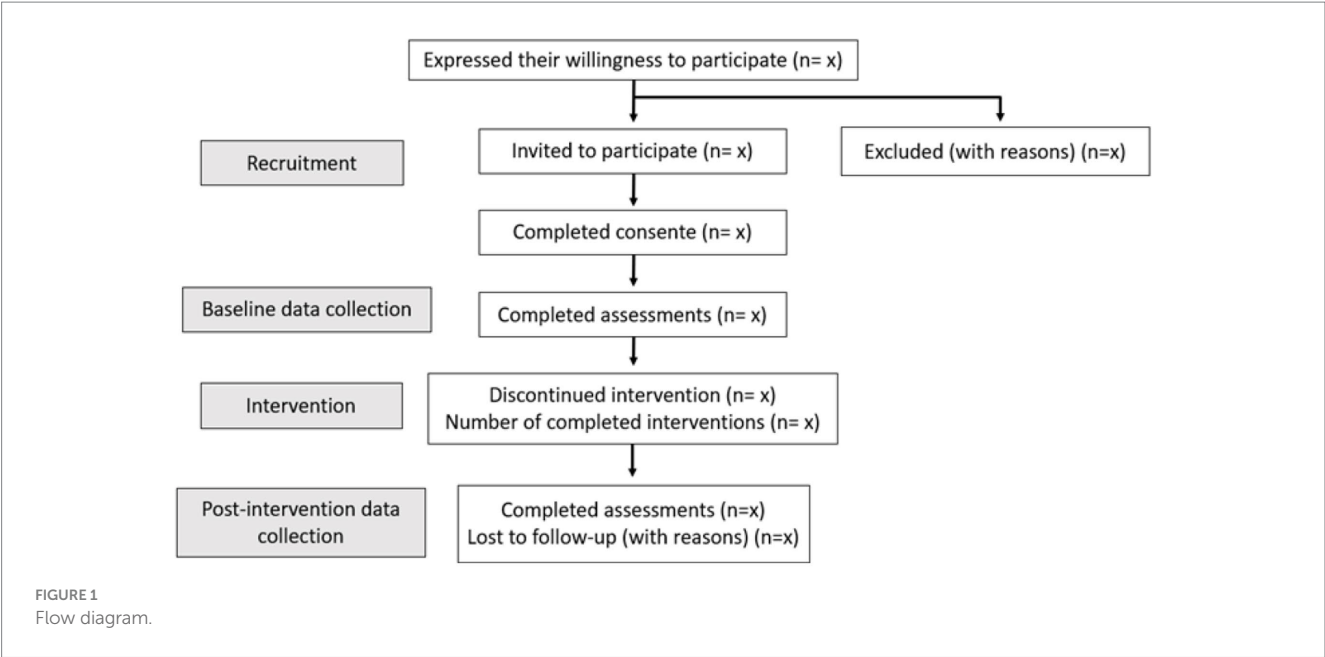


TABLE 1 Structure of the CBT sessions.

Phase 1: Warm-Up (5 min)	<ul style="list-style-type: none"><li>• Social interaction (e.g., greeting friends).</li><li>• Setting a positive and supportive tone for the session.</li><li>• Introduction to the session's topic.</li><li>• Brief review of the previous session (if applicable).</li><li>• Engaging in a warm-up activity to promote relaxation and focus.</li></ul>
Phase 2: Cognitive restructuring approach (20 min)	<ul style="list-style-type: none"><li>• Explanation of the concept being addressed.</li><li>• Discussion, group exercises, or role-playing related to the skill.</li><li>• Identifying and addressing cognitive and emotional aspects (e.g., fear of falling, negative thought patterns).</li></ul>
Phase 3: Sharing and Support (15 min)	<ul style="list-style-type: none"><li>• Encouraging participants to share their experiences or insights related to the session's topic.</li><li>• Providing support and feedback within the group setting.</li></ul>
Phase 4: Closing (5 min)	<ul style="list-style-type: none"><li>• Summary of the key points covered in the session.</li><li>• Homework assignments or practice exercises for participants to work on until the next session.</li><li>• Ending the session on a positive and motivating note.</li></ul>

- b. Forward elbow flexion (catch the ground with the outstretched arms while landing with the slightly flexed elbow);
- c. Side forward rotation (rotate forward during the descent to land on the outstretched hands).

To minimize the risk of injury, participants will practice the safe landing techniques on 12-inch thick gymnastics crash landing mats. The instructor will exemplify the technique before the participants. Each technique will be introduced gradually to protect the participants from falling directly at the beginning. In addition, two professionals will assist the participants' movements to ensure their safety throughout the session. Participants will be encouraged to lower their center of gravity and increase the area of their body's contact with the mats to decrease impact load. To help to protect the vital organs from damage, they must exhale to contract the muscles and constrict the rib cage on impact.

Participants will keep repeating the safe landing techniques to establish the conditioning reflex of instinctively and quickly assuming

the movements to protect themselves, exhale, relax, and allow the impact to spread through the body without injury.

To finalize, participants will perform five minutes of relaxation with active slow amplitude movements with music, stretching, and breathing exercises, followed by a brief group discussion to gather participant feedback on each exercise to guide future sessions.

The structure of the Safe landing training sessions is described in Table 2.

## 2.5. Data collection

Researchers defined the feasibility of trial design and procedures by six key domains for a subsequent registered randomized controlled trial. These key domains will be our primary outcomes and include:

- a. Recruitment strategy and rates (candidates screened, eligible, approached, consented, and excluded after screening).



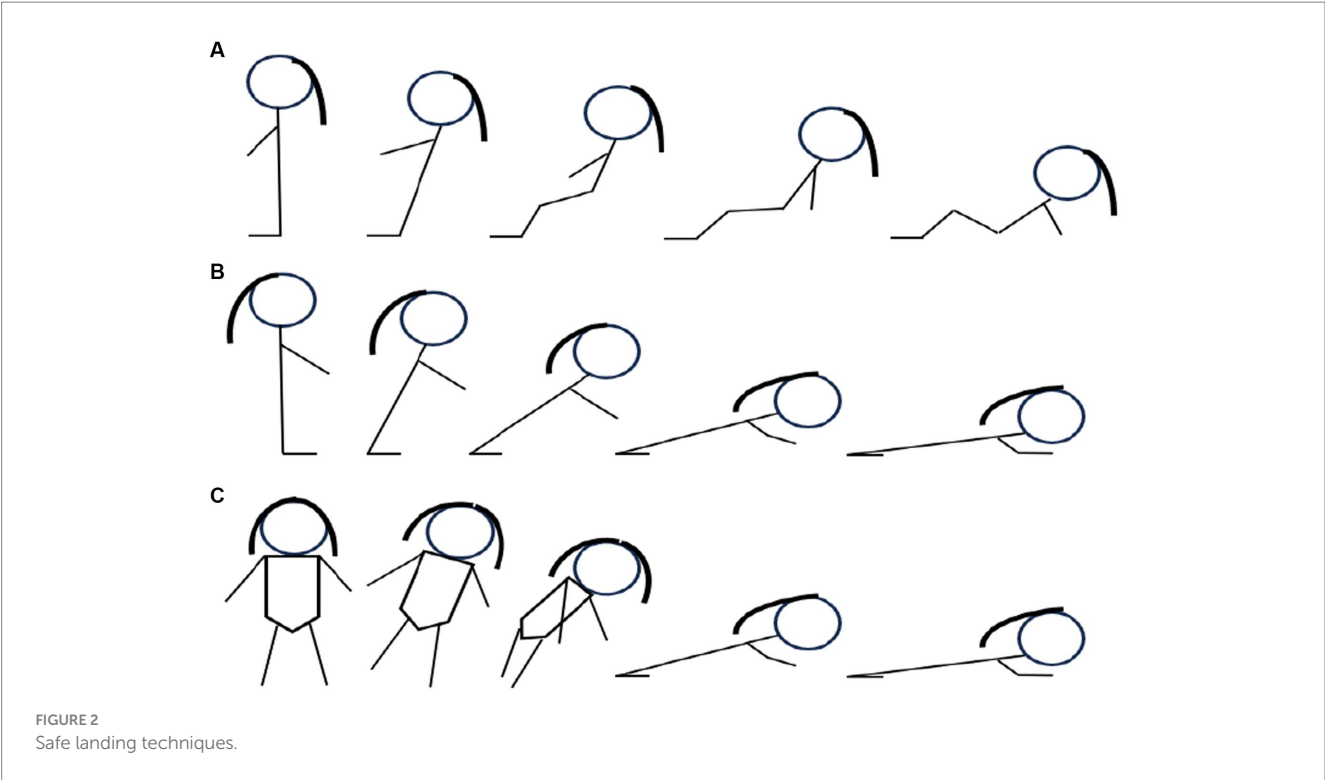


TABLE 2 Structure of the safe landing training sessions.

Phase 1: Warm-up (10 min)	<ul style="list-style-type: none"><li>• Warm-up exercises to prepare participants for safe landing training.</li><li>• Mobility and flexibility exercises</li></ul>
Phase 2: Improvisation (10 min)	<ul style="list-style-type: none"><li>• Participants have the freedom to move according to specific instructions.</li><li>• Encouraging participants to explore their movements and expand their physical capabilities.</li></ul>
Phase 3: Safe landing practice (20 min)	<ul style="list-style-type: none"><li>• Guided practice of safe landing techniques with instructor supervision</li><li>• Participants practicing controlled landings and loss of balance.</li><li>• Participants practicing safe landing techniques independently.</li><li>• Instructor providing feedback and corrections as needed.</li></ul>
Phase 4: Cool-Down and Conclusion (5 min)	<ul style="list-style-type: none"><li>• Cool-down exercises to relax muscles after safe landing practice.</li><li>• Summary of the key points covered in the safe landing training.</li></ul>

- b. Enrollment (number of participants that attended the program).
- c. Retention (percentage of enrolled participants who completed final program assessments).
- d. Acceptability (assessed with an *ad hoc* survey and semi-structured exit interviews). The exit survey will consist of Likert scale questions to evaluate the participants' satisfaction. The interviews aim to gain insight into participants' perspectives on the intervention's feasibility, acceptability, and usefulness and identify barriers and facilitators that may influence people with PD to participate in the program.
- e. Reasons for decline/withdrawal (the researchers will keep a record of reasons for decline/withdrawal).
- f. Adverse events (number of events involving injury).

A qualified research team member will collect secondary outcomes to identify an appropriate outcome and estimate parameters

for a sample size calculation for a randomized controlled trial. These assessments will be performed in the week before (T0) and after completing the training program (T1) using the following instruments:

- a. FOF (Short FES-I). The Short FES-I is a self-report questionnaire used to assess an individual's level of concern or FOF during various activities of daily living. The ratings are often done on a scale, typically ranging from 1 (not at all concerned) to 4 (extremely concerned). This scale had good test-retest reliability ( $r = 0.987$ ) and good internal consistency ( $\alpha = 0.958$ ) (33);
- b. Clinical impairments (The Movement Disorder Society Unified Parkinson Disease Rating Scale - MDS-UPDRS) (44). The MDS-UPDRS is a comprehensive clinical assessment tool to evaluate non-motor and motor experiences of daily living and motor complications. It includes a motor evaluation and characterizes the extent and burden of disease. This scale had



a test–retest reliability of 0.92 and internal consistency of 0.96 (45);

- c. Frequency and severity of falls (falls weekly registry). The registry collects data on falls, including when and where they occurred, the circumstances surrounding the falls, the individuals involved, and any resulting injuries (46);
- d. Gait (Timed Up Go - TUG). The Timed Up and Go Test is a reliable assessment tool for evaluating an individual's mobility and functional balance, as it necessitates the ability to transition, walk, and change direction (46). Concerning the test–retest reliability of TUG, the intra-class correlation coefficient (95% CI) for the total score was equal to 0.96 and presented excellent internal consistency ( $\alpha = 0.98$ ) (47). Participants will begin in a seated position with their backs supported and are required to stand, walk 3 meters in a straight line, pivot, return to the chair, and sit down, mirroring the initial position. The test score is determined based on the participants' time to complete the task. Completion within 10 s indicates normal mobility, while a duration of 11–20 s falls within the normal range for frail or partially independent adults with disabilities. A completion time exceeding 20 s is typically observed in individuals with a significant mobility impairment (46).
- e. Physical capacity (6 min walking distance test - 6MWD). The 6MWT evaluates a person's exercise tolerance, functional capacity, and endurance. Participants are instructed to walk back and forth in a hallway as far as they can within 6 min. They can walk at their own pace, and they are allowed to slow down, stop, or rest during the test if needed (46). This test presented excellent test–retest reliability (intra-class correlation coefficient = 0.95–0.96) (48).

## 2.6. Data analysis

**Quantitative method:** the sample will be characterized using descriptive statistics, including measures such as count, mean, standard deviation, median, minimum, maximum, and range. Differences between the scores obtained from initial and final assessments for Short Falls Efficacy Scale-International (Short FES-I), Movement Disorder Society Unified Parkinson's Disease Rating Scale (MDS-UPDRS), Timed Up Go (TUG), 6 Minutes Walking Distance (6MWD), and frequency and severity of falls will be evaluated using inferential statistics. Specifically, the parametric two-tailed paired samples t-test will be employed if the normality assumptions are met. Alternatively, the non-parametric two-tailed matched pairs Wilcoxon signed-rank test will be utilized in case of normality deviations. The statistical analysis will be conducted using the R statistical computing software.

**Qualitative method:** a research team member with a Ph.D. in Psychology will perform semi-structured interviews to obtain insight into participants' perspectives on the intervention's feasibility, acceptability, and usefulness and identify barriers and facilitators that may influence people with PD to participate in the program. This researcher is a skilled interviewer with no prior relationship with the participants. Two team members will transcribe verbatim the audio-recorded interviews into textual data using Microsoft Word. These researchers will independently perform an inductive thematic analysis process as described by Braun et al. (49). The analysis will be supported

by QDA Miner Lite software. This process will allow the identification of themes emerging from the interview data through pre-analysis, encoding, categorization, and interpretation of the data.

## 2.7. Ethics and dissemination

Researchers will conduct this study following the Helsinki Declaration (as revised in 2013). The leading researcher is responsible for seeking approval from the institutional Ethics Committee and preserving the confidentiality of participants taking part in the study.

All participants will sign an informed consent form before any procedures. This form contains comprehensive information concerning the study aims, procedures, voluntariness, and possible risks of participation. Participants have the right to withdraw their consent to participate at any time without any consequence. However, all anonymized data collected may be applied in data analysis because this will not be linked to any identifiable participant information. All information will be kept strictly confidential. All information will be destroyed 5 years after the completion of the research project.

Researchers will submit the study results for publication in scientific journals and disseminate them at national and international PD conferences/seminars and PD communities.

## 3. Discussion

This research will assess the feasibility of the Landing Wise program, which combines group CBT with training of safe landing strategies. The program's effectiveness will not be established in this study but will be the aim of a subsequent registered randomized controlled trial. The results of this study will decide whether it is feasible to proceed to a full trial and if any adjustments to procedures need to be made.

We expect that in addition to reducing the FOF, the program has the potential to challenge the balance system and be effective for balance outcomes and functional mobility.

Data from previous studies suggest that when applied separately, CBT and safe landing strategies are well accepted by the participants and have demonstrated efficacy (19, 20, 50, 51). However, it is essential to highlight that few studies employing safe landing strategies, including people with PD, were randomized controlled trials. It is also noteworthy that despite the positive health outcomes to the best of our knowledge, this is the first study that combines these interventions in people with PD.

The Landing Wise program can be an intervention adapted to the multidimensional impairments experienced by people with PD (e.g., motor, balance, and social impairments). CBT, a well-established psychotherapeutic approach, addresses cognitive processes, emotions, and behaviors. Individuals with PD are often challenged with physical motor impairments and cognitive and emotional challenges (24–26). The Landing Wise program integrates CBT to target these cognitive and emotional aspects, including FOF, negative thought patterns, and anxiety, which are prevalent in individuals with PD.

Furthermore, the program combines physical training with safe landing strategies to enhance motor skills and balance. Additionally, the group sessions within the Landing Wise program offer social interaction and support, potentially reducing social isolation and

withdrawal for those with PD. However, further research is needed to establish the effects of our program on people with PD FOF, balance, and gait. Therefore, this study is the first step to determining the program's feasibility for this population.

Although training safe landing techniques can be well accepted and enjoyable workout activity (50, 51), we acknowledge that it can also be intimidating for some people with FOF. However, the safety measures introduced by researchers can potentially mitigate this effect. In addition, the program has the potential to promote social interaction, as it will be performed in a group format. Thus, it is expected to develop a sense of camaraderie between participants (52, 53) and accomplishment (54), contributing to the intervention's satisfaction (52, 54). Given all these aspects, combining CBT and safe landing strategies can be an especially well-adapted and attractive way of optimizing care for people with PD.

Like in previous research that employs a safe landing intervention, we expect the level of risks associated with being low (50, 51). However, the potential risks should be foreseen and addressed to ensure participants' safety. Therefore, in addition to the protective gear and mattress, the instructor can adapt the exercise program to each participant's skills and abilities to keep it challenging and engaging.

This study has limitations. First, as we intend to establish the program's feasibility, the study procedures do not include a control group, which will prevent comparing the program's effects to additional treatment. Second, when evaluating the program's feasibility, we recognize the possibility of bias due to social desirability. As such, participants' reports might diverge from their real perceptions and feelings. To minimize the effect of this bias during the qualitative assessment, we will implement practices recommended by Bergen and Labonté (55). Therefore, all study details will be explained clearly to participants, including confidentiality and anonymity procedures, how the data will be used, and the dissemination of results. We will conduct the interviews in a private location and not within earshot of others. The interviewer will resort to different methods to establish rapport with participants (e.g., humor, self-disclosure, making displays of respect).

If the interviewer suspects an answer indicates social desirability biases, he will maintain a nonconfrontational and respectful attitude and attempt to produce a more authentic reply by offering context when asking questions, recognizing that participants have different understandings, posing indirect questions, and requesting that participants provide examples to illustrate their answer.

## 4. Conclusion

This study aims to establish the feasibility of the Landing Wise program among people with PD. There is a growing interest in

effective new forms of therapy in this population. However, the current literature has no studies on the use of combined group CBT with the training of safe landing strategies for people with PD. Therefore, this will be the first study to assess the program's feasibility and preliminary effects. If proven, this study precedes the development of a randomized controlled trial that may prove the effectiveness of combined group CBT with the training of safe landing strategies as a therapeutic intervention for people with PD.

## Author contributions

JF, JD, CF, SF, IS, and CG: conceptualization. JF, JD, CF, CS, DS, FG, IC, JA, LM, SM, TS, SF, IS, NS, CR, and CG: methodology, writing-original draft preparation, writing-review, and editing. JF, and CG: supervision. JF: project administration. All authors have read and agreed to the published version of the 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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# Development of an eLearning intervention for enhancing health professionals' skills for addressing COVID-19 vaccine hesitancy

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Like many countries, Greece has faced resistance to coronavirus disease 2019 (COVID-19) vaccination among residents for both the initial and booster doses. Supporting healthcare professionals with delivering brief advice on COVID-19 vaccination may assist with reaching national vaccination targets. We sought to rapidly develop, pilot test, and deploy an eLearning intervention on skills training on effective techniques for addressing COVID-19 vaccine hesitancy for primary health and social care professionals in Greece. A five-part, 1.5-h eLearning was produced in Greek which featured two behavior change techniques, Very Brief Advice (VBA) and Motivational Interviewing (MI) adapted for use in addressing COVID-19 vaccine hesitancy. Six-film-based case studies modeling the use of VBA and MI in the context of challenging scenarios typically seen in Greek health and social settings were produced for the eLearning. The CME was pilot tested using a pre-post design in a small convenience sample ( $n = 17$ ) of health care professionals. Pilot study results found the training provided new knowledge (80%), improved provider skills (80%), and was useful to provider's clinical practice (90%). There was a mixed effect in provider capability, motivation, and opportunity. Ninety percent of providers strongly agreed or agreed that they planned to use the information and skills provided by the training in their clinical practice. This project has resulted in new training assets for use by health and social professional tailored to the nationally context in Greece including supporting uptake of booster doses of the COVID-19 vaccine.

## KEYWORDS

COVID-19 vaccination, vaccination hesitancy, motivational interviewing, continuing medical education, training, Greece

## Introduction

Key to the success of national coronavirus disease 2019 (COVID-19) vaccination programs is the ability to reach immunization targets for both the initial and booster doses (1).

Vaccine hesitancy among residents may serve to undermine efforts of national governments and has been identified as being a target for both research and intervention (1–4).

Vaccine hesitancy is defined as a delay in acceptance or refusal of vaccines, despite availability of services (2, 3). Willingness to be vaccinated occurs along a continuum with some individuals being ambivalent, while others, strongly refuse to be vaccinated. Vaccine hesitancy



can be complex and influenced by the context in which the individual lives and works, personal and family health status and in many cases is not stable (2, 5, 6).

The health care community and, in particular, primary care providers (PCPs) and social care professionals have an important role to play in supporting vaccine uptake in communities which they serve (3, 4, 7–11). Few training resources are available to equip members of the health and social care community on how they can support the COVID-19 vaccine uptake and, in particular, which techniques will increase the likelihood they can influence the behaviors of residents. In order to support PCPs in this role, new training and resources are required to enhance providers' skill and confidence in addressing COVID-19 vaccine hesitancy among residents (2, 7). Such training needs to be based on existing international best practices but also be locally adapted and disseminated in the local language. In particular, available evidence and practice has identified perceived risk, motivation, and health literacy as important predictors of health-seeking behavior and adherence to COVID-19 measures including vaccination (12).

This brief report summarizes recent experience in the development pilot testing of an eLearning intervention on effective techniques for addressing COVID-19 vaccine hesitancy for primary health and social care professionals in Greece.

## Materials and methods

### Design and procedures

Figure 1 summarizes the three phases of this project. A rapid needs assessment and formative research was conducted to validate our understanding of vaccine hesitancy and its presentation locally and inform the design of the training (Phase 1). This was followed by a development phase in which the learning objectives, curricula, the adaptation of Very Brief Advice (VBA) and Motivational Interviewing (MI) for addressing COVID-19 vaccine hesitancy, and film-based skills demonstrations were developed (Phase 2). We pilot tested the eLearning and outreach intervention among a sample of PCPs on the island of Crete, Greece (Phase 3).

### Setting and target population and behavior

The target population for the intervention is primary care and social care providers who have contact with patients/persons who report vaccine hesitancy. The target behavior we are seeking to influence is conversations to address COVID-19 vaccine hesitancy with patients in their own clinical practice settings. In the pilot assessment of our training, we included general practitioners/family physicians (licensed or resident) and social care workers practicing in either public or private services. Providers not able to provide informed consent for participation due to any reason were excluded.

### Theoretical framework

The COM-B ('capability', 'opportunity', 'motivation' and 'behavior') model, the Health Beliefs Model (HBM) and the Theory of Planned

Behavior (TPB) was used to inform the eLearning design and pilot testing design (13–16). Specifically, the intervention targeted the following provider level constructs: provider confidence, attitudes, and motivation, and intentions. Additionally, we considered in the intervention design the influence of cultural factors, local belief systems and risk-communication methods.

### Phase 1 - rapid needs assessment and formative research

The project team conducted a review of existing training assets and knowledge and best practices on very brief advice and motivational interviewing to address COVID-19 vaccine hesitancy. We also conducted a rapid needs assessment with members of the local community in order to validate and enrich understanding of the target audience's needs. Two semi-structured focus groups were conducted with residents in both rural and urban regions of Crete, Greece. The interviews explored health literacy, perceptions related to COVID-19 and the COVID-19 vaccine, as well as intentions related to COVID 19 and perceived reasoning. Beliefs, barriers, and facilitators for the uptake of COVID-19 vaccination were documented and key themes identified.

### Phase 2 - eLearning intervention design, development, and production

An existing training program published by the World Health Organization was adapted.<sup>1</sup> The adaptation was informed by focus groups conducted among residents in Crete to identify factors and beliefs associated with ambivalence and hesitancy for COVID-19 vaccination, as well as consultation with a sample of health and social care workers, and expert input. The eLearning intervention provides skills training for PCPs and social care providers in discussing COVID-19 and COVID-19 vaccine with residents and addressing both low confidence in vaccines and indecision, as well as negativity about COVID-19 vaccination. The training program is focussed on: (1) skills training in behavior change techniques including Very Brief Advice (VBA) and Motivational Interviewing (MI) for addressing COVID-19 vaccination hesitancy; (2) patient-centered communication techniques and compassionate care (17–21). Motivational interviewing (MI) is widely used counseling technique for helping people to explore and resolve their uncertainties about changing their behavior (18, 20). It seeks to avoid an aggressive or confrontational approach and steer individuals toward choosing to change their behavior, and to encourage their self-belief.

1 <https://apps.who.int/iris/bitstream/handle/10665/340751/WHO-EURO-2021-2281-42036-57837-eng.pdf>

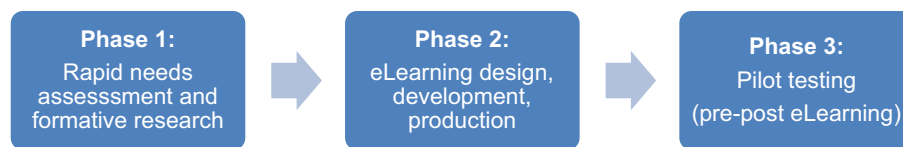


FIGURE 1  
Design.

## Phase 3 - pilot testing

A pre-post pilot evaluation of the CME was completed. Participating PCPs survey at two time points before, immediately following their exposure to the eLearning in order to assess:

- satisfaction with the eLearning and outreach resources and recommendations for improving the training.
- changes in capability (confidence), motivation, opportunity, and intentions in addressing COVID-19 vaccine hesitancy with patients.

A convenience sample of family physician and family practice medical residents serving in primary healthcare units and community services in the island of Crete, Greece were invited to participate in the eLearning using official listings from regional healthcare authorities. All providers who agreed to participate in the pilot study provided informed consent and were asked to complete the provider-level surveys immediately before and immediately after the completion of the eLearning. This study was approved by the Research Ethics Committee of the University of Crete (approval number: 121/20.09.2021). In order to reduce respondent bias all data collection occurred via anonymized online survey.

## Outcome measures

Key demographic characteristics of the pilot study sample were documented. Provider satisfaction with the eLearning was assessed via survey immediately after the training and included the extent to which the training provided useful information, was enjoyable, whether they would recommend the training to colleagues. Free text responses were used to assess what participants enjoyed most about the training and would recommend for improving the training.

We also examined the influence of the intervention on capability, motivation, opportunity, and behavioral intentions at the level of both providers and the population as defined by the COM-B model before and immediately following exposure to the eLearning with responses provided on a five-point Likert scale: (1) strongly agree through to (5) strongly disagree. At the time of this study there were no published tools which adapt assessment of capability, motivation, opportunity and intentions for COVID-19 vaccination and vaccine hesitancy. Our team developed a customized tool for use in this pilot study. We adapted existing tools for the assessment of training programs to the present behavior (16).

**Capability (Confidence):** Providers were asked to rate how confident they felt in raising the issue of COVID-19 vaccination with patients/families/community members using three items.

**Motivation and opportunity:** Four items were used to assess provider motivation to deliver very brief interventions toward

COVID-19 vaccination in daily practice and with specific patient populations was assessed. Two items were used to examine provider perception regarding the opportunity to intervene with patients.

**Behavioral intentions:** Intentions were measured as a proxy for clinical practice behaviors. Before and immediately following the eLearning, intentions of providers to deliver very brief interventions toward COVID-19 vaccination were assessed.

## Data analysis

Descriptive statistics were used to summarize provider demographic data. Non-parametric Wilcoxon Signed Rank tests were used to examine paired differences between timepoints (pre vs. post) as, due to small sample size data were skewed. Test value of  $p$  were calculated based on the sample of providers for which data was available at both timepoints being compared, as part of providers were lost-to- follow-up (i.e., did not respond to follow-up assessment after three reminding phone calls and/or email contacts). For remaining participants, no missing data were present. Statistical significance of  $<0.05$  was used for all analyses. SPSS was used to analyze the data.

## Results

### Phase 1 - rapid needs assessment and formative research

Six themes were identified as being most pertinent to vaccine hesitancy beliefs locally: (1) concerns about side effects ('I am worried about the adverse effects of the vaccine, you hear stories in media'), (2) concerns about safety of vaccines ('I am worried about side effects'), (3) pushback regarding government mandated health-related decision ('No one can tell me what to do'), (4) beliefs about low risk of susceptibility and illness ('I am young and healthy and not at risk'), (5) religiosity ('the church does not believe in vaccination'), and (6) beliefs regarding vaccine efficacy ('the vaccine does not work, people are who are vaccinated still get infected').

### Phase 2 - eLearning intervention design, development, and production

A five-part (1.5h) eLearning was produced. The eLearning features six video vignettes modeling how to assess, communicate and approach common dialogs about COVID-19 and COVID-19 vaccination hesitancy using VBA and MI in the context of challenging scenarios typically seen in Greek health and social settings in regard to COVID-19 vaccination. Modeling behavior change skills has been shown to be an effective technique for increasing PCPs skill and



TABLE 1 Skills training films.

Description	Link
George, 65 years, I am worried about adverse reaction to vaccine	<a href="https://youtu.be/6tqsXmSJoOU">https://youtu.be/6tqsXmSJoOU</a>
Eleni, 40 years, side effects of the vaccine	<a href="https://youtu.be/xIz_OgAc4wk">https://youtu.be/xIz_OgAc4wk</a>
Nikos, 30 years, I am young and healthy	<a href="https://youtu.be/9y-y7ANycoo">https://youtu.be/9y-y7ANycoo</a>
Maria, 75 years, religious beliefs	<a href="https://youtu.be/ucNuc6KGWco">https://youtu.be/ucNuc6KGWco</a>
Vasillis, 65 years – No one can tell me what to do	<a href="https://youtu.be/ynXjAoDhX54">https://youtu.be/ynXjAoDhX54</a>
Marina, 60 years – The vaccine does work	<a href="https://youtu.be/b7qJY4ExIEc">https://youtu.be/b7qJY4ExIEc</a>

TABLE 2 Sociodemographic characteristics and personal vaccination status of healthcare professionals participating in the eLearning pilot evaluation ( $N = 17$ ).

Variable	Value
Gender, $n$ (%)	
Male	9 (52.9)
Female	8 (47.1)
Age, median (IQR)	30 (7)
Profession, $n$ (%)	
Resident, family medicine	12 (70.6)
General practitioner	4 (23.5)
Other	1 (5.9)
Years of practice, median (IQR)	2 (3)
Setting, $n$ (%)	
Rural	6 (35.3)
Urban	11 (64.7)

IQR, interquartile range.

confidence in addressing behavior change with patients and residents (18, 20). Table 1 provides an overview of the training films.

A digital leaflet on leaflet on COVID-19 Vaccine Hesitancy for Health and Social Care providers was produced which provides a summary of key knowledge and skills related to addressing vaccine hesitancy in health and social settings to reinforce eLearning course content. A graphically designed slide deck for supporting webinar and/or face to face CME delivery was developed to support hybrid learning.

### Phase 3 - pilot testing

A total of 50 out of a list of 200 family physicians practicing in Crete were invited to participate in the pilot study. We also invited 20 family medicine residents affiliated to the university and all providers from 5 social care facilities of Crete. Of all these, 38 providers provided an initial positive response to our invitation, 22 provided informed consent and 17 completed the baseline evaluation. Post-course evaluation was completed by 10 participants. The primary reasons for

loss to follow-up was inability to find time to complete eLearning ( $n = 5$ ) and/or lack of interest in the eLearning subject matter ( $n = 2$ ).

Table 2 presents the sociodemographic characteristics of the  $N = 17$  healthcare professionals at baseline. Overall, 52.9% of the sample ( $n = 9$ ) were men, with median (IQR) age of 30 (7) years. The majority were resident GPs ( $n = 12$  or 70.6%), working in urban areas ( $n = 11$  or 67.7%).

### Provider satisfaction with the training

High levels of satisfaction with the training resources were documented among providers who participated in the pilot study (Table 3). The majority of participating providers agreed or strongly agreed that the training was useful (80%), interesting (90%) and enjoyable (80%). The majority of providers indicated the training provided new knowledge (80%), improved their skills (80%), and was useful to their clinical practice (90%). There was mixed evaluation of the training format and feedback from participants indicated the course duration should be reduced with a focus on applying skills to practice. Eighty percent of participants indicated they would recommend the course to other health care professionals.

### Provider capability, motivation, opportunity, and behavioral intentions

As shown in Table 4, there were some positive but non-significant changes in provider confidence in addressing vaccine hesitancy following exposure to the training. A positive effect documented for provider confidence on advising on the benefits of COVID-19 vaccine hesitancy that was not statistically significant ( $p = 0.059$ ).

Positive changes documented in several constructs relating to provider attitudes, beliefs and motivated related to COVID-19 (Table 4). There was a significant change in providers attitudes regarding the role of healthcare professionals versus government in addressing COVID-19 vaccine hesitancy among residents ( $p = 0.041$ ).

Ninety percent of providers strongly agreed or agreed that they planned to use the information and skills provided by the training in their clinical practice (Table 4). No further significant changes were documented in practice specific intentions.

## Discussion

### Main findings

This eLearning CME was designed to support health care professionals with having effective conversations with patients about COVID-19 vaccination. The training supports health care professionals with how to raise the discussion with patients and provide VBA on COVID-19 vaccination. It also addresses how MI techniques can be used to guide discussions with patient who are ambivalent or hesitant about COVID-19 vaccination. The training was informed by recent experience with addressing vaccine hesitancy internationally and we attempted to tailor the skills training to the local Greek dialog and context.

**TABLE 3 Provider satisfaction with CME and assessment of commercial bias (N = 17).**

Measure	n (%)
Overall, the training was useful	
Strongly agree	1 (10)
Agree	7 (70)
Neutral	2 (20)
Disagree	0 (0)
Strongly disagree	0 (0)
Overall, the training was interesting	
Strongly agree	1 (10)
Agree	8 (80)
Neutral	1 (10)
Disagree	0 (0)
Strongly disagree	0 (0)
Overall, the training was enjoyable	
Strongly agree	1 (10)
Agree	7 (70)
Neutral	2 (20)
Disagree	0 (0)
Strongly disagree	0 (0)
The training improved my skills	
Strongly agree	2 (20)
Agree	7 (70)
Neutral	1 (10)
Disagree	0 (0)
Strongly disagree	0 (0)
I would recommend this training to others	
Strongly agree	2 (20)
Agree	6 (60)
Neutral	1 (10)
Disagree	1 (10)
Strongly disagree	0 (0)
I was satisfied with the online training format	
Strongly agree	2 (20)
Agree	5 (50)
Neutral	2 (20)
Disagree	1 (10)
Strongly disagree	0 (0)
The training provided me with new knowledge	
Strongly agree	2 (20)
Agree	6 (60)
Neutral	2 (20)
Disagree	0 (0)
Strongly disagree	0 (0)
The training was useful to my clinical practice	
Strongly agree	3 (30)

(Continued)

**TABLE 3 (Continued)**

Agree	6 (60)
Neutral	1 (10)
Disagree	0 (0)
Strongly disagree	0 (0)

The pilot evaluation indicated high levels of satisfaction among providers and positive but mixed effects on providers confidence, attitudes, and intentions. The present study reported on a small pilot evaluation and a larger study would be useful for further examining the pre-post intervention effects.

We adapted existing evidence-based behavior change and counseling techniques with proven efficacy in changing other behaviors (Very Brief Advice) and uncertainty or resistance about behavior change (motivational interviewing) to address COVID-19 vaccine hesitancy. Since the initiation of this project several groups have examined the role of MI in addressing (22–25). This project adds to international work regarding the adaptation of MI counseling techniques for COVID-19 vaccine hesitancy that has been tailored to the national context in Greece.

## Implications for research and practice

The project mobilized existing knowledge and expertise to rapidly develop and deploy the educational intervention to rollout in parallel to the planned population-wide vaccination of residents in Greece. The assets created as part of the present project, including the eLearning and outreach supports are hosted on the Primary Care Training Hub of the University of Crete. The interventions strategies used for addressing COVID-19 vaccine hesitancy may have broader learnings for addressing vaccine hesitancy for other immunization programs (e.g., influenza). Future studies could be developed in other countries and involve other professionals (e.g., speech therapists, nurses, physical therapists). There will be an expected need to update the training to address booster doses of COVID-19 vaccine hesitancy that are tailored to residents' beliefs about the risk and value of booster doses. Future research should seek to incorporate novel eLearning tools such as massive open online courses (MOOCs) (26, 27). MOOCs are designed to promote quick and effective continuous education which are designed to reach large numbers of learners and make use of open access policies (27). MOOCs which are continuously updated are particularly relevant to subject areas such as COVID-19 vaccine hesitancy which is rapidly evolving and requires regular updates to ensure content remains relevant, evidence-based and addressing priorities over time (e.g., vaccine booster doses). While in the present eLearning was rated strongly in terms of learner satisfaction. Future research should also seek to ensure digital competencies of learners are considered in design process to enhance learner experience and participation rates (28). For example, reducing course length or organizing course content into “core” and “optional” may have served to assist with increasing course completion rates among participants.

This pilot study had limitations. Firstly, the sample size was limited and loss to follow-up fairly large. At the time of this study there were no published tools which adapt assessment of capability, motivation, opportunity and intentions for COVID-19 vaccination

TABLE 4 Changes in provider capability (confidence), motivation, opportunity and intentions related to COVID-19 vaccine hesitancy pre and post training.

Measure	Median (IQR)		Value of $p^d$
	Pre-training $n = 17$	Post-training $n = 10$	
Capability (Confidence) <sup>a</sup>			
I am confident in....			
Raising the issue of COVID-19 vaccination	4 (1)	4 (0)	0.180
Advising on the benefits of COVID-19 vaccination	4 (1)	4 (1)	0.059
Offering help and support regarding COVID-19 vaccination	3 (2)	4 (2)	0.496
Addressing common worries and misconceptions	4 (2)	4 (2)	0.453
Counseling patients who indicate they are uncertain or do not intend to be vaccinated	4 (2)	4 (1)	1
Motivation <sup>b</sup>			
It is important to intervene with patients/communities in order to reduce COVID-19 vaccination hesitancy.	4 (1)	5 (1)	0.083
It is important to support COVID-19 vaccination in high-risk and socially deprived populations.	5 (1)	5 (0)	1
I will intervene with COVID-19 vaccination only with high-risk patient with serious comorbidities.	4 (3)	3.5 (3)	0.671
Raising the issue of vaccination will create a problem in my professional relationship with patients.	2 (1)	2 (1)	0.180
Opportunity <sup>b</sup>			
It is the government's, not the healthcare professional's role to address misconceptions over COVID-19 vaccination.	3 (2)	1 (3)	<b>0.041</b>
I cannot assure my patients regarding the safety of COVID-19 vaccines.	3 (2)	2.5 (2)	0.480
Intentions <sup>c</sup>			
I intend to...			
Ask all my patients whether they have been vaccinated against COVID-19	4 (1)	4 (1)	1
Inform all my patients about their COVID-19 vaccination options	4 (1)	4.5 (2)	1
Address COVID-19 vaccination hesitancy with all my patients	4 (1)	4 (1)	0.157
Offer brief COVID-19 vaccination hesitancy interventions to all my patients who are unsure or unwilling to be vaccinated	4 (1)	4 (1)	1

IQR, interquartile range.

<sup>a</sup>Assessment question: On a scale of 1 to 5, how strongly would you agree with the following statements. I am confident in... (Response options (1) strongly disagree through to (5) strongly agree).<sup>b</sup>Assessment question: On a scale of 1 to 5, how strongly would you agree with the following statements. (Response options (1) strongly disagree through to (5) strongly agree).<sup>c</sup>Assessment question: On a scale of 1 to 5, how strongly would you agree with the following statements. I intend to.... (Response options (1) strongly disagree through to (5) strongly agree).<sup>d</sup>Wilcoxon Signed Rank test value of  $p$  calculated based on sample of providers for which data was available at both timepoints being compared.

The bolded values represent those with statistical significance.

and vaccine hesitancy. Our team developed a customized tool for use in this pilot study. We adapted existing evaluation tools for the assessment of training programs to assess COMB-B constructs as it relates to COVID-19 vaccine hesitancy practice behaviors. Further research in the field to validate and refine tools for this purpose would be recommended. It would be relevant for future research to examine the predictive value of these constructs as well as provider socio-demographic characteristics including personal vaccine status of providers on practice behaviors.

## Conclusion

This project has resulted in new training assets for use by health and social professional tailored to the nationally context in Greece which can now be used for dissemination nationally to support vaccination uptake.

## 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 University of Crete Research Ethics Committee. 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

SP: Conceptualization, Formal analysis, Funding acquisition, Investigation, Methodology, Writing – original draft, Writing – review & editing. MA: Conceptualization, Data curation, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing, Formal analysis. MG: Data curation,

Formal analysis, Investigation, Project administration, Writing – review & editing. XP: Project administration, Writing – review & editing, Methodology, Resources, Supervision, Visualization. EA: Methodology, Visualization, Writing – review & editing, Investigation. CL: Investigation, Methodology, Writing – review & editing, Conceptualization, Data curation, Funding acquisition, Project administration, 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.

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# Population health interventions for cardiometabolic diseases in primary care: a scoping review and RE-AIM evaluation of current practices

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**Introduction:** Cardiometabolic diseases (CMD) are the leading cause of death in high-income countries and are largely attributable to modifiable risk factors. Population health management (PHM) can effectively identify patient subgroups at high risk of CMD and address missed opportunities for preventive disease management. Guided by the Reach, Efficacy, Adoption, Implementation and Maintenance (RE-AIM) framework, this scoping review of PHM interventions targeting patients in primary care at increased risk of CMD aims to describe the reported aspects for successful implementation.

**Methods:** A comprehensive search was conducted across 14 databases to identify papers published between 2000 and 2023, using Arksey and O'Malley's framework for conducting scoping reviews. The RE-AIM framework was used to assess the implementation, documentation, and the population health impact score of the PHM interventions.

**Results:** A total of 26 out of 1,100 studies were included, representing 21 unique PHM interventions. This review found insufficient reporting of most RE-AIM components. The RE-AIM evaluation showed that the included interventions could potentially reach a large audience and achieve their intended goals, but information on adoption and maintenance was often lacking. A population health impact score was calculated for six interventions ranging from 28 to 62%.

**Discussion:** This review showed the promise of PHM interventions that could reaching a substantial number of participants and reducing CMD risk factors. However, to better assess the generalizability and scalability of these interventions there is a need for an improved assessment of adoption, implementation processes, and sustainability.

## KEYWORDS

population health management, cardiometabolic diseases, RE-AIM framework, population health impact score, modifiable risk factors



# 1 Introduction

Cardiometabolic diseases (CMD), which include cardiovascular disease, diabetes mellitus, and chronic renal failure, are the leading cause of death in high-income countries and are increasing worldwide. If this situation continues unchecked it could potentially compromise the sustainability of healthcare systems (1–3). Cardiometabolic diseases can be prevented for a large part by addressing modifiable risk factors, such as elevated blood pressure, unhealthy dietary habits, and smoking (4–7). To accomplish this, the proactive identification of high-risk patients is essential for early detection of these modifiable risk factors (8).

Population health management (PHM) is a strategy that supports proactive care by identifying and addressing missed opportunities in chronic disease management (9). Population Health Management, in a clinical context, is also known as panel management and can be defined as ‘the proactive management of a total population at risk for adverse outcomes through various individual, organizational and cultural interventions based on a risk-stratified needs assessment of the population’ (9). Primary care occupies a central position in the implementation of PHM thanks to its inherent capacity for care coordination and integration, coupled with access to comprehensively coded routine care data. These unique characteristics of primary care also promote the effective identification of individuals at increased risk of CMD progression and the provision of appropriate care related to identified risk (10, 11).

While there is increasing interest in PHM in relation to CMD, a clear overview detailing how PHM interventions are best implemented in primary care is lacking. Although various implementation theories and frameworks are available, the RE-AIM framework provides a vital tool for evaluating and comprehending the effectiveness and sustainability of PHM interventions in primary care. The RE-AIM framework assesses the impact of population health intervention initiatives using five critical factors: Reach, Efficacy, Adoption, Implementation, and Maintenance (12). Additionally, this framework aids in determining the potential population health impact of these interventions.

This scoping review aimed to identify PHM interventions, which were targeted at patients with a high risk of CMD in the primary care setting. This was accomplished by obtaining information according to the dimensions outlined in the RE-AIM framework and estimating their potential population health impact. In doing so, the study has the objective of contributing to an understanding of the implementation of PHM interventions, their potential population health impact, and to better inform future research efforts.

## 2 Methods

### 2.1 Search strategy

This scoping review followed the recommendations of Preferred Reporting Items for Systematic Reviews and Meta-Analyses for Scoping Reviews (PRISMA-ScR) (13). The search was conducted in the electronic databases Pubmed, Embase, Web of Science, COCHRANE Library, Emcare, Academic Search Premier, IEEE Xplore, ACM Digital Library, MathSciNet, [AAAI.org](https://www.aiaa.org/), arXiv, Epistemonikos, PsycINFO and Google Scholar. The search was

formulated as a combination of terms that included PHM, primary care, and implementation. The terms were identified through searches of the National Library of Medicine MeSH Tree Structures and by the review team expert. The full search strategy can be found in [Supplementary File 1](#).

### 2.2 Eligibility criteria

Peer-reviewed journal papers were included when they met the following eligibility criteria: (i) published between 2000–2023, (ii) written in English, (iii) published as original results, (iv) focused on risk-based identification of patient groups (panels) with a high risk of (progression of) CMD using a primary care data source or within a primary care setting, and (v) focused on original data about implementation as part of (pragmatic) randomized controlled trials, clinical trials, (retrospective) cohort, case–control, implementation studies, cost-effectiveness or (pilot) feasibility studies. Studies that focused on developing theoretical PHM interventions and those in which the strategy was implemented in a setting other than primary care were excluded.

### 2.3 Data extraction

Using the inclusion and exclusion criteria, two reviewers (M.M.R and S.P.C.P) independently screened all articles on title and abstract. Reading the full text, two team members (M.M.R and S.P.C.P) assessed the selected articles for eligibility. Disagreements were discussed by the core team (M.M.R, N.E.v.H, and S.P.C.P) until consensus was reached. Subsequently, the core team members (M.M.R., N.E.v.H, and S.P.C.P) independently completed full data extraction of study characteristics (publication year, purpose, target population, study design and steps within PHM), and the five dimensions of the RE-AIM framework (14). The three assessors addressed their differences until they came to a complete understanding.

For data extraction focused on RE-AIM dimensions, researchers employed a modified extraction technique created specifically designed for systematic reviews using a RE-AIM framework (see [Supplementary File 2](#)) (15, 16). Each of the five RE-AIM dimensions was broken down into a number of components, and the core team (M.M.R., N.E.v.H, and S.P.C.P) categorized each recorded article in relation to whether they reported on specific components. Components were based on inclusion criteria: process interventions to improve clinical health outcomes of a defined group of individuals through proactive care coordination and patient engagement. The components for *Reach* were: the description of the target population, method of identifying the population, recruitment strategies, inclusion/exclusion criteria, participation rate, and cost of the recruitment. For *Effectiveness*, quality of life measures, positive outcomes, unintended or negative consequences, and cost-effectiveness were reported. *Adoption* was extracted based on the site and staff participation rate, description of the intervention location, method of identifying setting and staff, level of expertise of providers, and inclusion or exclusion criteria for providers. *Implementation* was coded on intervention description, theory-based interventions, engagement, consistency of implementation, financial investment, and the number and timing of intervention contacts during implementation. Lastly, *Maintenance* was extracted based on follow-up time, program sustainability, and modifications to the original program.

Subsequently, the RE-AIM average  $\left[\frac{((\text{Participation rate} + \text{ESkey outcomes} + \text{adoption rate} + \text{implementation rate})/4) \times 100}{100}\right]$  was computed by aggregating the scores across the RE-AIM dimensions. This RE-AIM average represented the potential population health impact of the interventions (12, 17).

### 3 Results

#### 3.1 Intervention characteristics of the studies reviewed

Of the 1,110 studies initially identified, 78 remained after removing duplicates and screening titles and abstracts. Full-text

screening led to the inclusion of 26 studies, representing 21 unique interventions (see Figure 1). Most PHM interventions were published in the last five years (13 of 21). Seven of the 21 included interventions were randomized controlled studies, and eight were prospective cohort studies. The characteristics of the reviewed interventions included in the analysis are summarized in Table 1.

#### 3.2 RE-AIM evaluation

A comprehensive overview of RE-AIM dimensions, including individual components, can be found in Table 2 (detailed data extraction is provided in Supplementary File 3). Three of the PHM

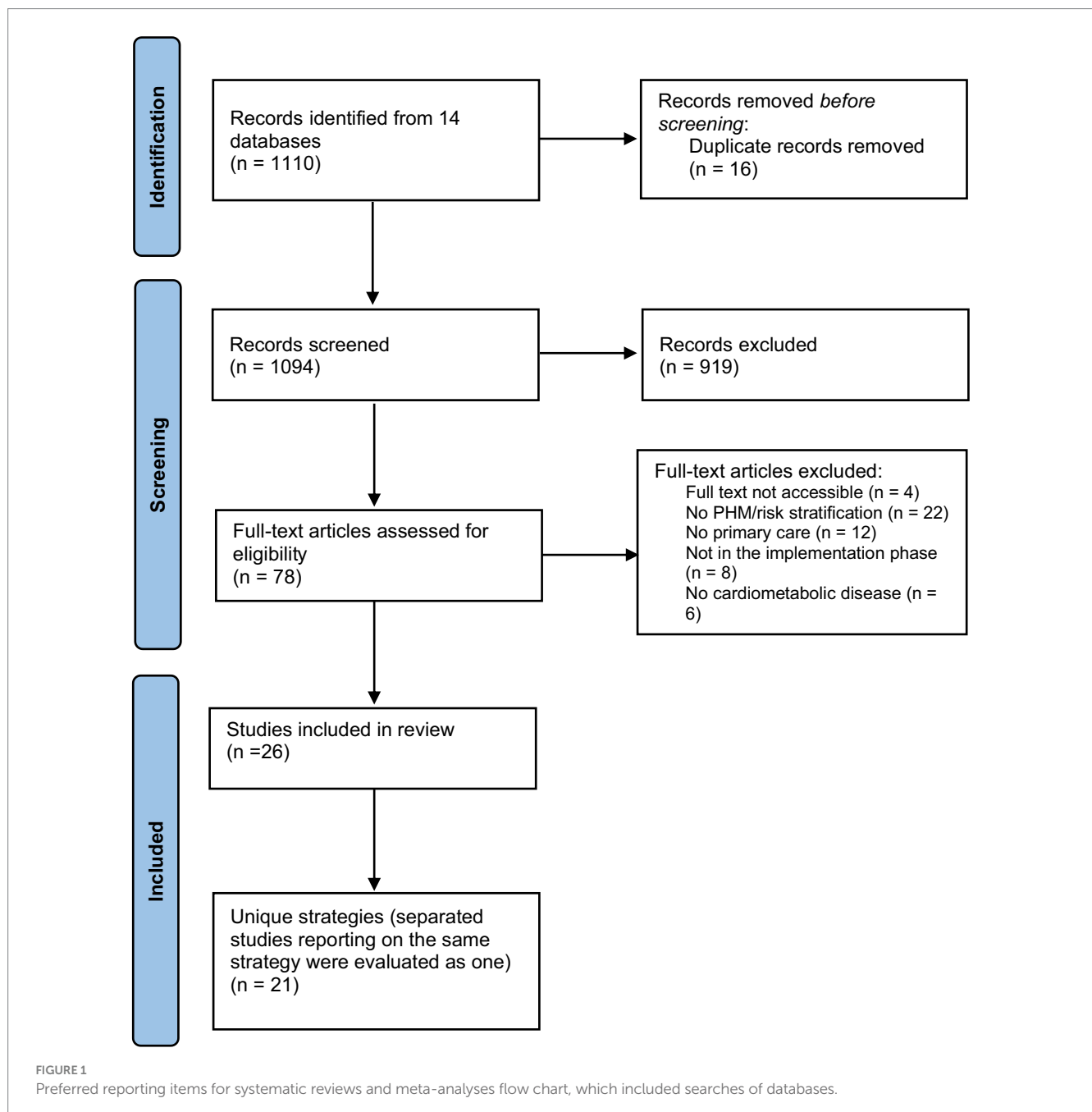


TABLE 1 PHM intervention characteristics of studies reviewed ordered chronologically.

Intervention (+ companion publications) <sup>a</sup>	Intervention location	Intervention focus	Target population and Sample size (n)	Study design	Primary outcome	Sig. outcomes
Singh et al., 2022 (18)	United Kingdom	West Hampshire Improving Shared Diabetes Outcome Measures (WISDOM) self-management intervention	40,548 DM2 patients receiving WISDOM	Difference-in-difference analysis	Diabetes-related complications, quality-adjusted life years (QALYs) and costs	Yes
Ross et al., 2022 (19)	United Kingdom	DDPP (Digital stream of diabetes prevention program)	3,623 non-diabetic hyperglycemia patients	Prospective cohort design	HbA1c and weight changes at 12 months	Yes
Plutzky et al., 2022 (20)	USA	Guideline-directed cholesterol management	1,021 high atherosclerotic CVD risk patients	Prospective cohort design	Program-achieved LDL-C levels	Yes
Sidebottom et al., 2021 (21) <sup>a,1</sup>	USA	Heart of New Ulm (HONU) Project, a rural population-based CVD prevention initiative	CVD risk patients, 4,056 residents of New Ulm matched with 4,056 residents from a different community	Prospective cohort design	Major CVD events	No
Wilson et al., 2021 (22)	USA	PHM approach to recruit participants to a diabetes trial	599 diabetes patients	RCT	Reach and representativeness	NM
Hickey et al., 2021 (23)	Kenya & Uganda	Evaluate effect of patient-centered, streamlined care intervention	32 communities, 10,928 patients with uncontrolled hypertension	RCT	3-year all-cause mortality	Yes
Kozłowska et al., 2020 (24)	United Kingdom	Collaborative diabetes care between primary, secondary and community care	Eighteen virtual clinics across seven teams, 150 patients with diabetes at risk of developing complications	Pilot feasibility study	Acceptability, feasibility and short-term impact	NM
Baer et al., 2020 (25)	USA	Combined intervention, including an online weight management program plus PHM.	840 patients with BMI between 27–40 and hypertension or type 2 diabetes	RCT	Weight change at 12 months	Yes
Cykert et al., 2020 (26)	USA	PHM intervention with practice facilitation and risk-stratification	146,826 high risk CVD patients	RCT	Change in the average 10-year CVD risk score	Yes
Jazowski et al., 2020 (27) <sup>a,2</sup>	USA	Team-supported, Electronic health record (EHR)-leveraged, Active Management (TEAM)	62 patients with uncontrolled hypertension	Pilot study	Feasibility changes in blood pressure	NM
Jølle et al., 2018 (28)	Norway	Basic lifestyle advice	2,380 high risk DM2 patients	Prospective cohort design	2-year diabetes risk	No
Van Houtven et al., 2018 (29)	USA	Southeastern Diabetes Initiative (SEDI)	65,683 patients with prevalent DM2	Pre-post cohort design	Utilization, screening, and costs	Yes
Wan et al., 2018 (30) <sup>a,3</sup>	Japan	Risk Assessment and Management Program–Diabetes Mellitus (RAMP-DM)	RAMP-DM group 29,396 patients; usual care group 29,396 DM2 patients	Prospective cohort design	All-cause mortality	Yes
Ashburner et al., 2017 (31)	USA	Health information technology-enabled PHM program for chronic disease management	66,091 patients with diabetes, CVD or hypertension	Prospective cohort design	Changes in diabetes, CVD, hypertension measures at 6 months	Yes
Price-Haywood et al., 2017 (32)	USA	Collaborative care models incorporating pharmacists	5,044 patients with diabetes and/or hypertension with high risk for disease complications	Retrospective cohort design	A1c level for diabetics and BP for patients with hypertension	No
Emerson et al., 2016 (33)	USA	PHM incorporating telemedicine tools and health coaches	Ten poorly-controlled diabetic patients	Pilot RCT	Feasibility of protocol implementation	NM
Yu et al., 2016 (34)	Japan	Multidisciplinary risk assessment and management program for patients with hypertension (RAMP-HT)	20,524 patients with hypertension	Longitudinal cohort study	Proportion of patients achieving satisfactory blood pressure	Yes
Schwartz et al., 2015 (35) <sup>a,4</sup>	USA	Incorporation of PMA into primary care teams	8,150 patients with hypertension and/or smoking	RCT	Hypertension and smoking variables	No
Krantz et al., 2013 (36) <sup>a,4</sup>	USA	Prevention CVD program with community health workers	698 CVD risk patients	Prospective cohort design	Change baseline 10-year FRS	Yes
Evans et al., 2010 (37)	Canada	Collaborative pharmacist intervention that used a systematic case-finding procedure	176 high risk CVD patients	Pilot RCT	Mean reduction in the 10-year Framingham risk score	No
Clark et al., 2001 (38)	USA	Diabetes management program that included risk stratification and social marketing	370 patients with diabetes	Prospective cohort design	Clinical diabetes outcomes	Yes

RCT, randomized controlled trial; Sig, statistically significant; NM, not measured; CVD, cardiovascular disease; LDL-C, low-density-lipoprotein cholesterol; BMI, body mass index; DM, diabetes mellitus; PMA, Panel Management Assistants; FRS, Framingham Risk Score. <sup>a</sup>Interventions with separate studies in which additional information was found: <sup>1</sup>Sidebottom et al., 2016 (39), Sidebottom et al., 2021 (21); <sup>2</sup>Lewinski et al., 2021 (40); <sup>3</sup>Jiao et al., 2014 (41); <sup>4</sup>Strauss et al., 2015 (42); <sup>5</sup>Smith et al., 2019 (43).

TABLE 2 Number of interventions reporting the RE-AIM dimensions.

RE-AIM dimensions (and components)	Number of interventions reporting <i>n</i> (%)	Interventions
<b>Reach</b>		
Description of the target population	21 (100)	(18–20, 22–29, 31–38, 44)
Method to identify the target population	20 (95)	(19, 20, 23–38, 44, 45)
Recruitment strategies	20 (95)	(18–20, 22–30, 32–38, 44)
Inclusion/exclusion criteria for individuals	20 (95)	(19, 20, 22–29, 31–38, 44)
Individual participation rate	19 (91)	(19, 20, 22–31, 33, 34, 36–38, 44)
Cost of recruitment	3 (14)	(22, 23, 28)
Qualitative methods to measure reach	1 (5)	(24)
<b>Effectiveness</b>		
Positive outcomes	19 (91)	(18–20, 23–27, 29–38, 44)
Quality of life	1 (5)	(18)
Negative consequences	2 (10)	(20, 23)
Cost-effectiveness	6 (29)	(18, 23, 26, 29, 33)
Qualitative methods to measure effectiveness	1 (5)	(24)
<b>Adoption</b>		
Site participation rate	17 (81)	(19, 20, 22–26, 29–33, 35–38, 44)
Description of intervention location	16 (76)	(20, 22, 24–26, 28–33, 35–37, 44, 46)
Method of identifying setting	7 (33)	(18, 20, 22, 23, 25, 26, 34)
Average number of persons served per setting	16 (76)	(19, 20, 22, 25, 26, 29, 31, 33, 35–38, 44)
Staff participation rate	5 (24)	(22, 25, 35, 36, 38)
Method of identifying target providers/staff	2 (10)	(20, 31)
Level of expertise of providers	18 (86)	(18–20, 23–25, 28–38, 44)
Inclusion/exclusion criteria for providers	3 (14)	(19, 20, 35)
Qualitative methods to measure adoption	1 (5)	(24)
<b>Implementation</b>		
Intervention description	21 (100)	(18–20, 22–38, 44)
Theory-based	2 (10)	(27, 36)
Engagement	5 (24)	(19, 25, 26, 36, 44)
Intervention contacts	15 (71)	(19, 20, 23–25, 27–30, 33–38, 44)
Timing of intervention contacts	17 (81)	(18, 19, 22–29, 32–38, 44)
Duration of intervention contacts	8 (38)	(19, 20, 22, 23, 28, 32, 36, 38, 44)
Consistency of implementation across settings or providers	12 (57)	(19, 20, 23–26, 30, 31, 36, 38)
Intervention costs	4 (19)	(18, 23, 29, 33)
Qualitative methods to measure implementation	3 (14)	(24, 25, 33)
<b>Maintenance</b>		
Follow-up outcomes measures at some duration after intervention	0 (0)	
Attrition of individuals	0 (0)	
Maintenance of the program after completion of the study	4 (19)	(27, 29, 33, 38)
Modifications made to the original program	3 (14)	(24, 25, 27)
Attrition of settings	0 (0)	

interventions only reported data on (or at least one of the individual components of) three dimensions: reach, adoption and implementation. Another 12 interventions reported data on four dimensions: reach, effectiveness, adoption and implementation. Six interventions provided information on all five dimensions of the RE-AIM framework.

### 3.2.1 Reach

Among all the evaluated dimensions in the included interventions, reach was documented most extensively. In total, 15 interventions reported five out of seven reach components (19, 20, 22–25, 27–29, 34, 36–38, 44). All interventions provided information on the target

TABLE 3 Potential population health impact (RE-AIM average).

Description	Reach (number of participants/ number of eligible and invited people)	Efficacy (effect size of the intervention)	Adoption (number of delivery setting/number of eligible and invited settings)	Implementation (consistency of delivering intervention components)	RE-AIM average [(participation rate + ESkey outcomes + adoption rate + implementation rate)/4] × 100
Hickey et al. (23)	10,928/86,078 = 13%	0.21	32/32 = 100%	The 32 practices implement all of the intervention activities.	59%
Ross et al. (19)	3,623/5,053 = 64%	0.5 (weight) 0.8 (HbA1c)	9/8 = 112.5%	The 9 demonstrator sites implement all of the intervention activities.	82% resp. 89%
Plutzky et al. (20)	1,021/1,631 = 63%	0.45	19/19 = 100%	All of the intervention activities are implemented by the 19 practices.	77%
Baer et al. (25)	840/26,393 = 3%	0.29	24/24 = 100%	The 15 practices implement all of the intervention activities.	58%
Cykert et al. (26)	146,826/437,556 = 34%	0.5	219 small primary care practices/801 = 27.3%	All of the intervention activities are implemented by the 219 practices.	56%
Mori et al. (36)	698/4,743 = 15%	0.22	22/22 = 100%	The 20 centers implement all of the intervention activities.	48%

population, and 20 described the method of identifying the target population. The sample size of the interventions ranged from 10 to 146,826 participants, with participation rates varying from 3 to 95%. Five interventions reported a participation rate below 10% (22, 24, 25, 33, 36); the participation rate of 3% was primarily due to non-compliance with inclusion criteria (25). In Mori's study, the algorithm could not calculate risk for most patients, rendering them unidentifiable. The primary method of participant recruitment for most interventions (11 out of 21) was electronic health record data assessment using algorithms (20, 22, 23, 25, 26, 31, 33, 34, 36, 38, 44), the first step in the panel management approach. However, only a small proportion of interventions (3 out of 21) reported the cost of recruitment activities (22, 23, 28).

### 3.2.2 Effectiveness

Among the 21 interventions reviewed, nine interventions (43%) focused on patients at risk of (progression of) cardiovascular diseases (20, 23, 26, 27, 34–37, 44), six interventions (29%) on diabetes (18, 19, 22, 24, 28, 33), and six interventions (29%) on CMD (25, 30–33, 38). Of the 12 interventions that evaluated diabetes outcome measurements, only one (5%) reported no statistically significant impact (28), while six reported significantly positive outcomes on diabetes control (18, 19, 25, 30, 31, 38). Two interventions (10%) focused on feasibility and acceptability outcomes and found positive results in terms of better understanding and proficiency in managing individuals with complex diabetes in a primary care setting through PHM (24, 33). Only two interventions reported unintended consequences of the intervention (20, 23), and only one measured quality of life (18). A minority of interventions (24%) addressed the cost of the intervention (18, 23, 26, 29, 33), of which one included a formal cost-effectiveness analysis (18).

### 3.2.3 Adoption

All included interventions ( $n=21$ ) documented adoption, but none reported all eight adoption components. The proficiency level of staff was reported in 18 interventions (86%) (18–20, 23–25, 28–30, 32, 34–38, 44), and 19 interventions (91%) described the intervention location (1, 18–20, 24–32, 34–37, 44, 47). However, the staff participation rate and the method of staff identification were

mentioned in only five (24%) and two (10%) interventions, respectively. Inclusion or exclusion criteria for staff were documented in three (14%) interventions (19, 20, 35). At the level of the clinical setting, 17 interventions (81%) reported the site participation rate, with an average of 50 to 12,000 individuals served per setting (19, 20, 22–26, 29–31, 33, 35–38, 44, 48). Only one study used qualitative methods to measure adoption, using surveys and observations (24).

### 3.2.4 Implementation

Descriptions of the intervention were provided for all 21 interventions. Only three interventions (14%) explained the theories or principles that guided the creation of the intervention (27, 34, 36). The frequency, duration, and timing of visits varied across interventions and were sometimes inadequately described. Patient engagement in intervention design was reported in only a single study (25), while five interventions (24%) involved healthcare professionals, experts, and local stakeholders in developing specific intervention components (19, 25, 26, 36, 44).

### 3.2.5 Maintenance

Maintenance was least often reported across all interventions. Five interventions (24%) reported on the continuation of the program after the study period (27, 29, 30, 33, 41), with just one providing details (27). Additionally, while three interventions (14%) reported modifications to the original program, these changes were implemented during the study period, not after completion (24, 25, 27).

### 3.2.6 Potential population health impact

Calculating the potential population health impact was possible for six out of 21 interventions (see Table 3), with scores ranging from 45 to 89%. The RE-AIM mean exhibited clear variation attributable to differences within each dimension, except for the implementation score, which remained consistent across all interventions.

## 4 Discussion

A total of 21 PHM interventions for patients at high risk of CMD in a primary care setting were identified. These interventions showed



promise in engaging a substantial number of participants and reducing CMD risk factors. However, this study also revealed a widespread deficiency in reporting across most RE-AIM components. While the included interventions exhibited higher reporting accuracy concerning *Reach*, followed by *Adoption* and *Implementation*, the constructs *Effectiveness* and *Maintenance* were barely addressed. A similar trend was found regarding the population health impact score, as the score could only be calculated for six interventions.

Compared with previous systematic reviews (15, 49–52), *Reach* (especially the description and the method of identifying the target population) was well described, with most interventions using algorithms or risk stratification tools in electronic health records to identify potential participants. Population surveys or routine care checks were employed for those who did not use electronic health records. However, it is worth noting that the risk calculation primarily relied on clinical health outcomes and did not incorporate health behaviors or social determinants of health. Given their significance in determining the risk of a particular group (53, 54), integrating health behaviors and social determinants into the risk model may be crucial to ensure that all potentially suitable patients are included.

Secondly, most studies reported positive outcomes while neglecting to address negative consequences of the intervention adequately. Awareness of negative outcomes, such as attrition and adverse outcomes, is essential for developing effective implementation strategies and ensuring the sustainability of interventions (55). Moreover, most interventions lacked follow-up data and information on attrition, which raises concerns about their long-term effectiveness. However, the short observation period of many interventions may be attributed to the research funding structure, often relying on one-off grants with limited duration and insufficient structural support (56). Nonetheless, long-term results on maintenance and sustainability are crucial for reliable cost-effectiveness analysis, which policymakers and healthcare providers weigh when deciding whether or not to scale up and implement health interventions (16, 57).

Another issue was the lack of comprehensive information regarding *Adoption*, a multifaceted process involving two levels: setting and staff. Specifically, the descriptions of staff involvement were inadequate, potentially leading to a lack of clarity regarding the qualifications necessary to properly implement an intervention. Effective staff involvement is of paramount importance. Previous studies have highlighted the significance of implementation strategies such as education, training, and staff participation in decision-making in promoting successful implementation. Additionally, utilizing champions and opinion leaders to facilitate intervention implementation has been recommended in previous research (16, 58, 59). A lack of reporting on the components of *Adoption* and *Maintenance* makes it challenging to determine whether success can be attributed to the intervention itself, the elements of its implementation, or a combination of both. This consequently limits the prospects of disseminating results and thus extends the reach of an intervention (60).

Finally, an assessment of potential population health impact was conducted for six interventions, utilizing the RE-AIM average score as defined by Glasgow et al. (12). It is important to note that this score does not encompass all facets of the RE-AIM dimensions, necessitating caution in its interpretation. Two interventions resulted in the highest potential population impact scores, which may be linked to their higher participation rates in the *Reach* dimension (19, 20). This can in turn, be attributed to contacting eligible patients via email and

telephone, as well as maintenance of extensive intervention contacts. These contacts, including navigator support, website and telephone services, were associated with significant reductions in risk factors for CMD. Moreover, these interventions consistently delivered all components as intended in their respective settings (19, 20).

## 4.1 Limitations of this review

Several limitations need to be taken into account when interpreting the results. Firstly, the search strategy was designed to capture information from English language publications only. Consequently, valuable publications utilizing other languages, housed in other databases, or employing alternative applicable MeSH terms may have been overlooked. Two widely used terms, “panel management” and “PHM,” were utilized to describe the proactive management of an entire population at risk of adverse outcomes. These terms are frequently used interchangeably in the literature, but their recent emergence suggests that a broader search might have yielded more publications. Secondly, current study focused exclusively on the RE-AIM framework and did not explore other frameworks such as the widely used Consolidated Framework for Implementation Research. This decision may have limited the exploration of potential barriers and facilitators to successful implementation. Nonetheless, as the objective was to better understand the potential of interventions for broader dissemination and adoption, the RE-AIM framework was intentionally selected because of its specific emphasis on assessing how interventions perform in real-world implementation settings. We acknowledge that the RE-AIM framework is not the only framework. Rather, it was used as an appropriate framework in which to present carefully systematized findings to enable readers to exercise their own discernment. Finally, another noteworthy limitation pertains to the scope of this review, which was centered on primary care. As the organization of primary care can vary considerably across different countries, it is prudent to exercise caution when applying the findings to countries with different healthcare systems. Nonetheless, it is worth emphasizing that the shared goal of providing accessible and appropriate care to all patients remains a common thread across these diverse settings.

## 4.2 Implications for research and practice

In line with the findings in this study, other health interventions tend to underreport aspects covered by RE-AIM dimensions, which may result in a poor understanding of the factors contributing to the success or failure of intervention implementation (15, 49–52). Providing clear, standardized documentation of the effectiveness of implementation would improve understanding of potential public health impacts and better inform future research efforts (16, 61). Moreover, a better understanding would help demonstrate practical impacts and potentially stimulate wider adoption of such interventions.

Decision-makers can use the population health impact score to assess the feasibility of implementing an intervention within their specific setting (55). However, caution is advised when interpreting an average score because it may not encompass all dimensions outlined in the RE-AIM framework. It may be more insightful to compare the scores for each dimension across different PHM interventions (62).

This practical method allows for better visual communication with relevant stakeholders (63), providing a comprehensive view of intervention strengths and weaknesses regarding reach, effectiveness, adoption, implementation, and maintenance.

In conclusion, while many interventions did not fully report results across all RE-AIM dimensions, those that reported on Reach, Effectiveness, Adoption, Implementation, and Maintenance showed positive outcomes. Population Health Management interventions demonstrated their potential by reaching a significant number of participants and reducing CMD risk factors. Assessment of the RE-AIM average indicated that achieving the highest potential population health impact required reaching eligible participants through email or telephone, maintaining extensive intervention contacts via navigator support, website and telephone services, and consistently delivering all intended components within a specific setting. However, to further substantiate these results, reporting on adoption, implementation processes and the sustainability of these interventions must improve.

## 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.

## Author contributions

MR: Conceptualization, Formal analysis, Methodology, Project administration, Writing – original draft. NH: Conceptualization, Formal analysis, Writing – review & editing. SP: Formal analysis, Writing – review & editing. NC: Supervision, Writing – review & editing. HO: Funding acquisition, Supervision, Writing – review & editing. RV: Supervision, 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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## Supplementary material

The Supplementary material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fmed.2023.1275267/full#supplementary-material>

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# Are we saying it right? Communication strategies for fighting vaccine hesitancy

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Vaccine hesitancy is a multi-faceted phenomenon, deeply rooted in cultural, socioeconomic and personal background. Communication is deemed fundamental in fighting vaccine hesitancy. Medical communication should be accessible, relying both on an emotional approach and accurate information. Trained professionals should curate communication with the public.

## KEYWORDS

vaccine advocacy, anti-vaccination arguments, vaccine literacy, healthcare workers training, vaccination coverage

## Introduction

According to current definition, vaccine hesitancy (VH) consists in “delay in acceptance or refusal of vaccination despite availability of vaccination services” (1). It has been identified by the World Health Organization as one of the 10 most serious threats to global health since it hinders vaccination efforts, thus creating vulnerable niches of individuals in which infection diseases’ outbreaks might occur (2). The loss of community immunity due to suboptimal vaccination coverage also increases the risk of vaccine preventable diseases and their complications for vulnerable subjects who failed to respond to vaccination or could not be vaccinated (3).

It is surely imperative to address this critical topic; however, inaccurate interventions may backfire. In recent years, anti-vaccination movements have grown more structured and sturdier to criticism, relying on rhetoric and strongly refusing authority (4). Official communication is often met with disbelief, and lack of cohesion within the scientific community results in a failure to respond to the organized backlash of internet-based anti-vaccination movements (5).

Mandatory vaccination policies have also proven to be only partially effective: while increasing vaccination coverage, they are currently met with a significant degree of scepticism, sometimes evoking conspiracy sentiments (6, 7). People subjected to mandatory vaccination were found to fight it by pseudoscientific arguments (8), and even healthcare workers were observed to strongly oppose such measures (9). Therefore, different kind of interventions appear to be needed to fight hesitancy.

## Policy options

VH is currently recognized to be a multi-faceted phenomenon, rooted in both socioeconomic, cultural, and individual factors (1, 3). Communication regarding vaccination is therefore tricky: it should be simple enough to be understood by as many people as possible,



yet with a complex structure. In fact, pro-vaccination messages should target different aspects of VH at once, account for the target audience's diversity and use a technically correct but non-elitist language.

To date, however, several websites encouraging vaccination are often more difficult to understand for non-specialized readers than anti-vaccination platforms (10), and similar differences in readability are observed in various online settings (11). Classic communication based on dramatic narratives regarding the dangers of VH, despite still being widely used to sensitize the public about the importance of vaccination, has been proven to not be effective, while also stoking the fear of adverse events (12, 13).

When pondering and designing communication endeavors, policymakers should also take into consideration communication's relationship with health literacy and vaccine literacy, specifically. In fact, according to a recent definition provided by Sørensen et al., (14) health literacy encompasses a variety of aspects, including "knowledge, motivation and competences to access, understand, appraise, and apply health information." As far as vaccine-specific literacy is concerned, Lorini et al. (15) suggested that it is a "relational concept" related to one's ability, motivation, and knowledge to seek, understand, appraise and apply information regarding vaccination in a larger conceptual work frame extending to themselves, their family, and their community. It is apparent that the "understanding" dimension of vaccine literacy can be at least partially impacted by communication's quality.

## Actionable recommendations

First of all, medical communication should be accessible: relegating it to dedicated online databases makes it difficult to reach for the general audience. Providing additional sources of referenced information, both on digital and analog platforms, could help move medical notions closer to the public (16).

Secondly, VH often has a strong emotional component, and communication should take this factor into consideration (17). Addressing fear should be the top priority for all healthcare professionals, also considering that emotional wellbeing is part of the very concept of health (18). Additionally, the possibility of harm should be acknowledged and addressed properly to establish and maintain a stable relationship of communication and trust (13, 19, 20).

The role of frontline healthcare workers in promoting vaccination among their patients also represents a valuable asset. Various studies have highlighted how vaccine providers' opinion was perceived as relevant by patients, contributing to orient their decision to accept the vaccine (21–23). By establishing a strong network of adequately trained healthcare workers at a community level, this positive influence might be expanded and result in an overall increase in vaccine acceptancy and vaccination coverage.

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## Conclusion

Increasing people's trust in healthcare professionals is a fundamental goal for modern healthcare systems. Patience is needed when talking to those who feel betrayed, abandoned, or even damaged by institutions. Most importantly, communication should be a profession: trained personnel should be responsible for spreading ideas the right way, making sure that everyone understands and no one is left behind.

Training of personnel should be adequately designed and directed in order to ensure the presence of competent frontline healthcare workers in all main healthcare settings. This aspect should be incorporated into governmental practice for uniformity's sake, while its application should be curated by locally competent healthcare administration.

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# Building community engagement with caregivers through online interaction and a salutogenic approach in a period of isolation

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**Background:** Informal caregivers are essential figures that deal with the effects of dependence in the elderly. However, they suffer from poorer health-related quality of life, particularly regarding mental health. Social support is crucial, but this was suspended or dramatically reduced during the Covid-19 pandemic. Salutogenesis theory explores the contributing factors for the promotion and maintenance of health. Considering all these, we offered caregivers the opportunity to join a participatory project aimed at creating communication spaces where they could share experiences, think together about potential solutions, and explore which salutogenic actions they used in their daily basis and how they had changed during Covid-19 restrictions.

**Methods:** We used a qualitative methodology with a socio-constructivist and phenomenological approach and purposive sampling. We organized two focus groups consisting of online semi-structured discussions with seven participants in total. Conversations were videotaped and transcribed and we conducted content thematic analyses using the NVivo software.

**Results:** Caregiving in our setting are primarily women with high levels of education that do not always feel comfortable with this load because it interferes with their personal and professional lives. The pandemic increased caregivers feelings of loneliness, resignation, and burden, directly affecting their mental health. Furthermore, the disappearance of prevention programs and the difficulties to access healthcare services produced negative consequences on the already fragile elderly and their family caregivers.

**Conclusion:** The pandemic and its restrictions exacerbated the problematics affecting informal caregivers. Although these people are aware of their situation and have valued knowledge of how to improve their health, they cannot always put it into practice. We call policymakers to reframe interventions aimed at caregivers by introducing the voice of the community in the planning and to rethink the management of vulnerable people and their carers in other potential health crises.

## KEYWORDS

caregivers, informal caregiving, Covid-19 pandemic, salutogenesis, community engagement

## 1 Introduction

Spain is at the top 10 of the Organization for Economic Co-operation and Development (OECD) ranking regarding the frequency and intensity of informal care (1). Informal caregivers (IC hereafter) are people who take care of family or friends, usually without economical retribution. In 2018, 12.4% of the elderly residents of Barcelona required IC (2). Informal caregiving is shaped by the social context of each country and the policies that they establish to support IC. Differences are observed in this regard because the perceived duty to care for relatives varies across countries. In family-based societies and more deprived countries, informal caregiving prevails professional care (3). Relevant gender differences have also been identified throughout the world. For instance, in Barcelona, women do not only double the number of IC compared to men, but they also tend to take care of non-close relatives (2). In addition, as informal caregiving is unpaid work, it can become a private and domestic task undervalued both socially and economically. Oftentimes, this leads female IC to accept precarious jobs with worse working conditions and/or part-time positions, which has an obvious impact on their careers and quality of life (1).

Many studies have shown that IC suffer from poorer health-related quality of life than people of similar age, gender, ethnicity, and level of social deprivation (4, 5). Gonzalez-de Paz et al. (5) observed that IC are more likely to have received diagnoses of depression and anxiety and tend to report worse psychological well-being overall. Moreover, IC declare having a worse experience with healthcare services concerning the access and use of community care compared to other populations, which results in less support and more barriers and burdens (6). For instance, as it has been described in the study of Martin et al. (7), IC are often relied upon to ensure that patients adhere safely to treatment and to monitor any untoward side effects. However, IC often believe that healthcare professionals neglect them when it is time to evaluate different treatments options even if new disease management alternatives end up in new additional burdens for them. Furthermore, their role in the decision-making process can be confusing when the person who cares presents any kind of cognitive impairment such as chronic or temporary condition, as it happened with the covid-19 vaccinations (8).

Salutogenesis is the human health approach that examines the contributing factors to the promotion and maintenance of health (9). It is based on two fundamental concepts: Generalized Resistance Resources (GRR) and the Sense of Coherence (SOC). GRR are resources found within an individual or in his/her environment that can be used to counteract the stressors of everyday life and construct coherent live experiences (10). The SOC is defined as “a global orientation that expresses the extent to which one has a pervasive, enduring through dynamic feeling of confidence: (a) that the stimuli deriving from one’s internal and external environments in the course of living are structured, predictable, and explicable; (b) that the resources are available to one to meet the demands posed by these stimuli; and (c) that these demands are challenges worthy of investment and engagement” (9).

Findings suggest that the SOC could be an important determinant of IC’s well-being and may protect them from high levels of psychological distress and caregiver burden (10, 11). Moreover, studies have shown that the SOC might be a particular protective factor against subjective hardship, anxiety, and depression in IC of elderly dependent relatives (12). In fact, a significant reverse association was found between the burden of care and the SOC’s meaningfulness factor (13). There are also documented experiences of the use of the salutogenesis concept to improve IC’s wellbeing. For example, Wennerberg et al. (14) found a positive correlation between GRR and IC’s SOC applying guided interviews with a salutogenic approach. The interviews seemed to provide a reflective experience, mostly positive, empowering and enlightening, due to the focus on health improvement and the positive aspects of a situation that is usually described in negative terms. Similarly, Agulló-Cantos et al. (15) conducted 45 interviews to IC with a salutogenic perspective and observed that, even though these people are exposed to a source of stress, caregiving might act as a GRR since they can obtain positive experiences from being IC which can positively influence their health.

On a related note, literature has shown that highly participatory projects contribute to an enhanced understanding of the community assets and needs and contributes to strengthen empowerment and agency (16). Participatory Research Actions (PAR) aim to rethink our interventions by introducing the voice of the targeted population in the planning process. Through such a methodology, we ensure that problems are contextualized and interventions are tailored for the community in study (17). PAR have been reported to: (a) produce sustained collaborative efforts toward health improvement, (b) generate spin-off projects, and (c) achieve systemic transformations (16). Overall, shaping outcomes together and using participation techniques can encourage the use of resources to respond to internal and external stimuli (17) and provide purpose and a sense of belonging. There are documented experiences of PAR projects with IC that showed that their insights and suggestions enabled institutions to shape effective and successful interventions for them and their relatives (18).

For this reason, we created a salutogenic and participatory project for IC in three different health care centers of Barcelona: the INTerACT Project (INTroducing bidirectionality to the community: a salutogenic participatory Research ACTION in caregivers). The project had the objective to build bidirectional relationships with healthcare professionals by enabling communication spaces where IC could identify their problems and think together about potential solutions to improve their health and wellbeing. The project was started in 2019 but, shortly after, Covid-19 stroke. Social isolation measures hit the hardest in the most vulnerable, IC among them. In front of this situation, the IC involved with INTerACT reached out to the healthcare promotion professionals to find a way to keep sharing experiences.

During 2020, academics showed their concerns about the potential mental health repercussions derived from the pandemic restrictions on vulnerable people, such as the IC community, calling researchers and funding bodies to focus their actions on them (19).

Additionally, Greenberg et al.'s (20) review, highlighted the positive impact of coping strategies for IC during this critical period such as exercise, keeping contact with friends and relatives through social media, or sticking to daily routines. Nonetheless, we also found studies in the literature which stated that the effects of the suspension or dramatic reduction of support and care systems were gaged in IC, showing a notable increase of their burden, loneliness, and depressive symptomatology (21–23). All these papers collected data from online surveys or telephonic interviews. However, we found no participatory and salutogenic experiences tackling this issue in the literature.

Therefore, as the initially-divised face-to-face meetings were no longer a safe option given the particular circumstances of IC and their dependents, we redefined the methodology to enable the project to continue remotely. INTerACT was transformed then into INTerREDACT, where the added RED stands for 'network' in Spanish. This paper reports thus a specific participatory action initiated by IC in collaboration with healthcare professionals and aims to explore two main issues. Firstly, how these people lived the social isolation during the Covid-19 lockdown, focusing on which differences they experienced and how they felt providing care to their relatives. Secondly, we wanted to explore which salutogenic actions IC adopted to overcome this situation, asking for specific GRR that they used during this period.

## 2 Materials and methods

### 2.1 Study design

We defined a qualitative study adopting a phenomenological and socio-constructivist approach. We wanted to focus the study on the social phenomena through IC's life stories by exploring the meaning and common characteristics of their daily life experiences. Likewise, we analyzed the data by contextualizing and understanding their narratives within their social context (24).

### 2.2 Target community, sampling, and recruitment

We identified participants for the INTerACT project using purposive sampling. Social workers from the three health centers of Barcelona provided us with an initial list of IC that had already participated in caregiving training courses and had showed high rates of engagement during those activities. Then, we completed our group of participants via snowball recruitment. That is, by asking the initial selected participants if they knew anyone else with similar views or situations that could also be interested in taking part in the research (25). IC joined the training courses if they committed to a minimum of 80% of the training and did not meet any of the following exclusion criteria: suffering from a non-stable or non-treated severe mental disorder, consuming any addictive substances, having any cognitive or relevant sensorial impairments, or were taking part in other IC training groups in a different center. All participants included were contacted by phone and underwent a personal interview in which we confirmed that they complied with the aforementioned criteria and we asked for confirmation of agreement on the objectives and design of the study. In the

recruitment interview we also explored and registered their caring situation and gathered demographic data.

During the Covid-19 lockdown, we kept contact with the participants by phone. As explained above, when they asked to continue with the social interactions we introduced the digital aspect and INTerREDACT was born. For this specific subproject, we also used purposive sampling. In this case, we selected participants from the INTerACT pool that shared similar social and caregiving literacy and we took into account previous interactions between them reinforcing already-established relationships. Since this was a participatory study, the INTerREACT participants agreed on focusing the research on their perspectives as IC during the lockdown. They were also able to modify the scripts of the focus groups and, later on, share their views on the analysis and results if they deemed necessary.

### 2.3 Data collection

We organized two focus groups consisting of on-line semi-structured discussions. This methodology has been widely used in qualitative research and aims to explore a specific set of issues. Moderators often initiate the discussion by asking broad questions about the topic of interest and then they advanced to the focal issues. Although participants individually answer the facilitators' questions, they are encouraged to talk and interact with each other. This technique is built on the notion that the group interaction promotes respondents to explore and clarify individual and shared perspectives (24, 26).

We created a topic guide that included two main items and several sub-items (see Table 1). This guide worked as a check-list of the issues to cover during the sessions, but the focus group methodology framework enabled us to explore other topics that emerged from the participants' interactions. The first item was an exploratory view into their experience during the lockdown. The second had the aim to observe their salutogenic actions during that time. We created an additional moderators' guide with detailed prompts and which contained an approximate schedule for each topic to ensure that the semi-structured discussions were successful. The content of the topic guide was presented to the participants and they were able to propose changes if they considered necessary. The two researchers of the INTerREDACT project acted as moderators. In each session, we outlined the objectives and the functioning of the focus group and then we started the discussion. Moderators registered relevant notes about the issues that were discussed and the social interaction of

TABLE 1 Topic guide.

Caring experiences during the lockdown
How did you manage with the remote working?
Which differences have you observed regarding the medical attention?
How did you felt with these differences?
Experiences that helped you to get care of yourselves and improve your wellbeing during this period
Which actions had made you feel good mentally and physically?
Which actions that you had not made do you think it would have help you to feel better?
Have you used digital resources during the lockdown?
What rewards you from this situation?



participants during the focus group. We videotaped the focus groups and the audio was transcribed afterwards.

## 2.4 Data analyses

The qualitative data were analyzed by two different researchers using content analysis. Krippendorff (27) defined content analysis as “a research technique for making replicable and valid inferences from texts (or other meaningful matter) to the contexts of their use.” The process followed in conducting qualitative content analysis is composed of four stages: decontextualization, recontextualization, categorization, and compilation (28). To increase the validity of all the results, the topics were discussed and clarified until a consensus was reached (29).

## 2.5 Ethics approval and informed consent

The Ethical Committee (EC) of Hospital Clínic granted the approval for this study through the submission of an amendment of the INTERACT protocol (previously approved by the same EC) and registered with the reference number HCB/2020/0396. The EC ensured that the study followed the ethical principles laid down by the Helsinki Declaration (30) and all applicable legal laws.

After the first in-person INTERACT interview, we conducted phone interviews explaining INTEREDACT and then sent the documentation to sign the specific informed consent ensuring participants' anonymity, data confidentiality, and the possibility of withdrawal from the project. Another consent for voice and image recording was used for the sessions to be recorded and verbatim transcribed. Participants were informed that the results could be shared for research purposes.

## 3 Results

### 3.1 Participants

A total of seven people participated in the two focus groups; one with four participants and the other with three (see Table 2). All of them were women over 50 years old (range: 50–75). They came from the three different health care centers from the same Barcelona city district. Six of them had higher education. We have used pseudonyms to refer to the different participants throughout the document.

All participants took care of a relative with some degree of cognitive impairment. Monica, Evelina, Sara, Amelia, and Helena took care and lived with their mothers. Henar took care of both of her parents, who lived outside the family household. Maria was an IC for her husband. Evelina, Sara, Henar, and Amelia had also dependent children. Besides her mother, Helena took care of two brothers with mental health diseases who lived outside the family household.

### 3.2 Group dynamics

We found some differences in participation time among IC (see Figure 1). Maria and Monica were the most active and Amelia and Sara the least. However, we can observe that all of them contributed to the focus groups and expressed their opinion.

### 3.3 Discourse analyses

The main issues covered during both focus groups were: (a) aspects related to the caregiver's context, (b) experiences of informal caregiving during the lockdown and the pandemic situation, and (c) salutogenic resources that IC usually employ to overcome their situation and those that they particularly used during the lockdown and the pandemic situation.

#### 3.3.1 Informal caregivers' context

During the focus groups, IC described their context focusing mainly on their feelings about caring, but also how this situation affected their mental health and their caring perspectives, as well as which socioeconomic factors were involved.

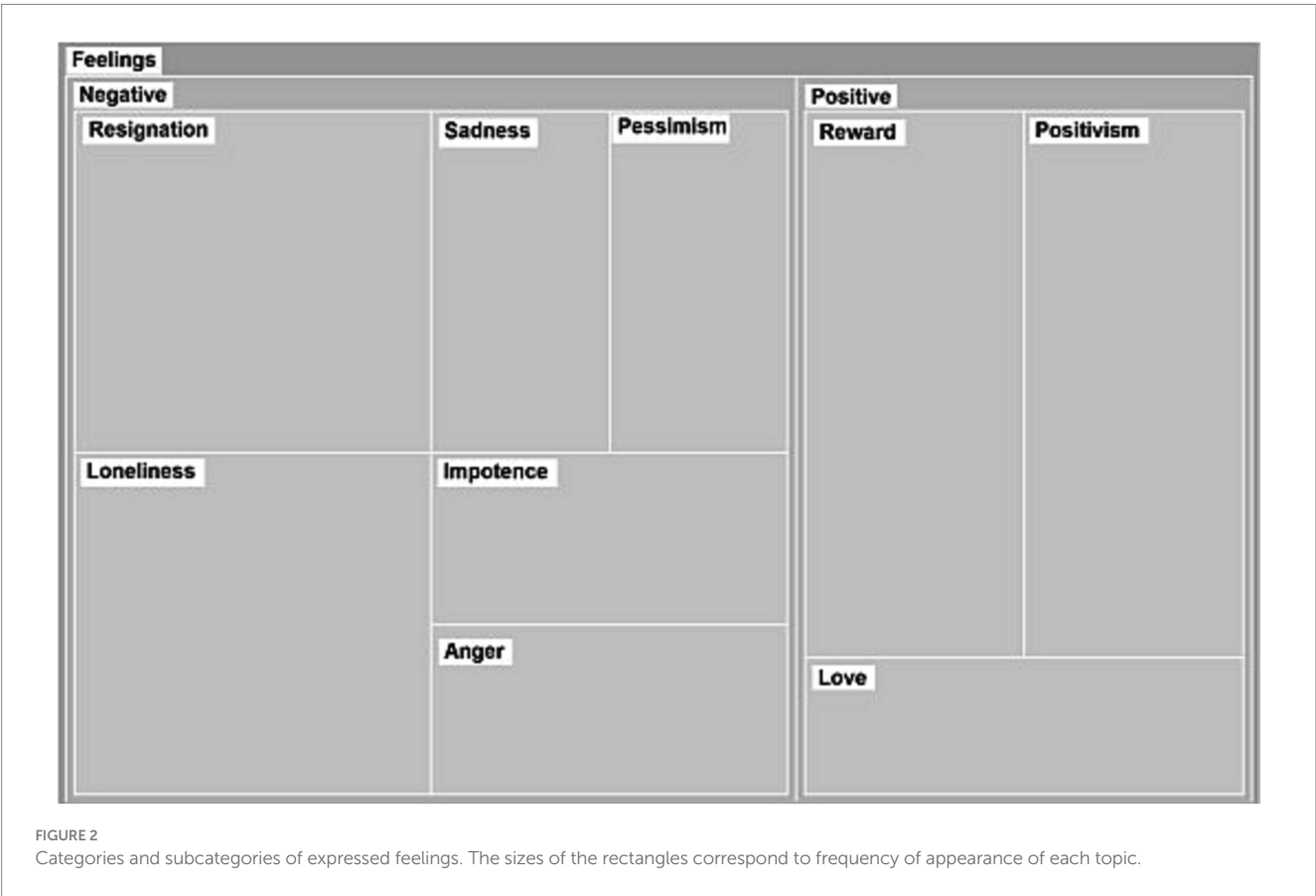
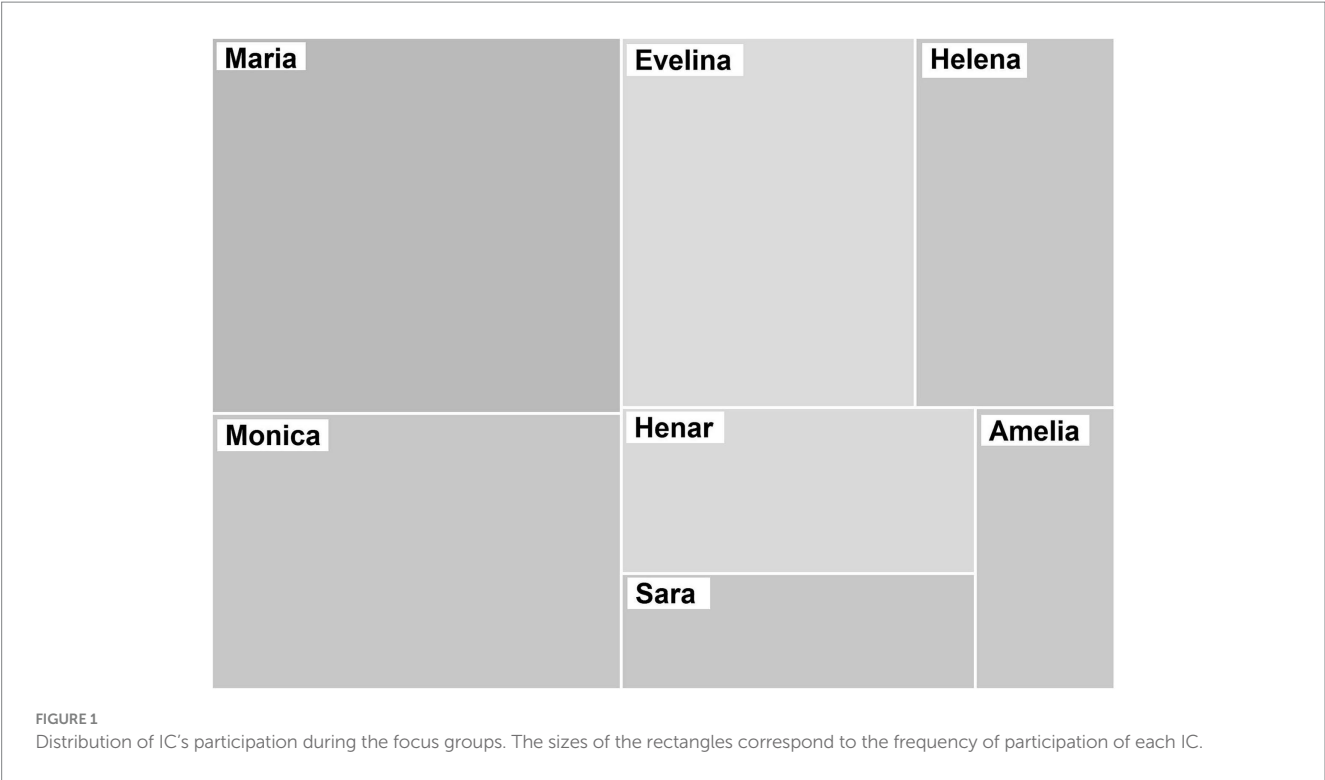
Loneliness and resignation were the dominant feelings in our conversations (see Figure 2). However, while resignation was indirectly expressed, loneliness was verbally specified during the conversations. Moreover, IC expressed that they felt they had to carry the weight of caregiving by themselves, even when there were other family members. This feeling was increased during the pandemic because they considered that healthcare professionals were not present the way they expected them to be.

*“... lonely, lonely, I mean I know I am with other people, lonely in the sense that I do not have the knowledge, I mean, that you do not know...” (Henar).*

*“... I felt very isolated, very lonely, without doctors, with no one that could come to, to help...” (Evelina).*

TABLE 2 Participants' characteristics.

Participants	Gender	Age	Employment status	Civil status	Education level
Monica	Female	66	Unemployed	Single	Higher
Maria	Female	75	Retired	Married	Secondary
Evelina	Female	55	Unemployed	Separated	Higher
Sara	Female	58	Active	Separated	Higher
Henar	Female	57	Active	Married	Higher
Helena	Female	68	Retired	Single	Higher
Amelia	Female	54	Active	Divorced	Higher



Resignation was widely identified in the transcripts, as the participants expressed discomfort in their current caregiving situation. They declared how they had to renounce to aspects of their life in order to provide assistance to their relatives. Notwithstanding, they usually found balanced feelings acknowledging also the associated rewards of caregiving and the love received by their relatives.

*"... I feel rewarded for what I am doing, but I feel also bitter in my life, I cannot deny..." (Monica).*

When talking about mental health issues and caregiving, they expressed the psychological consequences of overcoming daily problems related with their relatives' diseases. The most common symptom among participants was burden, but they also highlighted the loss of personal space and anxiety-related feelings.

*"... I was putting up with the situation, but I was really at my limit. My limit of what I can endure. Every day, I was going to sleep asking for help, help, and that, at least, I could wake up. It was as if I woke up with a different mood and I could put up with the whole day and again another night..." (Evelina).*

However, it was interesting to observe the empowerment one specific participant obtained from her condition.

*"... I grew stronger. I am stronger in the sense that I had to work internally with my emotions. I had to have more patience.... I think that this has made us stronger and that we got to know more about ourselves..." (Monica).*

Most of the participants felt that home-caring was an option they wanted to choose for their elderly, and they criticized people choosing other forms of caring. But one particular IC, Sara, said she regarded home-caring as a natural process in life and not an option, highlighting the fact that she is Colombian and, in her country, this conception is normalized. In addition, as shown in other studies, IC criticize the expenses of formal care and the difficulties in getting benefits from the government due to bureaucracy (3).

Amelia also introduced the gender perspective of caring, stressing how women usually adopt the caregiver role while carrying out their professional careers with little help of other family members or with no formal support available.

*"... as women, we need to overwork. I am a consultant and I work during nights losing sleeping hours. I have to look for someone to watch out my mother, well, television watches her out and sometimes my son..." (Amelia).*

There were also participants such as Evelina or Henar who had to stop working in order to take care of their family.

*"... I did it, what I am doing is right, but when I look backwards, and I see what I had to renounce to, I was an economist, I had a profession, I had responsibilities, I enjoyed my life... I had to renounce... I have become a housewife and caregiver, but this wasn't on my list of things to do in life..." (Henar).*

### 3.3.2 Experience of informal caregiving during the lockdown and the pandemic situation

During the pandemic, IC were initially home-locked with their relatives for 3 months and an extended period of social restrictions, which kept interfering in their caring situation, followed for several months. This situation changed their context, particularly in the way the medical and the formal care was provided, and also in the support they received from their social network, which was mostly already scarce. Figure 3 shows the most popular topics related to this area.

The participants were not willing to use hospital services because there were strict restrictions concerning visits and they feared that the elderly would be alone with high odds of a fatal situation occurring because of their fragility or them being more disoriented.

*"... if you want, you can visit (my mother) here but not at the hospital, because she is completely vulnerable... I understand that they are doing it for her own good, but my mother already has lived her life.*

*There is no need, if it's her time I would rather be with her... I do not know if I will be able to do it, but I do prefer to be with her, holding her hand..." (Helena).*

*"... I would not take my mother to the hospital, because I knew that if I took her to a hospital, she would not get back..." (Evelina).*

Furthermore, most of the participants felt neglected by the medical care authorities and had issues with remote medical attention.

*"... I did not receive any calls from the health center to check on her, not even once..." (Amelia).*

*"... something that worried me a lot during the lockdown were the medical appointments, because the doctor called us: How are your parents doing? I did not know, how could I tell them, I really did not know if they had something serious, I cannot know this, I am an economist not a doctor..." (Henar).*

Day care centers closed and short-stay residence programs were canceled. Moreover, some of them opted out from the help that they were getting from formal caregivers to reduce the number of contacts and avoid chances of Covid-19 infection. Later on, during the restrictions period and with the reopening of the day centers, many of them were not willing to re-enroll them because they still feared that their elderly could get infected.

Therefore, due to the pandemic restrictions, most of the IC reported that they were assuming all the caring load in order to reduce social contacts. These changes in the care support interfered with the IC's work and other personal tasks, increasing the risk of burden. They also felt that the situation worsened the cognitive capacities of the elderly.

*"... my sister sometimes comes once or twice a week, but since she lives in Tarragona she cannot come because of the restrictions..." (Monica).*

*"... My father has lost a lot with the pandemic.... he used to read the newspapers, did additions, write... now he does not even bring his planner. He used to talk with everyone..." (Henar).*

During the focus groups, participants got emotional because they mentioned the hard times they suffered fearing about the safety of their relatives and not being able to control the situation because of the general uncertainty of the moment.

Nevertheless, it was interesting to observe the resilience of some of the participants finding also positive aspects among this situation. They especially valued the time spent with their relatives:

*"... for me, it was beneficial because I am always working... and it was a moment of being back all together..." (Sara).*

### 3.3.3 Salutogenic resources

Discourse was categorized following salutogenic principles: comprehensibility, manageability, and meaningfulness. We paid special attention to the examination of the possible role of the digital resources during the pandemic, included in the manageability sphere (Figure 4).

The comprehensibility dimension in the salutogenic theory expresses that the stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable. During the focus group, we observed that IC had gone through an introspective process to get know themselves better and learn about their needs and acceptance of their situation.

*"... I've learnt to downplay things to relativise things. To stop planning that much.... I planned too much, one day here another there, everything under control, everything must be arranged, I need to have*

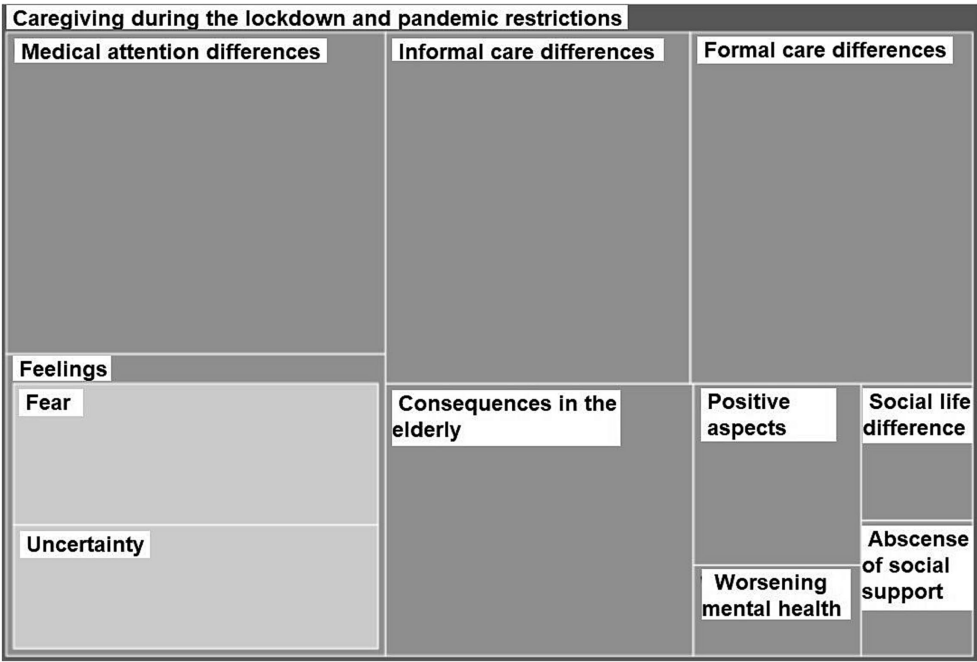


FIGURE 3 Subcategories of caregiving during the lockdown and the pandemic restrictions. The sizes of the rectangles correspond to frequency of appearance of each topic.

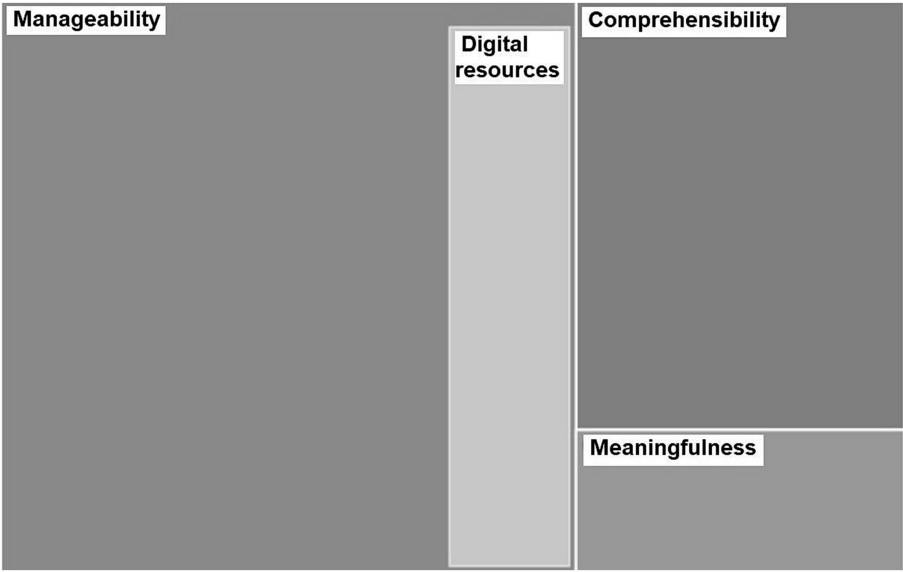


FIGURE 4 Subcategories of salutogenic dimensions. The sizes of the rectangles correspond to frequency of appearance of each topic.

everything alright. Now I take things slowly, I've learnt that I am able to calm down, because otherwise I cannot do anything but destroy myself."(Sara).

"... I am two hours alone, I am always going to sleep very late, but it is what I need, some time for me..." (Maria).

The manageability dimension means that the resources are available to one to meet the demands posed by these stimuli. IC showed us that they used plenty of resources that helped them to

overcome their situation. Economic resources such as the benefits that the government provides for the elderly dependent in Spain, the use of their social network, or sport practice. Also, cultural resources like reading, music, photography, meditation, or mindfulness.

"... during the pandemic I worked out by going upstairs and downstairs, I moved. I also sunbathed with my mom in the balcony... These things helped me to take good care of my body... These things help me..." (Helena).

Broadly speaking, taking time for themselves, which allowed them to perform these activities, was reported as a widely used and valued tool to keep them healthy. Notwithstanding, time for themselves was claimed to be the hardest to achieve, as Monica clearly exemplifies in the following verbatim:

*“... I see my sister as heavenly help. When she comes, she cooks, she is the caregiver. She makes all this, but I say: there are 365 days and you help 2 of them, that means 363 for me...” (Monica).*

Finally, with the pandemic, digital resources became a primordial connection with society and our IC took advantage of them. Video conferences with friends, YouTube tutorials for practicing sport, or inspirational speeches were some of the on-line resources they mentioned. During the lockdown, Evelina also found comfort in an Instagram account of a famous Spanish actor who decided to confine with her grandmother and showed their daily life together.

Lastly, the meaningfulness dimension introduces the concept that the demands posed by the stimuli deriving from one's internal and external environments are challenges worthy of investment and engagement. Broadly, IC agreed that the core reason that made them take the decision to become IC was because they thought it is the right thing to do and they receive the love from their relatives.

*“...When I see my mother so well, and well-cared for, I swear I experience great joy, when she kisses me and tells me how beautiful I am I know she is all right, that I've done what I had to do, and I will do it again...” (Henar).*

## 4 Discussion

In our setting, informal caregivers (IC) were primarily women with high levels of education that do not always feel comfortable with this load because it interferes in their personal and professional lives. On top of this structural hardship, the Covid-19 pandemic and the consequent social restriction policies imposed worsened their situation. During that period, they experienced increased feelings of loneliness, resignation, and burden, directly affecting their mental health. Furthermore, the disappearance of prevention programs and the difficulties to access healthcare services, produced negative consequences on their fragile elderly dependents and themselves. The IC studied here showed good comprehension of their obstacles and had the knowledge to improve their health, but we observed that they were not always able to put their own coping strategies into practice. We believe that the focus group technique allowed us and our participants to better and more profoundly understand their problems and helped to build community-engagement among caregiving peers.

When we analyzed their dialogs, the most prominent observation was that participants believed that taking care of their relatives is a duty that they have to accomplish, but which causes contradictory feelings. On the one hand, they valued being able to provide care in their home settings and they were able to get positive experiences from it, such as love and reward. However, on the other hand, this situation interfered with their professional careers and social life and, consequently, raised frustrating feelings. As it happened to some participants of our study, Pickard et al. (31) evidenced that many IC move to part-time paid employment or just leave their jobs, with direct consequences not only to themselves and their families but also to the society as a whole. Our participants' professional interferences cause social exclusion, which results in the inability to participate in

ordinary relationships and activities available to the majority of people in the society (32).

Another important aspect that surfaced during the study was the issue of gender. Jimenez and Moya (33) conducted a qualitative study about women's naturalization of the caregiver role. Their findings suggested that women usually hold a moral and emotional duty to care for the family but, at the same time, they desire their own personal development. Similarly, the 2018's Barcelona Women Caregivers Report (34) concluded that this moral sense of duty usually makes women to do this work alone, often having troubles finding consistent help from other family members. Our participants repeatedly reported this struggle and they expressed strong feelings of loneliness associated with it. These findings are congruent with other studies in which it is shown that women tended to assume more caregiving tasks than men during the pandemic and also expressed more burden than men (35, 36).

Relatedly, before the pandemic, our IC usually benefitted from other formal aid provided by the government or their own private resources, which reduced their daily caring load. Some of them also had available informal aid like family members or friends that could occasionally help them out with their elderly or give them emotional support. In the Spanish context, formal aid is provided by the dependence law (37), which provides relatives of dependent people with family workers' hours to attend the dependent person or a monthly payment to help families with the expenses of the caregiving task. There are other formal and local programs aimed mainly at improving the functionality of dependent people and reduce the load of caregivers, such as day-care centers, which vary across city districts or towns. However, when Covid-19 stroke, they lost this support net which IC heavily depend on (e.g., closure of day centers or reduction or abolition of formal caregiving solutions to minimize social contact). Therefore, their basal feelings of loneliness and burden raised, impairing their mental health status. These findings agree with the literature found in other countries (38, 39). For instance, in the UK, Gallagher and Wetherell (22) analyzed data from a national survey during the first year of the pandemic and they observed that higher levels of loneliness increased the risk of depression symptoms almost four-fold in IC.

Moreover, during this period, participants particularly highlighted the troubles in getting medical attention for their elderly. They narrated different experiences in which their relatives got medical conditions that required from the evaluation of healthcare providers but community healthcare centers had limited their access, prioritizing remote channels to respond to health demands. IC felt neglected and helpless without face-to-face assistance. IC did not felt comfortable with the remote support of healthcare workers, as they believed that they were not able to properly explain the health problem of their relative and they feared they might miss something relevant. The problematics of access to healthcare services and its consequences during the pandemic scenario, particularly for chronic patients, have been also described in other Spanish regions (40). However, regarding the emerging technological solutions where caring is involved, reports from caregivers from other countries contrast those from Spain, as these technologies have been considered to enable rather than hinder the attention of people with dementia (41).

Participants were also sometimes reluctant to seek help in the hospital setting since companions were restricted during the hospitalization, and they feared that their elderly could get a fatal



Covid-19 infection there. In the Canadian study of Hindmarch et al. (42) was proved that visitor restrictions during the pandemic produced negative outcomes to IC, including social isolation, strain, and reduced quality of life. Similarly, other studies (21, 38, 43) have pointed out that one of the consequences of the lockdown and social restrictions in the elderly affected with dementia was the worsening of their cognitive impairment and behavior.

With respect to the participants' salutogenic agency, we could assess that, although they were not always able to apply them, overall, they were aware of the elements that help them moving toward a healthy and good quality of life. Such knowledge was shown to have a protective effect on the psychological state of IC during the pandemic (44). The use of on-line resources had also a positive impact on our participants, incrementing their resilience mechanisms to overcome that particular scenario. This correlates with the study of Yoon et al. (45), which examined topics and feelings expressed by IC on Twitter and concluded that on-line social media have the potential to be a platform to promote positive coping strategies and resilience.

Compared to other investigations, the present study did not only aim to collect data, but also to build a social network among IC that will be later involved in a larger project to reframe their relationships with healthcare providers. A participatory action research intervention that helped to think together about IC's needs and possible solutions in their context. We found different qualitative studies in the literature involving IC and the Covid-19 pandemic, mostly individual surveys (21, 22, 42–44, 46–48). However, the focus groups here had the purpose of giving voice to participants to express themselves comfortably, creating a trust space between equals. We believe that this structured methodology, which additionally followed the COREQ checklist (26), enriched the discourses and facilitated the creation of social connections. We also think that while many studies have focused on gaging the depressive, anxiety, and burden symptoms that IC suffered during the pandemic, the qualitative approach used in this research facilitated exploring the triggers of these feelings. Furthermore, the salutogenic perspective that we introduced promoted participants' recognition of their own coping strategies to overcome the daily obstacles that they faced and those derived from the pandemic situation.

## 4.1 Limitations of the study

On the one hand, while the sample of the present study is small, we believe that the women studied (above their 50s, some of them already retired and with a background of high levels of education) are representative of the upper-middle socioeconomic context of the Barcelona city district where the project was set and can be extrapolated to the target population with a certain degree of confidence. On the other hand, we acknowledge that the use of a purposive sample with highly experienced IC (both in terms of caregiving itself and informal caregiving group training) could somewhat hinder its projection. However, we were interested in that the data gathered was knowledgeable, as this intervention is the first of a series of a larger project involving other IC from the same city district and has the purpose to help us build solutions to apply in our primary care setting. On a different note, the fact that the focus groups needed to be conducted on-line had the advantage that we could

connect despite social restrictions and it was more practical for IC given that their schedules were already limited due to their caring obligations. Despite this, videoconferences may interfere with fluent communication because of connection problems and they can hinder natural human interactions, as well as inhibit some non-verbal communication that is also relevant for qualitative studies. Therefore, although digitalization tools in general have proven to mitigate the burden of care for caregivers (49), they may have damaged the quality of social interaction that we pursued in this intervention.

## 4.2 Implications for clinical practice

The pandemic crisis was an unfortunate opportunity to expose the vulnerability of the care system of our society, and it has been useful to rise awareness about how institutions may respond to the most fragile. The salutogenic perspective and qualitative methods of the present study allow not only to deeply understand the problematic of this population, but also to focus on their coping strategies. This data can be useful to build new intervention programs adjusted to the IC's daily needs and in potential future health crisis. For this purpose, we believe that we need new participatory action research focused on understanding IC's social phenomena to build, together with them, eventual interventions directed to their community.

## 4.3 Conclusion

In our setting, informal caregiving is a feminized population who expresses feelings of discomfort with its caregiving activity, as it hinders women's personal and professional development. Moreover, they referred feelings of loneliness, resignation, and burden that affect their mental health. Social restriction policies during the pandemic had a direct effect on this group, increasing their social isolation. The absence of prevention programs for vulnerable people and the barriers to access healthcare services during this period, also produced negative consequences on the fragile elderly and their family caregivers. Informal caregivers are aware of their situation and have valued knowledge of how to improve their health, but oftentimes cannot apply it due to their intrinsic circumstances.

In order to improve the quality and the safety of the services aimed at caregivers, we call policymakers to reframe interventions aimed to them by introducing the voice of the community in the planning, and to rethink the management of vulnerable people and their carers for other potential health crisis. Based on the findings of this study, we suggest that institutions should focus on three key points:

1. Reducing the gender gap observed in IC by improving the reconciliation of informal care and paid work, by increasing the formal aid targeted to reduce the caregivers' load, and by incentivizing women caregivers' networks to enhance their resilience and reduce and share their burden.
2. Rethinking the management of formal aid provided for the dependent population during a pandemic by finding new formulas to keep this population active and, at the same time, by aiding caregivers with their caring tasks.

- Healthcare institutions should improve telemedicine and communications targeted at vulnerable people and transform them into a more satisfying experience for families and patients.

## Data availability statement

The raw data supporting the conclusions of this article will be made available by the authors, without undue reservation. Requests to access these datasets should be directed to the corresponding author.

## Ethics statement

The studies involving humans were approved by Ethical Committee (EC) of Hospital Clínic. 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

OM-C and LT-P: study design, recruiting, interviewing, data gathering, transcription, data analysis, and writing manuscript. AM-C: writing, reviewing, and editing. GR-G, AB, and DJ-C: reviewing and editing, visualization, and supervision. All authors have read and agreed to the published version of the 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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# Culturally sensitive patient-centered healthcare: a focus on health behavior modification in low and middle-income nations—insights from Indonesia

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Patient-centered, culturally sensitive healthcare acknowledges the profound impact of cultural beliefs on health behaviors and outcomes, particularly vital in low and middle-income countries (LMICs). Within Indonesia, distinct cultural factors are pivotal in empowering patients, necessitating their integration into healthcare practices. For example, the cultural concept of *gotong royong*, emphasizing communal collaboration, presents an opportunity to foster community support networks among patients. Moreover, honoring familial ties and involving family members in decision-making enhances patient empowerment. Acknowledging and incorporating spiritual and religious beliefs, which are deeply rooted in Indonesian culture, into healthcare interventions further augments patient empowerment and well-being. In LMICs, including Indonesia, achieving patient empowerment demands implementing critical strategies. Community-based interventions harness local resources and engage the community to drive health behavior change. Culturally sensitive communication bridges the gap between healthcare providers and patients, respecting language nuances and cultural norms. Patient education fosters a comprehensive understanding of health conditions, thereby encouraging active involvement in decision-making. Tailored behavior modification techniques, aligned with cultural beliefs and practices, support the adoption of healthier behaviors among patients. This review emphasizes the pivotal role of patient-centered, culturally sensitive healthcare in LMICs, particularly in Indonesia. It delves into strategies to promote health behavior change within these unique contexts, emphasizing the importance of cultural sensitivity and patient-centered care. The discourse also explores the cultural landscape impacting healthcare, acknowledging the challenges faced in delivering comprehensive healthcare services within these diverse cultural contexts. Additionally, it outlines innovative approaches and success stories in implementing patient-centered care, highlighting how cultural factors intersect with healthcare outcomes. By advocating for integrating culture-specific patient empowerment practices into healthcare methodologies, this article underscores the potential for improved health outcomes, heightened patient engagement, and the delivery of culturally relevant services within LMICs.



## KEYWORDS

patient-centered, culturally sensitive care, health behavior change, low and middle-income countries (LMICs), culture-specific patient empowerment, patient education, behavior modification techniques

## 1 Introduction

Patient-centered, culturally sensitive health care prioritizes each patient's cultural background, tailoring healthcare services to align with their individual needs. This approach holds particular significance in LMICs, where cultural beliefs and practices substantially influence health behaviors and subsequent outcomes. At the core of this paradigm lies the crucial significance of utilizing patient-centered, culturally sensitive strategies to accomplish enduring changes in health behavior (1, 2). This manuscript delves into the paramount importance of patient-centered, culturally sensitive healthcare within LMICs. Specifically, we explore diverse strategies to foster health behavior change within these unique settings.

LMICs face multifaceted challenges in delivering comprehensive healthcare to their populations. These hurdles encompass scarce resources, inadequate infrastructure, and the need for more trained healthcare professionals. Furthermore, cultural beliefs significantly impact health behaviors, decision-making, and health outcomes. For instance, Indonesian culture, though varied between tribes, religion, and living settings (urban vs. rural), usually places substantial emphasis on traditional medicine. This often leads to preference for traditional healers over Western medical practices (1, 2). Additionally, the culture promotes profound reverence for elders, who play significant roles in decision-making processes. It upholds communal decision-making, where local leaders, community elders, and family members play pivotal roles in treatment implementation and decision-making processes.

Recognizing the undeniable influence of cultural beliefs and practices on health behaviors and outcomes, patient-centered, culturally sensitive healthcare strives to integrate these factors into healthcare services. This is particularly crucial within primary care settings. Some evidence underscores the positive impact of this approach on patient satisfaction, treatment adherence, and overall health outcomes (2, 3).

## 2 Health behavior change

In general understanding, behavior is considered a determinant of health and is the target of promotion for behavior change. The process encompasses shifting from negative (unhealthy) behavior to positive behavior that aligns with health values, fostering the development or enhancement of positive behavior, and maintaining pre-existing positive behavior or behavior consistent with health norms and values (4–6). Emphasizing the preservation of already established healthy behaviors, this transformative journey acknowledges that an individual's behavior can change when an internal imbalance exists within them (3, 4).

Several stimuli can lead individuals to change their behavior; social factors, as external influences on behavior, include social structures, social institutions, and other social issues (4). Factors

influencing behavior change include the pre-existing personality, influenced by individual characteristics, assessment of offered changes, interactions with healthcare professionals recommending behavior change, past experiences attempting similar changes, and general cultural values that serve as either rewards, reinforcers, and/or punishers. For example, tobacco smoking for men is connected to cultural practice in many parts of Indonesia, while for women, it is just a relatively recent or urban practice, and the latter are often viewed quite negatively by the larger society. Stimuli originating from emotions such as fear and love or personal and cultural expectations can also influence behavior (7).

Behavior change usually takes time, and few individuals instantly alter their behavior. Sometimes, people change due to societal pressures or a desire to conform to existing norms (8). The process of change is not immediate and should be thoroughly tested. Prochaska and DiClemente's model proposes a structured framework consisting of five stages in the behavior change process that provide a comprehensive and sequential understanding of the dynamic journey individuals undergo when striving for change, namely health behavior change (9).

The relationship between health and behavior is closely intertwined, with a healthy individual reflecting healthy behavior and vice versa. The crucial benefits of a healthy life include enhancing our productivity and utilizing our abilities and potential to the fullest. Therefore, the concept of healthy living, such as promoting Clean and Healthy Behavior (*Perilaku Hidup Bersih dan Sehat* or PHBS program in Indonesian Health Centers), needs to be nurtured by every individual to improve overall health quality. Healthy behavior and behavior change aim to establish a healthy lifestyle pattern that reflects positive habits (10).

In the health behavior change process, a significant aspect is the formation and alteration of behavior, serving as the objective of health education or health counseling to support other health programs. The intended changes go beyond and encompass covert behavior. Concrete and positive efforts are necessary within health programs to achieve behavioral changes aligned with health norms (9, 10).

Behavioral change strategies can be divided into three categories: utilizing power or incentives that lead to rapid but less sustainable changes, providing information that leads to enduring public awareness, and participatory discussion that leads to active participation resulting in more steadfast and profound changes (11). The effectiveness of these strategies may be further improved by tailoring them to the patient's needs and culture (10).

Patient-centered, culturally sensitive healthcare is therefore vital for improving health behavior and achieving better health outcomes. The process may include various approaches such as education, counseling, and behavior modification techniques (BMT) (12). Unhealthy behaviors such as smoking, poor diet, and lack of physical activity are major risk factors for chronic diseases such as heart disease, diabetes, and cancer. Health behavior change is essential for prevention; modifying the risk of chronic diseases will improve overall health and



well-being and is also important for the management of chronic diseases (12). For example, individuals with diabetes may need to modify their diet and exercise habits to manage their blood sugar levels. Health behavior change can also improve medication adherence and reduce the risk of complications associated with chronic diseases.

Education entails providing tailored information about health conditions and the significance of behavior change, utilizing visual aids based on the individual's education level and intellectual development. Counseling involves collaborative efforts to identify and overcome barriers to behavior change, with healthcare providers or trained counselors offering support. Behavior Modification Techniques (BMT) utilize positive reinforcement, incorporating rewards and incentives to induce health behavior change. Techniques such as peer support groups and community networks foster an environment conducive to sustained behavioral shifts. These methods leverage incentives, such as facility access or health-related service discounts, promoting adherence to desired behaviors. Social support networks promote mutual encouragement and the exchange of experiences, reinforcing long-term commitment to behavior change. The combination of these techniques, incentives, and social networks offers a comprehensive approach to catalyzing enduring health behavior modifications effectively (13).

Facilitating health behavior change within LMICs presents intricate challenges rooted in cultural beliefs that diverge from Western medical practices. For instance, some cultures prioritize traditional healers over Western medicine, perceiving the pursuit of medical care as indicative of vulnerability. These entrenched cultural paradigms serve as substantial impediments obstructing efforts toward behavior modification (14). In this context, the significance of patient-centered, culturally sensitive healthcare surfaces as a pivotal determinant.

### 3 Implementation of culturally sensitive patient-centered healthcare to change health-related behavior: challenge and potential strategies

Despite the challenges, some strategies can effectively promote health behavior change in LMICs. These strategies include community-based interventions, culturally sensitive communication, patient education, and BMT (15, 16).

#### 3.1 Community-based interventions

Community-based interventions are indeed effective in promoting health behavior change. A systematic review of community-based interventions found that these approaches successfully promoted physical activity, healthy eating, and tobacco cessation (17). Additionally, they have been shown to promote medication adherence and improve health outcomes in individuals with chronic diseases (18).

Community-based interventions are particularly effective when tailored to the community's cultural background. For example, community-based interventions involving traditional healers have effectively promoted health behavior change in some cultures (19). Community-based interventions involving peer support groups and other social support networks have also effectively promoted health behavior change (20).

Posyandu (*Pos Pelayanan Terpadu*), or Integrated Health Posts, are widespread throughout Indonesian villages and suburbs. Efforts to revitalize Posyandu have focused on strengthening community involvement, providing additional training to health workers, and integrating new services, such as chronic disease management or mental health support, to better address the evolving health needs of communities. The establishment of Posyandu within communities, particularly in underserved regions, significantly fosters advancing health and familial well-being within a given locality. In this context, Posyandu must operate efficiently, as evidenced by data provided by the Ministry of Health of the Republic of Indonesia in 2018, which indicated the presence of 173,750 active Posyandu dispersed across Indonesia, boasting an operational engagement rate of 61.32% (21).

Even during the COVID-19 pandemic, Posyandu continued their activities by conducting mobile visits to the homes of toddlers, facilitated by the *kader*, a term used to describe community health workers (CHWs). In the existing system, these *kader* have not yet been officially incorporated into the healthcare system and therefore are not officially funded. Authors' field experience and anecdotal reports suggest that *kader* are delegated by the local health service, often without their voluntary consent or prior training, yet they are expected to run Posyandu activities and mobilize the community. These activities include administering vitamin A supplementation, vaccinations, and providing education on complementary feeding, among others (22, 23).

In the domain of mental health, leveraging the influence of religious and grassroots community leaders to facilitate access to mental health professionals, such as psychiatrists and psychologists, has proven beneficial in reaching isolated patients and enhancing their outcomes. This approach aids in preventing further harm, such as instances of shackling and chronic disability. Collaborative efforts between family physicians and local *kader* are often necessary to implement these initiatives effectively. Furthermore, in Indonesia, individuals can access free preventive measures, consultations, and treatments through the national health insurance scheme, *BPJS Kesehatan*. This ensures that mental health services are accessible to all, regardless of socioeconomic status (24).

Additionally, *kaders* and primary care physicians conduct home visits to administer long-acting antipsychotic injections for patients with schizophrenia, ensuring continuity of care and adherence to treatment regimens. Training sessions offered to individuals with mental disorders (known as "ODGJ" or *Orang Dengan Gangguan Jiwa*) in essential life skills and productivity not only assist them in their daily routines but also engage the participation of their immediate social circles. This benefit aligns with the program's goals, which aim to enhance the involvement of families and communities. Consultations for families of ODGJ, including discussions about the condition of the individuals, are also offered to increase understanding and empathy towards ODGJ, given the significant role that families play. This benefit is consistent with the program's objective of increasing family involvement in mental health efforts (25).

Community-based interventions in Indonesia often intertwine health practices with religious beliefs to promote health and well-being. By recognizing and respecting the significance of these practices within the community, interventions can effectively engage community members and foster meaningful participation. For example, initiatives may collaborate with local religious leaders or traditional healers to integrate health promotion messages into religious gatherings or formal healing sessions. This approach ensures

cultural relevance and acceptance and enhances the reach and impact of interventions by tapping into existing community structures and networks. Additionally, community-based interventions may facilitate dialogue and collaboration between healthcare providers and community members to develop culturally sensitive health programs that align with religious and cultural values, ultimately contributing to improved health outcomes at the community level (21, 22).

Indonesia, as the country with the largest Muslim population in the world, serves as a significant hub for Islamic culture and practices. With approximately 87% of its population adhering to Islam, Indonesia boasts a diverse and vibrant Muslim community that permeates various aspects of Indonesian society, including daily life, governance, cultural traditions, and health. In addition to serving as centers for health promotion and education, mosques in Indonesia often host free mass circumcision events for Muslims (26).

Additionally, efforts are made to portray it as promoting cleanliness and personal hygiene. These endeavors aim to provide scientific credibility and a moral basis for the practice. Because accumulations of urine and smegma beneath the foreskin can lead to impurity on clothing and the body, many Islamic scholars interpret circumcision legislation as a means to purify the body from such impurities. Further research has provided increasing evidence for the health benefits of circumcision, including a lower risk of Human Immunodeficiency Virus (HIV), Herpes Simplex Virus Type 2 (HSV-2), and Human Papillomavirus (HPV) infection. Among female partners of circumcised men, bacterial vaginosis was reduced by 40%, and *Trichomonas vaginalis* infection was reduced by 48%. Urinary tract infections in infants during their first year can pose serious risks, potentially requiring hospitalization. The likelihood of a urinary tract infection in an uncircumcised male infant is ten times higher than in a circumcised male infant, with rates of 1 in 100 and 1 in 1000, respectively (26).

In Indonesia, Friday prayer sermons often incorporate messages about health and hygiene, serving as platforms to encourage congregants to adopt healthy lifestyles and seek medical care when necessary. These sermons are vital in disseminating health-related information and promoting preventive healthcare practices within Muslim communities. Islamic teachings emphasize the importance of cleanliness and hygiene as integral aspects of faith and daily life. The Qur'an instructs believers to maintain cleanliness and purification, as stated in Surah Al-Ma'idah (5:6). Additionally, authentic Hadiths, such as those found in Sahih Muslim and Sahih Bukhari, emphasize the significance of cleanliness and regular ablution (wudu) before prayer. These teachings influence health behaviors among Muslims, promoting practices that enhance personal hygiene and contribute to overall well-being. The emphasis on cleanliness extends beyond physical rituals to encompass mental, spiritual, and environmental cleanliness, reflecting Islam's holistic approach to health and hygiene (26).

Despite their effectiveness, community-based interventions face several challenges. These challenges include limited resources, inadequate infrastructure, and a shortage of trained healthcare providers. Additionally, cultural beliefs such as communities trusting traditional healers more than Western medicine are still prevalent in rural areas (27).

Some strategies can be effective in overcoming the challenges of community-based interventions. These strategies include working with community leaders. Community bonds and collective decision-making play a vital role in Indonesia. Implementing community-based health approaches that involve local leaders, community elders, and traditional healers can foster a sense of ownership and

empowerment among patients. Community leaders can help to promote health behavior change and encourage community members to seek medical care when necessary (28).

Building rapport with non-health stakeholders, such as local government officials, school teachers, and community leaders (often religious leaders), is pivotal to addressing limited resources by seeking donations from stakeholders (27, 28).

Addressing limited infrastructure can involve setting up an integrated network of school clinics with the public health system or establishing Posyandu at local mosques. Additionally, utilizing technology, such as mobile phones and social media, can help overcome infrastructure barriers by providing health education, counseling, and other healthcare services to community members (27, 28).

The shortage of healthcare providers may also be alleviated by training community leaders and willing participants in the community to be CHWs, enabling health education to be delivered by prominent members in the community (28).

### 3.2 Culturally sensitive communication

Culturally sensitive communication operates within the broader framework of cultural sensitivity, which requires individuals to be aware of cultural diversity and its implications for a patient's beliefs and attitudes, while also respecting individual differences (29). Cultural sensitivity is defined as 'the ability to recognize, understand, and react appropriately to the behaviors of persons who belong to a cultural or ethnic group that differs substantially from one's own' (30). Healthcare communication, involving the exchange of information between patients and healthcare providers, extends to interactions with families and caregivers. This form of communication entails bi-directional engagement, involving patients in decision-making processes and care planning.

Culturally sensitive communication is essential in patient-centered, culturally sensitive healthcare. It involves tailoring health messages to the patient's cultural background (27). This constitutes a fundamental aspect of healthcare delivery, as it can significantly impact the quality of care and patient and family satisfaction. When cultural disparities arise, they may lead to poor adherence to treatment, worse health outcomes, and an increased prevalence of adverse events (28).

The concepts of culturally sensitive communication involve three major parts: antecedents, attributes, and consequences. Antecedents are aspects that precede circumstances or events. In culturally sensitive communication, antecedents include the environment and culture of the ward, organizational structures, the clinician's education and communication experience, sociocultural characteristics of patients, families, and clinicians, and the personal and professional experiences of the clinicians (29). The next concept is defining attributes, which involve communication between clinicians, patients, and families. It is divided into four attributes: encouraging patients and families to participate in decision-making, prioritizing cultural considerations in planning, developing a trusting relationship, and using personal interpreters where language differences exist. The last concept is consequences, which are incidents that occur due to culturally sensitive communication. Outcomes include increased patient and family satisfaction, improved adherence to treatment regimens, better engagement in patient and family-centered care, and improved health outcomes (31).

Indonesia is the fourth most populous country in the world, with an estimated population of 260 million people. It is also known as a culturally diverse country with more than 1,300 ethnic groups and six official religions. The multifaceted nature of health behavior in Indonesia can be attributed to the nation's diverse ethnic composition and multicultural demographic, which includes various health providers. Despite the wide availability of formal health services, cultural or traditional health providers comprise a significant component of health services. Some examples in Indonesia include mind–body therapies, such as hypnotherapy, physical therapies with tools like acupuncture, physical therapies without tools such as body massage, and biologically based therapies using substances from nature (31).

This highlights the importance of culturally sensitive communication in LMICs. Health messages tailored to the patient's cultural background are more likely to be understood and followed. Culturally sensitive communication can also help overcome cultural barriers to health behavior change. For example, in some cultures, seeking medical care may be viewed as a sign of weakness, leading individuals to prefer traditional healers over Western medicine. In instances such as the treatment of prevalent conditions like depression and anxiety, cultural perceptions emphasizing spiritual fortitude may inadvertently engender moral assessments and perpetuate stigmatization.

A culturally attuned clinician confronted with barriers, such as language, socioeconomic status, literacy, and occupation, must navigate them by integrating culturally resonant narratives and metaphors that align with prevailing cultural beliefs, while concurrently providing scientific rationale. This approach facilitates a bridge between cultural understanding and evidence-based medical practice, allowing for the effective prescription of routine care within culturally diverse contexts (32).

Culturally sensitive communication is effective in promoting health behavior change. A systematic review of culturally sensitive interventions found that these interventions were effective in promoting physical activity, healthy eating, and tobacco cessation. Using language and symbols familiar to the patient can help promote understanding and adherence to health messages. This may involve the use of local dialects and visual aids that are tailored to the cultural background of the patient (32).

Several strategies can be implemented to facilitate culturally sensitive communication. Awareness of one's own culture, including an understanding of one's own cultural beliefs, attitudes, values, and practices, is crucial. This is particularly significant in Indonesia, with its diverse ethnic composition that requires greater interpersonal cultural awareness associated with patient and family satisfaction. Clinicians are more likely to deliver personalized and culturally sensitive care to patients by enhancing their comprehension of diverse cultures, including values, attitudes, and beliefs. This initial step necessitates self-awareness to mitigate the risk of overgeneralization and stereotyping of cultures (32).

Establishing open and sensitive communication is essential, incorporating active listening and respect for an individual's cultural beliefs and practices. This approach fosters a therapeutic relationship built on trust and respect. It also aids in collaborating on treatment strategies with the patient and family in decision-making regarding healthcare (32).

Another strategy involves prioritizing cultural consideration in the planning and provision of care. Clinicians can achieve this by asking culturally sensitive questions about the patient's and family's

values, beliefs, and practices. This includes exploring their beliefs associated with the presenting illness and assessing the individual's psychological and sociocultural needs, such as secondary languages, religion, and food preferences (32).

### 3.3 Patient education

Patient education is important for promoting health behavior change. Patients who are informed about their health condition and the importance of health behavior change are more likely to take an active role in their healthcare and make positive changes to their health behaviors. Patient education can also help to overcome cultural barriers to health behavior change. For example, the coexistence of traditional healers and Western medicine doctors in Indonesia reflects the country's rich cultural and healthcare landscape. Both systems play significant roles in addressing the health needs of the population, including patient education. People often navigate between the two based on accessibility, personal beliefs, cultural preferences, and the nature of their health conditions. In some cases, collaboration between traditional healers and Western medicine practitioners is becoming more common, especially in addressing chronic conditions or complex health issues such as diabetes, hypertension, maternal mortality, and promoting health behavior change (33).

Research conducted regarding culture-based patient education among the Makassarese People in South Celebes, Indonesia, found that integrating educational materials into the local Makassarese language and modifying intervention programs to suit local culture, for example, using local produce and foodstuffs, has been effective in diet modification and reducing blood sugar levels in people with diabetes (34). Storytelling methods, such as using Wayang (Indonesian traditional puppets) and folk stories, also effectively promoted tobacco cessation, drug abuse prevention, and a healthy lifestyle in adolescents (35). Another study about collaborative programs between local health services and community and religious leaders in Central Java has also shown to promote medication adherence and improve health outcomes in individuals with diabetes mellitus (36).

Using visual aids, such as diagrams and charts, can enhance the understanding of health messages, especially in rural societies with low literacy rates. Health communication in the local language is crucial for effective communication. In Indonesia, utilizing local languages in health communication materials can bridge the communication gap and empower patients to better understand their health conditions and treatment options (37).

Tailoring patient education to the patient's needs, by using language and symbols familiar to the patient and presenting information in a format that is easy to understand, promotes better understanding and adherence to health messages. Additionally, tailoring education to the patient's culture by designing health education materials that are culturally relevant to the Indonesian context can improve health literacy and empower patients to make informed decisions about their health (37).

Providing ongoing patient education and support is vital for reinforcing health messages and promoting long-term behavior change. This may involve follow-up visits, telephone calls, or text messages. Another strategic approach is the use of social media, given its pervasive reach across urban and rural landscapes. Leveraging social media involves collaborating with influential figures who serve as role models



for promoting healthy lifestyles. Engaging these influencers in advocating and exemplifying healthful behaviors enhances visibility and fosters credibility and resonance among the younger demographic, significantly influencing health behavior modification initiatives (37).

An essential consideration for clinicians involves being attuned to patients' comprehension after disseminating medical information. Cultural perception is a significant filter, and in our clinical experience, neglecting to assess patient understanding can yield detrimental outcomes. Certain terms, such as '*cuci darah*' (hemodialysis), may evoke considerable fear, leading to the refusal of crucial life-saving treatments. Moreover, initial resistance, particularly regarding invasive procedures or interventions affecting reproduction in women, often necessitates a nuanced approach. Decision-making processes frequently involve the individual, their male partners, and extended family, highlighting the collective nature of decision-making in contrast to the Western perception of autonomy. Addressing these dynamics requires a dialectical approach within clinical interactions (38).

### 3.4 Behavior modification techniques

Behavior Modification Techniques (BMT) are an essential component of health behavior change. They involve using rewards and incentives to promote positive health behavior change (13). BMT is important for promoting health behavior change, particularly for behaviors such as smoking, poor diet, and lack of physical activity, which are often difficult to change. BMT can provide incentives and rewards that motivate individuals to positively change their health behaviors, and they can also help overcome cultural barriers to health behavior change. For example, in some cultures, seeking medical care may be viewed as a sign of weakness, and traditional healers may be preferred over Western medicine. BMT can help overcome this barrier, by giving incentives to motivate the community to change their views (13, 39).

Facilitating the establishment of social support is another effective strategy. Social support through peer support groups and other social networks can reinforce positive health behaviors and incentivize behavior change. In our experience, empowering patients and their families to join a group with a similar context, not necessarily a similar diagnosis, and facilitating them to lead and support each other has proven effective. A clinician-centered group may not be sustainable in the long run, and patient and family-led groups are often more effective based on our observations (39).

Utilizing technology, such as mobile phones, social media, and disease-specific web-based or mobile applications, can provide incentives and rewards for behavior change. Technology can offer reminders, feedback, and other incentives for positive health behaviors. For instance, a web-based application has been developed to assist patients, families, and cadres in monitoring the symptoms of schizophrenia and ensuring medication adherence. Another mobile application was also found to be effective in promoting physical activity, healthy eating, and tobacco cessation (39).

## 4 Discussion

Patient-centered, culturally sensitive healthcare is essential in healthcare delivery, particularly in low- and middle-income

countries (LMICs). This literature review highlights the importance of patient-centered, culturally sensitive healthcare in promoting health behavior change in LMICs. Health behavior change is a critical aspect of healthcare delivery, especially in LMICs with a high burden of preventable diseases. It refers to adopting healthy behaviors and ceasing unhealthy ones. Patient-centered, culturally sensitive healthcare can promote health behavior change in LMICs by addressing cultural barriers to behavior change.

Healthcare providers need to understand and appreciate the cultural diversity of their patients to provide appropriate care that addresses cultural barriers to behavior change. Studies have shown that culturally appropriate health education and counseling are associated with improved health behavior change. Healthcare providers who understand and appreciate cultural beliefs can provide appropriate health education and counseling that resonates with patients' cultural beliefs. This can lead to improved patient satisfaction, adherence, and health outcomes.

Future research endeavors should prioritize the development of culturally tailored health education and counseling interventions to drive health behavior change within LMICs. A crucial aspect involves crafting interventions that align with patients' cultural beliefs, practices, and values. Active engagement of patients and community members in formulating these interventions is fundamental. Culturally appropriate interventions bear the potential to foster meaningful health behavior changes, thereby contributing to enhanced health outcomes. Additionally, research efforts should explore optimal methodologies for training future clinicians, especially within the primary care sector, spanning undergraduate, postgraduate, and continuing medical education (CME) frameworks.

## 5 Conclusion

Patient-centered, culturally sensitive healthcare is an approach that considers the patient's cultural background and tailors healthcare services to meet the patient's needs. This approach is particularly important in low- and middle-income countries (LMICs), where cultural beliefs and practices can significantly impact health behaviors and outcomes. Strategies that can effectively promote health behavior change in these settings include community-based interventions, culturally sensitive communication, patient education, and behavior modification techniques.

## 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.

## Author contributions

DC: Conceptualization, Writing – original draft, Writing – review & editing, Project administration, Supervision. DA:

Conceptualization, Writing – original draft. AT: Conceptualization, Data curation, Project administration, Writing – original draft. AU: Conceptualization, Writing – original draft. HH: Conceptualization, Writing – original draft. DW: Supervision, Writing – review & editing. NR: Project administration, Writing – review & editing. MH: Conceptualization, Project administration, Writing – review & editing. NL: Conceptualization, Supervision, Writing – review & editing.

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# Assessing patient satisfaction among COVID-19 survivors in Northeast India: a cross-sectional study

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**Introduction:** This study investigates patient satisfaction among COVID-19 survivors in Northeast India, motivated by the unique long-term healthcare needs of survivors and the critical role of patient satisfaction in assessing and enhancing healthcare quality. By focusing on this underexplored region, the research aims to uncover insights that can guide improvements in patient-centered care and healthcare service delivery in similar contexts.

**Materials and methods:** The study was conducted using a Simple Random Sampling technique. Data were collected through telephone interviews using a semi-structured questionnaire, including the Patient Satisfaction Questionnaire-18 (PSQ-18) for analysis. The PSQ-18 yielded seven subscale scores representing different dimensions of patient satisfaction. Statistical analysis using SPSS software was conducted to summarize socio-demographic characteristics, medical history, and patient satisfaction levels, employing both descriptive and inferential statistics.

**Result:** The results indicated a high acceptance of COVID-19 vaccination, with the majority of participants having received both doses. Patient satisfaction with healthcare services is generally positive, particularly in aspects related to doctor-patient communication and medical care quality. However, there are notable concerns regarding the affordability and timeliness of care. Regional variations across states, as well as factors like education and income, significantly influence patient satisfaction levels.

**Conclusion:** The study revealed generally good patient satisfaction levels in Northeast India. However, challenges in healthcare affordability and timeliness persist, influenced by regional disparities and socio-economic factors. Targeted interventions are needed to improve healthcare in the region.

## KEYWORDS

patient satisfaction, COVID-19 survivors, healthcare services, Northeast India, healthcare delivery

## 1 Introduction

The COVID-19 pandemic has not only reshaped healthcare delivery and patient experiences globally but has also brought to the forefront the critical importance of patient satisfaction as a cornerstone of healthcare quality (1, 2). This is particularly relevant in regions like Northeast India, where the healthcare landscape was already fraught with challenges even before the onslaught of the pandemic. The area has long grappled with issues such as inadequate healthcare infrastructure, limited medical facilities, and a scarcity of healthcare professionals, which have compounded the difficulties faced by patients in accessing quality care (3).

These pre-existing challenges in Northeast India's healthcare system underscore the need for a nuanced understanding of patient satisfaction, especially in the wake of COVID-19. The pandemic added layers of complexity to an already strained system, making the assessment of patient satisfaction among COVID-19 survivors not just a measure of healthcare quality but a critical indicator of the system's capacity to withstand and adapt to unprecedented crises. In this context, patient satisfaction serves as a lens through which the resilience, adaptability, and responsiveness of healthcare services to the heightened demands of a global health emergency can be evaluated (4).

The scarcity of studies specifically focusing on the experiences of COVID-19 survivors in India's intricate socio-cultural and healthcare setting highlights a significant gap in the literature. This gap is more pronounced in the context of Northeast India, where the unique confluence of socio-economic, geographical, and cultural dynamics necessitates a tailored approach to healthcare satisfaction research. Such an approach is vital not only for enhancing the understanding of healthcare quality in the region but also for informing policy-making that prioritizes patient-centric care in the aftermath of the pandemic (5).

The distinct challenges and experiences faced by COVID-19 survivors in Northeast India, ranging from the struggle to access overstretched healthcare services to navigating the socio-cultural nuances of illness and recovery in a region with diverse ethnicities and traditions, demand an in-depth exploration. This exploration is crucial for unveiling the layers of patient satisfaction and the multifaceted interactions between patients and the healthcare system during and after the pandemic (6).

This study, by focusing on the comprehensive assessment of patient satisfaction among COVID-19 survivors in Northeast India, aims to address these critical issues. It intends to employ a cross-sectional research design and use validated assessment tools to examine various dimensions of patient satisfaction, including but not limited to, overall satisfaction with care, the technical quality of healthcare services, interpersonal interactions with healthcare providers, and accessibility to medical facilities. The outcomes of this study are anticipated to contribute significantly to the existing body of knowledge, providing evidence-based insights that can guide the enhancement of healthcare delivery in the region.

Furthermore, by spotlighting patient satisfaction among COVID-19 survivors in Northeast India—a region already burdened with healthcare challenges prior to the pandemic—this research endeavors to fill a notable void in existing studies. It aims to offer a detailed examination of patient experiences and satisfaction levels, thereby facilitating the development of healthcare practices and

policies that are not only effective but also culturally and socially attuned to the unique needs and challenges of the region in the post-pandemic era.

## 2 Materials and methods

The primary objective of this cross-sectional study is to evaluate patient satisfaction among COVID-19 survivors in the Northeast State of India. In the context outlined in the introductory section, our study focused on the Northeast region of India, a region where healthcare infrastructure is notably under-researched. This discrepancy has led to uneven and often unsatisfactory improvements in healthcare infrastructure. The COVID-19 pandemic further underscored these challenges, underscoring the importance of assessing patient satisfaction, levels related to the healthcare delivery in these states. The study was conducted from February and August, 2023. During this period, the pandemic's dynamics, including the emergence of new variants, changes in transmission rates, and the impact of vaccination campaigns have evolved significantly. This allows for a comprehensive understanding of patient satisfaction across different epidemiological situations and thus providing insights into how these changes influence patient satisfaction.

The study population consisted of individuals aged 18 and above who were hospitalized for COVID-19 treatment in the Northeast State of India and were subsequently discharged. Participants were included if they provided informed consent, were residents of the Northeast State, and were above 18 years of age at the time of their hospital admission. Exclusion criteria included those who did not provide informed consent, were under 18 years of age at the time of admission, were deceased, or were residents of other states in India.

The study received ethical approval from the University of Amity Institutional Review Board (IRB No. AUUP/IEC/MAY/2023/4).

### 2.1 Study population and sampling technique

In this study, among the 4,500 participants approached, a total of 2,000 respondents completed the questionnaire, resulting in a response rate of 44.4%. We aimed for a 95% confidence level with a 0.5 standard deviation and a 5% margin of error, leading to an initial sample size of 385 per state, across 7 states, totaling 2,695 respondents. However, due to higher-than-expected non-response rates, we adjusted our target and concluded the study with 2,000 respondents, ensuring the study's integrity and reliability despite the challenges.

The selection process involved a carefully compiled list of discharged COVID-19 patients, ensuring each individual had an equal chance of being selected, in line with simple random sampling principles. Participants were recruited through a telephonic survey, where they were thoroughly briefed on the study's objectives and ethical considerations, including the significance of their participation. To maintain a uniform and accessible informed consent process through the telephonic survey, verbal consent was obtained from all participants. This approach was aimed to accommodate all participants, ensuring clear understanding and voluntary participation.

## 2.2 Data collection tool

A semi-structured questionnaire was prepared and divided into five segments: socio-demographic profile, medical history, vaccination status, details of hospitalization, and the Patient Satisfaction Questionnaire-18 (PSQ-18). The socio-demographic profile included details such as age, gender, household income, etc., whereas the section medical history included questions addressing pre-existing co-morbidity disorders and family medical history. Vaccination status included the details as to if the respondents were vaccinated and reasons for non-vaccination. Details of hospitalization included questions about the type of hospital and the duration of the hospital stay. The PSQ-18 is a validated instrument developed by Grant N. Marshall and Ron D. Hays in 1994, and it employs a 5-point Likert scale ranging from “Strongly Agree” to “Strongly Disagree.” This tool is globally recognized for its efficacy in measuring patient satisfaction, allowing for the results to be compared and accepted by the international research community (7). The PSQ-18 section of the questionnaire consisted of 18 items related to general satisfaction, technical quality, interpersonal manner, communication, financial aspects, time spent with doctor, accessibility, and convenience.

To enhance accessibility, the questionnaire was available in English and Hindi, respecting regional linguistic preferences. Primarily conducted in English, provisions were made for Hindi-speaking respondents to ensure inclusivity. The questionnaire's validity was ensured through a rigorous translation and back-translation process by independent experts.

We have defined key variables to comprehensively assess patient satisfaction among COVID-19 survivors in Northeast India. Patient Satisfaction, our primary variable, is gauged through individuals' perceived quality of care and services received during their hospitalization for COVID-19. This includes evaluating technical quality, interpersonal manner, communication, accessibility, and convenience, as measured by the Patient Satisfaction Questionnaire-18 (PSQ-18). The Healthcare Delivery Context variable captures the conditions and infrastructure surrounding healthcare service provision, such as hospital type, infrastructure quality, and healthcare provider availability. Patient Demographics are considered to include age, gender, household income, and other socio-demographic factors that could influence satisfaction levels. Furthermore, Vaccination Status is scrutinized to understand if pre-hospitalization COVID-19 vaccination, including the number of doses and vaccine type, impacts patient satisfaction. Medical History is also a critical variable, encompassing pre-existing comorbidities and health conditions that might influence a patient's experience and satisfaction during hospitalization. These variables are framed within the Patient Satisfaction Model, which theorizes that satisfaction is influenced by the quality of healthcare delivery, patient-provider interactions, and the healthcare environment, with our study extending this model to incorporate the unique challenges posed by the COVID-19 pandemic in the context of Northeast India.

The inclusion of these particular variables—Patient Satisfaction, Healthcare Delivery Context, Patient Demographics, Vaccination Status, and Medical History—is crucial for providing a holistic understanding of the factors that influence patient satisfaction. These variables were carefully chosen to capture a comprehensive view of the patient experience, recognizing that satisfaction is not only a reflection of the immediate healthcare services received but also influenced by

broader contextual factors such as demographic characteristics, the patient's health background, and their vaccination status. This multi-dimensional approach is essential for identifying actionable insights that can improve healthcare delivery and patient experiences, especially in the challenging context of a global pandemic.

For assessing the questionnaire's internal consistency, a Cronbach's alpha coefficient of 0.96 was computed, indicating a high level of reliability.

Data was collected via telephone interviews, where the questionnaire was administered to the participants. All data will be anonymized to maintain confidentiality and will be stored securely.

## 2.3 Patient satisfaction outcomes/scoring

In the analysis of the Patient Satisfaction Questionnaire-18 (PSQ-18), the instrument was scored to yield seven distinct subscale scores, each representing a different dimension of patient satisfaction. These dimensions include General Satisfaction, Technical Quality, Interpersonal Manner, Communication, Financial Aspects, Time Spent with Doctor, and Accessibility and Convenience. It is noteworthy that the PSQ-18 contains items phrased both positively and negatively to capture varying levels of satisfaction or dissatisfaction. Regardless of the phrasing, all items were scored in a manner that a higher score consistently indicated greater satisfaction with medical care. Following the item-level scoring, the responses within each of the seven subscales were averaged to generate the respective subscale scores. In essence, each subscale score represents the mean score of all answered items within that specific dimension. This scoring methodology represent the average for all items in the scale that were answered.

In our study, we have identified patient satisfaction as the primary outcome of interest. The constructs of General Satisfaction, Technical Quality, Interpersonal Manner, Communication, Financial Aspects, Time Spent with Doctor, and Accessibility and Convenience were defined as exposure variables within the framework of this study. Additionally, demographic and socio-economic covariates, including age, gender, and socioeconomic status, were analyzed to ascertain their potential influence on the variability observed in patient satisfaction metrics.

## 2.4 Data analysis

Statistical analyses were conducted on the 2,000 collected data using SPSS software. Initial steps involved descriptive statistics to outline the basic features of the participants' socio-demographic information, medical history, and their satisfaction with healthcare services. Further, inferential statistics were employed to discern patterns and significant connections in the data. Chi-square test was performed to assess the influence of various factors on patient satisfaction.

## 3 Results

The demographic analysis of our participant pool highlights significant diversity and varying characteristics. Predominantly, the age distribution skewed toward younger adults, with significant representation in the 18–25 and 26–33 age brackets. Gender distribution was notably skewed, with a higher proportion of male

TABLE 1 Socio-demographic characteristics of the study participants.

	Variables	No. of participants	Percentage (%)
Age	<18 years	4	0.2
	18–25	290	14.5
	26–33	567	28.4
	34–40	401	20.1
	41–47	279	14
	48–55	201	10.1
	56–63	140	7
	>63 years	118	5.9
Gender	Female	481	24.1
	Male	1,517	75.9
	Others	2	0.1
Marital status	Married	1,532	76.6
	Single	454	22.7
	Divorced/Widowed	14	0.7
Religion	Hindu	1,752	87.6
	Muslim	146	7.3
	Sikhs	22	1.1
	Christian	60	3
	Buddhism	6	0.3
	Others	14	0.7
Education	Illiterate/uneducated	106	5.3
	Secondary	190	9.5
	Higher secondary	300	15
	Graduate	1,019	50.9
	Post-graduate and above	385	19.3
Occupation	Unemployed	108	5.4
	Student	106	5.3
	Security guards	2	0.1
	Police	14	0.7
	Healthcare workers	311	15.6
	Others	1,459	73
Employment sector	Government	532	26.6
	Private	840	42
	Self-employed	402	20.1
Household income (INR)	Less than 50,000	112	5.6
	50,000–1.5 lac	432	21.6
	1.6 lac-2.5 lac	719	35.9
	2.6 lac and above	737	36.9

participants. A considerably high number of the respondents were married, and the predominant religion among participants was Hinduism, followed by other religions including Islam, Sikhism, Christianity, and Buddhism in smaller proportions.

Educational status among participants varied widely, yet a significant portion held graduate degrees. The occupational background was diverse, with a notable percentage of participants

working in the healthcare sector. Most of the participants were employed in the private sector, reflecting a range of employment sectors within the study population. Household income levels were diverse, indicating a broad socio-economic representation among the participants (Table 1).

Geographical distribution of the study participants showed a notable variance across regions, with Assam leading in participant

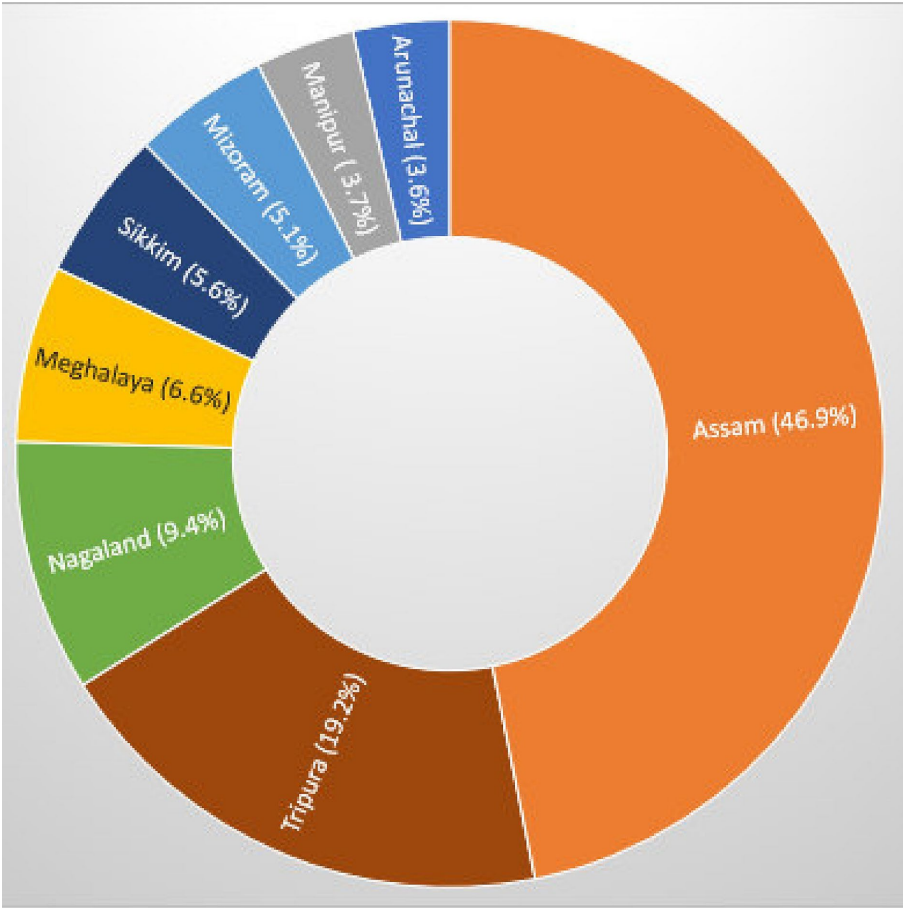


FIGURE 1  
State-wise distribution of study participants.

TABLE 2 Habits, pre-existing co-morbidities and family history of the study participants.

Variables			No. of participants	Percentage (%)
Habits	Use of alcohol	Current user	255	12.8
		Past user	68	3.4
		Never used	1,677	83.9
	Use of tobacco	Current user	220	11
		Past user	44	2.2
		Never used	1,736	86.8
Pre-existing co-morbidities		Yes	341	17.1
		No	1,659	83
Family medical history		Yes	323	16.1
		No	1,677	83.9

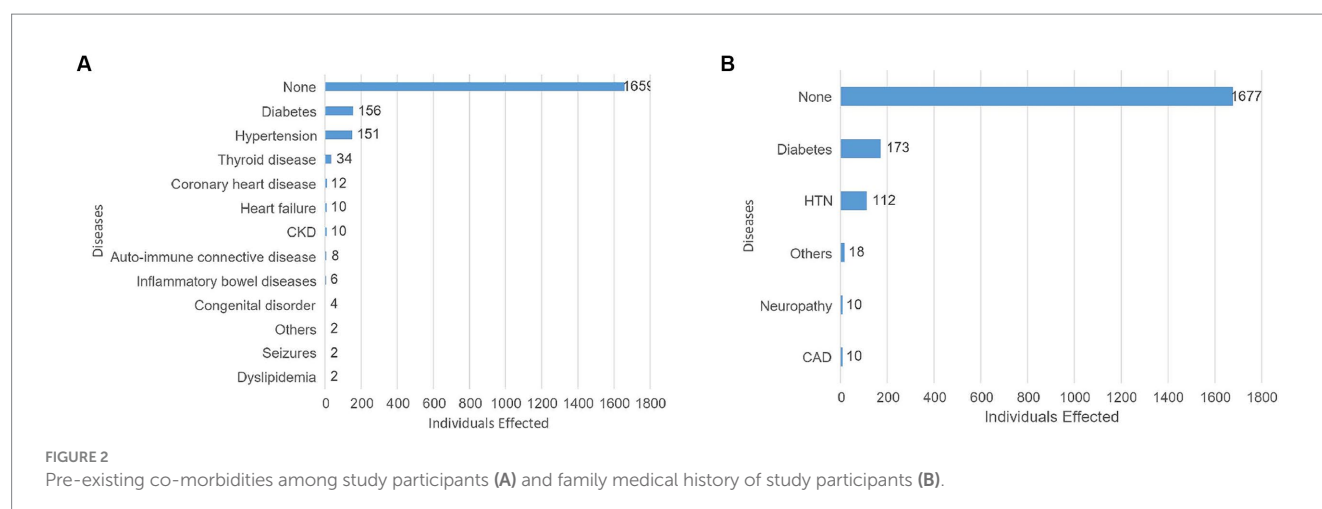
representation, followed by a significant number from Tripura. Contributions from smaller states such as Manipur, Arunachal, and Sikkim were comparatively minimal (Figure 1).

Table 2 presents an overview of health-related behaviors and conditions among participants. It highlights the prevalence of alcohol and tobacco use, with most of those indicating no history of use in both categories. Additionally, the table details the presence of pre-existing co-morbidities and family medical history of diseases,

showing a larger proportion of participants without such conditions or histories.

The most common co-morbidities among the study participants were Diabetes and Hypertension. However, the vast number of participants, reported having no pre-existing conditions at all. Diabetes was also the most commonly reported family medical history condition, followed by Hypertension (HTN). However, a overwhelming number indicated that they have had no family history of medical conditions (Figure 2).





The study revealed valuable insights about the COVID-19 vaccination status and related factors among the study's participants. Notably, a significant proportion of participants had received their first dose of the COVID-19 vaccine. Additionally, a substantial portion had also completed their second dose. For the minority who had not been vaccinated, reasons ranged from a perceived lack of necessity to vaccine unavailability and medical contraindications. Geographic analysis revealed variations in vaccination rates across different states, with Arunachal Pradesh, Meghalaya, and Mizoram showing higher rates compared to Assam and Tripura (Table 3 and Figure 3).

The analysis of healthcare settings indicated that a large number of participants were treated in government hospitals, followed by private and semi-government facilities. The duration of hospital stays also showed a range, with many participants having shorter stays of less than 1 week, and a decreasing proportion staying for longer periods, up to more than 3 weeks.

The study also provides information on post-COVID-19 complications. While a significant number of the study participants reported no complications following recovery, a subset experienced various issues, including acute cardiac injury, acute respiratory failure, mental health challenges such as anxiety and depression, respiratory symptoms like asthma and chest pain, chronic fatigue, gastrointestinal problems, pneumonia, and loss of smell (Table 3).

The most frequently reported clinical symptom combination was "Cough, Sore throat, Fever." This was followed by "Cough, Fever" and isolated "Fever." Interestingly, a significant portion of the study population reported experiencing no symptoms (Figure 4).

The study analyzed the relationship between how patients are distributed across the eight northeastern states and the different types of hospitalizations, and the results were found to be statistically significant (Figure 5).

Based on the responses to the Short-Form Patient Satisfaction Questionnaire (PSQ-18), most patients had a positive perception of their medical care. They felt doctors explained medical tests well, their doctor's office was well-equipped, and the care they received was almost perfect. However, financial concerns and long wait times for emergency treatment were areas of concern. Additionally, some patients felt doctors were impersonal or ignored their concerns,

indicating room for improvement in doctor-patient interactions (Table 4).

Table 5 demonstrates the PSQ-18 Sub-Scale Scores that provide a concise overview of patient satisfaction in various healthcare aspects. Patients reported an average score of 4 for General Satisfaction, Technical Quality, Interpersonal Manner, Communication, Financial Aspects, Time Spent with Doctor, and Accessibility and Convenience. This suggests an overall positive perception of healthcare experiences across these dimensions.

Figure 6 elucidates the relationship between COVID-19 vaccination and patient satisfaction across multiple healthcare dimensions. High levels of satisfaction were observed in domains such as doctor-patient communication and medical care quality, with over 80% of participants agreeing or strongly agreeing. However, significant dissatisfaction was noted in areas like affordability and timeliness of care, where over 75% disagree or strongly disagree. Most observations were statistically significant with *p*-values below 0.05.

The study also examined the relationship between participants' education status, household income, and states of residence in relation to patient satisfaction with various aspects of medical care using a chi-square test. The analysis showed significant variations across education, income, and states (Table 6). Upon analyzing the association between hospital type, patient stay duration, and patient satisfaction, findings consistently indicated high patient satisfaction across hospital types and stay durations, with almost all *p*-values showing strong statistical significance (Table 7).

## 4 Discussion

The results of this study provide valuable insights into the demographics, health-related variables, COVID-19 vaccination status, healthcare settings, post-COVID-19 complications, and patient satisfaction among participants in Northeast India. In the forthcoming discussion, the implications and significance of these findings are discussed.

The study's diverse sample population, comprising a large portion of the participants in the 26–33 age bracket, with fairly balanced gender distribution, revealed nuanced insights into patient satisfaction. A significant proportion of married

TABLE 3 Vaccination status and hospitalization details of the study participants.

Variables		No. of participants	Percentage (%)
Received COVID-19 vaccine (Dose 1)	Yes	1,934	96.7
	No	66	3.3
Received COVID-19 vaccine (Dose 2)	Yes	1,892	94.6
	No	108	5.4
If no, reason for not receiving the vaccine	Didn't feel the need to get vaccinated	56	28
	Fear of side effects	4	0.2
	Unavailability of vaccine	24	1.2
	Medical conditions	20	1
	Not aware about the vaccine	4	0.2
Type of hospital	Government	1,304	65.2
	Private	640	32
	Semi-government	56	2.8
Duration of stay in the hospital	<1 week	715	35.8
	1 week	522	26.1
	2 weeks	400	20
	3 weeks	293	14.7
	>3 weeks	70	3.5
Post COVID-19 complications	Acute cardiac injury	22	1.1
	Acute respiratory failure	26	1.3
	Anxiety, depression	72	3.6
	Asthma, breathlessness, chest pain	74	3.7
	Chronic fatigue, excessive weakness, excessive weight loss	74	3.7
	GI problems	18	0.9
	Pneumonia	40	2
	Loss of smell	28	1.4
	None	1,646	82.3

participants had distinct healthcare expectations compared to single individuals or divorced/widowed participants. A predominant number of the study participants identified as Hindus, followed by Muslims, which illustrated the cultural diversity that might have influenced healthcare practices and preferences (8). Education levels varied, with graduates forming the largest group and a smaller but significant portion being illiterate or uneducated, potentially impacting health literacy and healthcare decision-making (9). The occupation mix, including healthcare workers and others, suggested differences in healthcare perspectives, while the predominance of participants from the private sector highlighted potential variations in healthcare access and coverage compared to government and self-employed individuals (10). The household income distribution, with a substantial portion earning 2.6 lac and above, indicated potential disparities in affordability and access to healthcare services (11). These socio-demographic variables collectively contribute to a comprehensive understanding of how patient satisfaction may vary across distinct demographic groups within Northeast India's population.

The study's findings indicated a noteworthy and positive trend in COVID-19 vaccination among participants in Northeast India, with a substantial majority having received the vaccine, both the first and the second dose. This high vaccination rate of the study participants underscored the success of widespread vaccination efforts in the region, contributing to community-level immunity against the virus (12). However, it is equally vital to examine the reasons behind the comparatively lesser number of those participants who had not received their first dose and the second dose. The data revealed that reasons for non-vaccination included concerns about perceived need, fear of side effects, vaccine unavailability, medical conditions, and a lack of awareness about the vaccine. Addressing these concerns and barriers is imperative to further enhance vaccination rates and ensure that a larger proportion of the population is protected against COVID-19. By understanding these reasons, public health strategies can be refined to provide targeted information, resources, and support to address hesitancy and improve vaccine accessibility, ultimately contributing to the region's overall health and safety.

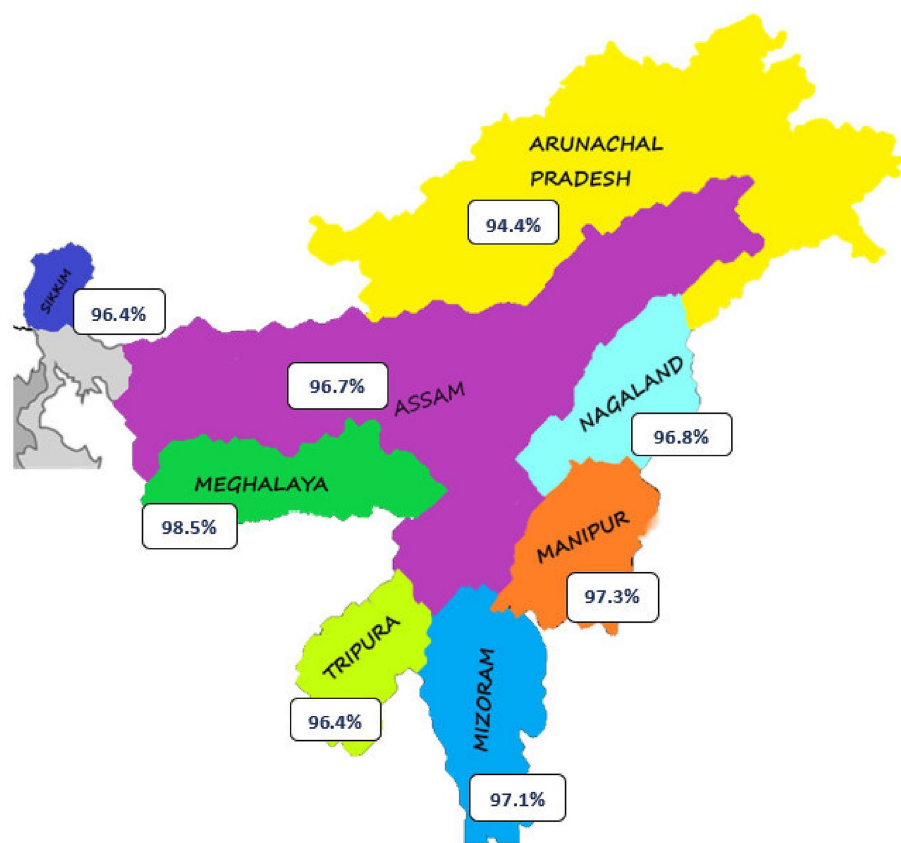


FIGURE 3  
COVID-19 vaccination status across 8 north-eastern states as per the study findings.

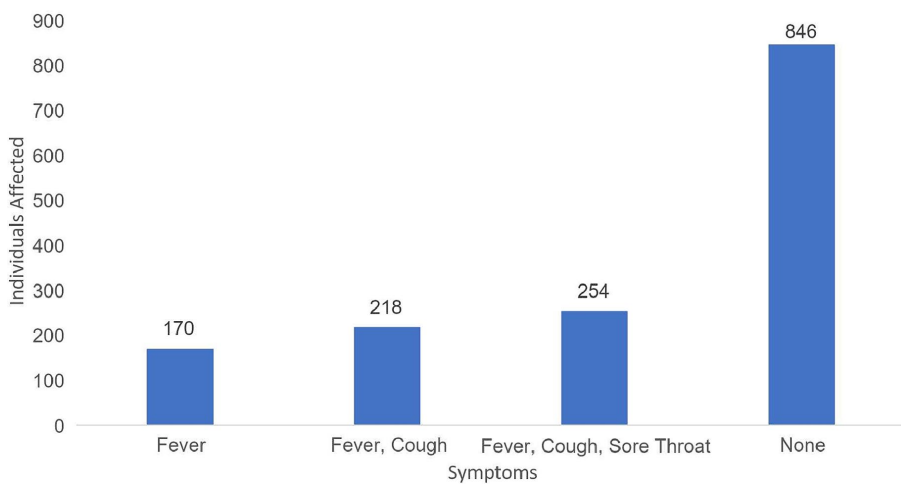
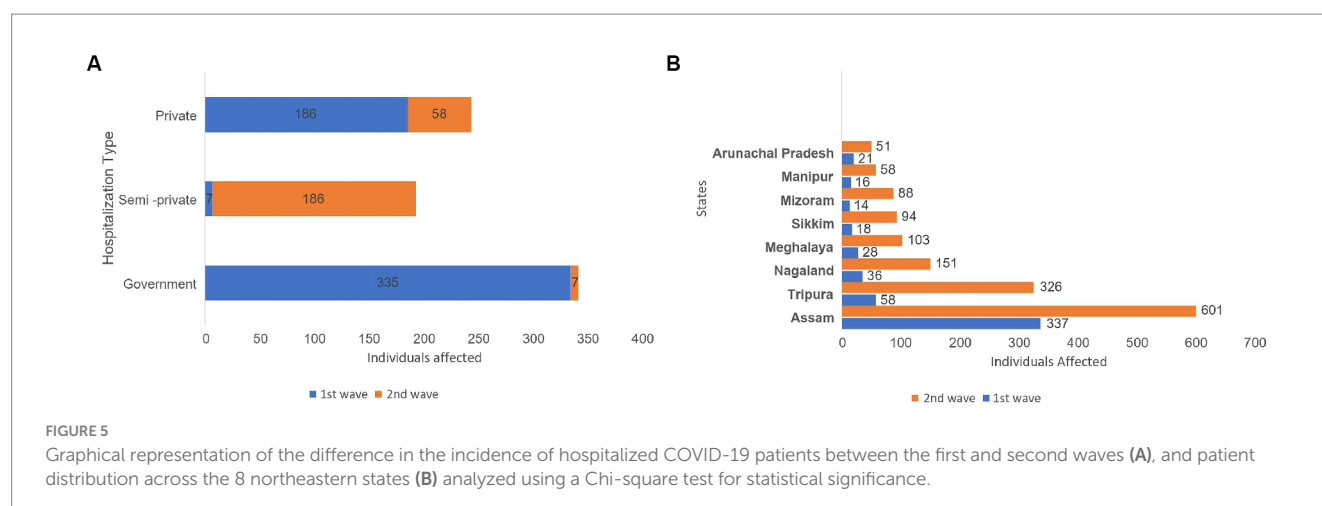


FIGURE 4  
Major clinical symptoms reported in the study participants.

The study’s findings on post-COVID-19 complications underscored the diverse and multi-faceted health impacts experienced by the COVID-19 survivors in Northeast India. Notably, participants reported a range of complications, with a significant number of those reporting no post-COVID-19 complications, indicating that a substantial portion of survivors

did not experience additional health issues after recovering from the virus. However, the data also revealed specific complications affecting some participants, including acute cardiac injury, acute respiratory failure, anxiety and depression, asthma, breathlessness, and chest pain, chronic fatigue, excessive weakness, weight loss, GI problems, pneumonia, and loss of



smell. These findings highlighted the need for healthcare providers to be prepared to address a wide range of post-COVID-19 complications, providing tailored care and support to those who require it (13). Additionally, ongoing research and monitoring of these complications can contribute to a better understanding of the long-term health effects of COVID-19 and inform strategies for comprehensive post-recovery care in the region.

The distribution of participants across various healthcare settings provided valuable insights into the accessibility and utilization of healthcare services in Northeast India. Notably, a vast number of the participants received treatment in government hospitals, which suggested a significant reliance on government healthcare facilities, possibly influenced by factors like affordability and perceived quality of care (14). Additionally, the study found a notable variation in the duration of hospital stays, with majority staying for less than 1 week, and only a small percentage of the participants stayed for more than 3 weeks. These varying hospitals stay durations can be attributed to the severity of COVID-19 cases, the healthcare infrastructure's capacity, and individual patient needs. Understanding the factors driving these choices and durations is vital for healthcare planning and resource allocation, ensuring that healthcare services can effectively cater to the diverse needs of the population while maintaining high-quality care and accessibility.

The analysis of patient satisfaction using the PSQ-18 questionnaire offered a comprehensive understanding of the healthcare experiences of participants in Northeast India with a large number of the participants expressing overall high satisfaction, with positive perceptions in areas such as doctor-patient communication and medical care quality where most of the participants agreed or strongly agreed with the provided statements. This finding reflected the commendable efforts of healthcare providers in delivering effective and informative care. However, areas of concern emerged, including financial aspects and long wait times for emergency treatment, where most of the participants disagreed or strongly disagreed. These findings highlighted the need for strategies to address financial barriers and reduce wait times to enhance overall satisfaction. Additionally, some participants reported feeling that doctors

were impersonal or ignored their concerns, indicating room for improvement in doctor-patient interactions. Strengthening these interactions can contribute to a more holistic and patient-centered healthcare experience, ultimately fostering higher satisfaction levels among COVID-19 survivors in the region (15).

The study's analysis of factors influencing patient satisfaction, including education status, household income, and states of residence, offered valuable insights into the determinants of healthcare experiences among COVID-19 survivors in Northeast India. On examining the data, it became evident that these demographic and regional factors significantly correlated with satisfaction levels. For instance, participants with higher education levels reported higher satisfaction scores, with those in the "graduate" category notably comprising the majority. Similarly, household income played a role, with a substantial portion reporting incomes of 2.6 lac and above expressing higher satisfaction levels. Additionally, variations across states of residence were observed, suggesting that regional differences may influence patient satisfaction. These results reflect the necessity of customizing healthcare policies and services to accommodate the distinct requirements and preferences of various demographic groups and regions, with the ultimate goal of enhancing healthcare experiences in an equitable manner for all.

The consistently high levels of patient satisfaction observed across various hospital types and lengths of hospital stays in Northeast India was a reassuring finding. It suggested that patients tend to receive satisfactory care irrespective of whether they seek treatment in government hospitals, private hospitals, or semi-government hospitals. Furthermore, the diverse duration of hospital stays demonstrated that patients experience high satisfaction levels regardless of how long they are hospitalized. These results indicate that healthcare quality is maintained consistently across different healthcare settings and durations of care, emphasizing the region's commitment to providing satisfactory healthcare services to its population, regardless of where and for how long treatment is sought.

Based on these findings, several implications for healthcare policy and practices can be drawn:

**Improving Doctor-Patient Interactions:** Efforts should be made to enhance doctor-patient communication and address patient concerns

TABLE 4 Short-form Patient Satisfaction Questionnaire (PSQ-18).

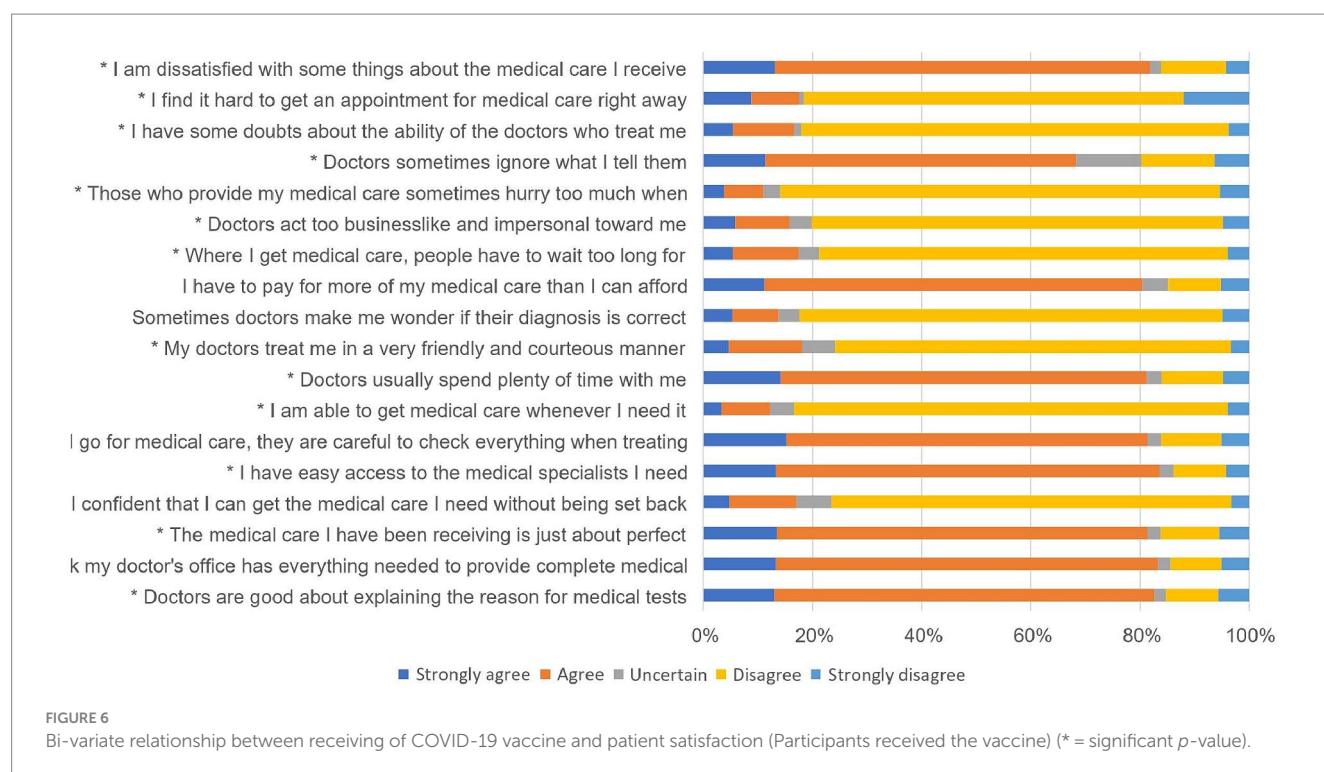
Questions (Item numbers)	Strongly agree	Agree	Uncertain	Disagree	Strongly disagree	Original response value	Scored value
1. Doctors are good about explaining the reason for medical tests.	261 (13.1%)	<b>1,382 (69.1%)</b>	40 (2.0%)	202 (10.1%)	115 (5.8%)	2	4
2. I think my doctor's office has everything needed to provide complete medical care.	272 (13.6%)	<b>1,385 (69.3%)</b>	44 (2.2%)	200 (10.0%)	99 (5.0%)	2	4
3. The medical care I have been receiving is just about perfect.	274 (13.7%)	<b>1,349 (67.5%)</b>	46 (2.3%)	225 (11.3%)	106 (5.3%)	2	4
4. Sometimes doctors make me wonder if their diagnosis is correct.	96 (4.8%)	246 (12.3%)	126 (6.3%)	<b>1,464 (73.2%)</b>	68 (3.4%)	4	4
5. I feel confident that I can get the medical care I need without being set back financially.	268 (13.4%)	<b>1,394 (69.7%)</b>	50 (2.5%)	202 (10.1%)	86 (4.3%)	2	4
6. When I go for medical care, they are careful to check everything when treating and examining me.	304 (15.2%)	<b>1,317 (65.9%)</b>	48 (2.4%)	229 (11.5%)	102 (5.1%)	2	4
7. I have to pay for more of my medical care than I can afford.	64 (3.2%)	183 (9.2%)	84 (4.2%)	<b>1,589 (79.5%)</b>	80 (4.0%)	4	4
8. I have easy access to the medical specialists I need.	284 (14.2%)	<b>1,333 (66.6%)</b>	54 (2.7%)	233 (11.7%)	96 (4.8%)	2	4
9. Where I get medical care, people have to wait too long for emergency treatment.	90 (4.5%)	279 (14.0%)	120 (6.0%)	<b>1,445 (72.3%)</b>	66 (3.3%)	4	4
10. Doctors act too businesslike and impersonal toward me.	106 (5.3%)	182 (9.1%)	74 (3.7%)	<b>1,544 (77.2%)</b>	94 (4.7%)	4	4
11. My doctors treat me in a very friendly and courteous manner.	226 (11.3%)	<b>1,379 (69.0%)</b>	90 (4.5%)	197 (9.9%)	108 (5.4%)	2	4
12. Those who provide my medical care sometimes hurry too much when they treat me.	104 (5.2%)	255 (12.8%)	74 (3.7%)	<b>1,491 (74.6%)</b>	76 (3.8%)	4	4
13. Doctors sometimes ignore what I tell them.	112 (5.6%)	215 (10.8%)	82 (4.1%)	<b>1,499 (75.0%)</b>	92 (4.6%)	4	4
14. I have some doubts about the ability of the doctors who treat me.	74 (3.7%)	158 (7.9%)	60 (3.0%)	<b>1,600 (80.0%)</b>	108 (5.4%)	4	4
15. Doctors usually spend plenty of time with me.	228 (11.4%)	<b>1,133 (56.7%)</b>	240 (12.0%)	270 (13.5%)	129 (6.5%)	2	4
16. I find it hard to get an appointment for medical care right away.	105 (5.3%)	234 (11.7%)	30 (1.5%)	<b>1,559 (78.0%)</b>	72 (3.6%)	4	4
17. I am dissatisfied with some things about the medical care I receive.	179 (9.0%)	182 (9.1%)	18 (0.9%)	<b>1,380 (69.0%)</b>	241 (12.0%)	4	4
18. I am able to get medical care whenever I need it.	268 (13.4%)	<b>1,363 (68.2%)</b>	38 (1.9%)	245 (12.3%)	86 (4.3%)	2	4
<b>Total score (Out of 90)</b>							<b>72</b>

Bold values indicates all the statistically significant *p* values.

TABLE 5 PSQ-18 sub-scale scores.

Scale	Questions (Item numbers)	Average score
General satisfaction	3, 17	4
Technical quality	2, 4, 6, 14	4
Interpersonal manner	10, 11	4
Communication	1, 13	4
Financial aspects	5, 7	4
Time spent with doctor	12, 15	4
Accessibility and convenience	8, 9, 16, 18	4





to improve overall satisfaction. Training programs for healthcare providers in interpersonal skills and empathy may be beneficial.

**Addressing Financial Concerns:** Strategies to make healthcare more affordable and reduce financial burdens on patients, such as insurance schemes or subsidies, could be explored.

**Vaccination Awareness and Accessibility:** To further increase vaccination rates, awareness campaigns should address concerns about vaccine safety and availability.

**Tailoring Services:** Healthcare services can be tailored to meet the specific needs of different demographic groups and regions, considering education, income, and state of residence.

**Continued Monitoring:** Regular monitoring of patient satisfaction and healthcare quality is essential to identify areas for improvement and track the impact of healthcare interventions.

## 5 Limitations

Despite its valuable insights, the study acknowledges limitations that warrant consideration. Recall bias could have influenced participants' recollection of specific details, potentially impacting the accuracy of self-reported information. The sampling strategy, concentrated in specific regions, may have introduced sampling bias, limiting generalizability to the entire Northeast Indian population. Additionally, the demographic homogeneity might not sufficiently represent the region's diverse demographics. Finally, relying solely on self-reported data introduces the possibility of inaccurate responses due to social desirability bias or incomplete understanding of medical terminology. Addressing these limitations in future research is crucial for refining future understanding of healthcare experiences in Northeast India.

## 6 Conclusion

The study emphasized the need for tailored healthcare policies and services in Northeast India, given the diverse demographic factors that influence patient satisfaction. The high vaccination rate signifies the success of public health efforts, yet understanding vaccine hesitancy remains crucial. Similarly, while many reported overall satisfaction, concerns regarding affordability, wait times, and doctor-patient communication demand attention. Financial hardships and impersonal interactions can significantly impact patient experiences. The study also highlights the importance of tailoring healthcare services to diverse demographic groups. Education, income, and regional variations influence satisfaction, necessitating targeted interventions. Addressing the needs of the less educated, lower-income populations, and residents of specific states becomes pivotal. The diverse range of post-COVID complications underscores the need for comprehensive care beyond recovery. Healthcare providers must be prepared to manage long-term effects, while ongoing research offers valuable insights into these complexities. These findings call for a collaborative approach involving policymakers, healthcare providers, and communities. Training programs to enhance doctor-patient interactions, financial assistance schemes, targeted awareness campaigns, and tailored healthcare services are necessary steps toward a more equitable and patient-centered healthcare system. Regular monitoring of patient satisfaction and healthcare quality is vital to ensure sustained progress. By acting on these insights, stakeholders can empower individuals in Northeast India to navigate the healthcare landscape with confidence and experience the full potential of quality care.

TABLE 6 Bivariate relationships: education, household income, state of residence, and their impact on patient satisfaction.\*

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001–1.5 lac	1.6–2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q1.	SA	10 (0.5)	22 (1.1)	40 (2.0)	151 (7.6)	38 (1.9)	4 (0.2)	30 (1.5)	156 (7.8)	71 (3.6)	2 (0.1)	129 (6.5)	2 (0.1)	20 (1.0)	2 (0.1)	24 (1.2)	10 (0.5)	72 (3.6)
	A	68 (3.4)	136 (6.8)	210 (10.5)	676 (33.8)	292 (14.6)	98 (4.9)	304 (15.2)	429 (21.5)	551 (27.6)	57 (2.9)	643 (32.2)	55 (2.8)	87 (4.4)	86 (4.3)	127 (6.4)	87 (4.4)	240 (12.0)
	U	0 (0.0)	6 (0.3)	4 (0.2)	22 (1.1)	8 (0.4)	2 (0.1)	14 (0.7)	12 (0.6)	12 (0.6)	0 (0.0)	2 (1.0)	1 (0.1)	5 (0.3)	1 (0.1)	3 (0.2)	0 (0.0)	10 (0.5)
	Di	26 (1.3)	18 (0.9)	34 (1.7)	102 (5.1)	22 (1.1)	8 (0.4)	68 (3.4)	82 (4.1)	44 (2.2)	8 (0.4)	93 (4.7)	10 (0.5)	10 (0.5)	12 (0.6)	25 (1.3)	10 (0.5)	34 (1.7)
	SD	2 (0.1)	8 (0.4)	12 (0.6)	68 (3.4)	25 (1.3)	0 (0.0)	16 (0.8)	40 (2.0)	59 (2.9)	5 (0.3)	53 (2.7)	6 (0.3)	9 (0.5)	1 (0.1)	8 (0.4)	5 (0.3)	28 (1.4)
	<i>p</i> -value	<0.001					<0.001				<0.001							
Q2.	SA	12 (0.6)	28 (1.4)	34 (1.7)	162 (8.1)	36 (1.8)	2 (0.1%)	30 (1.5%)	158 (7.9%)	82 (4.1)	14 (0.7)	129 (6.5)	7 (0.4)	14 (0.7)	3 (0.2)	22 (1.1)	12 (0.6)	71 (3.6)
	A	72 (3.6)	130 (6.5)	228 (11.4)	667 (33.4)	288 (14.4)	98 (4.9)	308 (15.4)	427 (21.3)	552 (27.6)	45 (2.3)	650 (32.5)	51 (2.6)	100 (5.0)	84 (4.2)	123 (6.2)	85 (4.3)	247 (12.4)
	U	2 (0.1)	6 (0.3)	8 (0.4)	26 (1.3)	4 (0.2)	2 (0.1)	10 (0.5)	16 (0.8)	16 (0.8)	0 (0.0)	22 (1.1)	0 (0.0)	2 (0.1)	3 (0.2)	6 (0.3)	3 (0.2)	8 (0.4)
	D	18 (0.9)	22 (1.1)	22 (1.1)	108 (5.4)	30 (1.5)	8 (0.4)	72 (3.6)	80 (4.0)	40 (2.0)	8 (0.4)	92 (4.6)	10 (0.5)	9 (0.5)	11 (0.5)	27 (1.4)	8 (0.4)	35 (1.8)
	SD	2 (0.1)	4 (0.2)	8 (0.4)	56 (2.8)	27 (1.4)	2 (0.1)	12 (0.6)	38 (1.9)	47 (2.4)	5 (0.3)	45 (2.3)	6 (0.3)	6 (0.3)	1 (0.1)	9 (0.5)	4 (0.2)	23 (1.2)
	<i>p</i> -value	0.001					<0.001				0.021							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q3.	SA	10 (0.5)	28 (1.4)	40 (2.0)	160 (8.0)	36 (1.8)	4 (0.2)	30 (1.5)	162 (8.1)	78 (3.9)	14 (0.7)	125 (6.3)	12 (0.6)	15 (0.8)	4 (0.2)	20 (1.0)	9 (0.5)	75 (3.8)
	A	76 (3.8)	128 (6.4)	220 (11.0)	645 (32.3)	280 (14.0)	100 (5.0)	308 (15.4)	403 (20.2)	538 (26.9)	45 (2.3)	637 (31.9)	46 (2.3)	92 (4.6)	81 (4.1)	127 (6.4)	86 (4.3)	235 (11.8)
	U	2 (0.1)	4 (0.2)	4 (0.2)	24 (1.2)	14 (0.7)	0 (0.0)	10 (0.5)	14 (0.7)	22 (1.1)	2 (0.1)	21 (1.1)	2 (0.1)	3 (0.2)	4 (0.2)	1 (0.1)	2 (0.1)	11 (0.5)
	D	18 (0.9)	26 (1.3)	22 (1.1)	126 (6.3)	33 (1.7)	8 (0.4)	68 (3.4)	98 (4.9)	51 (2.6)	6 (0.3)	107 (5.4)	8 (0.4)	12 (0.6)	11 (0.5)	33 (1.7)	9 (0.5)	39 (2.0)
	SD	0 (0.0)	4 (0.2)	14 (0.7)	64 (3.2)	22 (1.1)	0 (0.0)	16 (0.8)	42 (2.1)	48 (2.4)	5 (0.3)	48 (2.4)	6 (0.3)	9 (0.5)	2 (0.1)	6 (0.3)	6 (0.3)	24 (1.2)
	p-value	<0.001					<0.001				0.006							
Q4.	SA	4 (0.2)	12 (0.6)	18 (0.9)	44 (2.2)	18 (0.9)	0 (0.0)	12 (0.6)	46 (2.3)	38 (1.9)	17 (0.9)	38 (1.9)	11 (0.5)	2 (0.1)	0 (0.0)	5 (0.3)	3 (0.2)	20 (1.0)
	A	28 (1.4)	20 (1.0)	28 (1.4)	132 (6.6)	38 (1.9)	18 (0.9)	104 (5.2)	64 (3.2)	60 (3.0)	19 (1.0)	104 (5.2)	22 (1.1)	10 (0.5)	18 (0.9)	27 (1.4)	11 (0.5)	35 (1.8)
	U	2 (0.1)	16 (0.8)	14 (0.7)	56 (2.8)	46 (2.3)	2 (0.1)	76 (3.8)	20 (1.0)	28 (1.4)	6 (0.3)	57 (2.9)	7 (0.4)	17 (0.9)	7 (0.4)	6 (0.3)	3 (0.2)	23 (01.2)
	D	72 (3.6)	132 (6.6)	238 (11.9)	749 (37.5)	273 (13.7)	92 (4.6)	228 (11.4)	533 (26.7)	611 (30.6)	29 (1.5)	706 (35.3)	33 (1.7)	101 (5.1)	77 (3.9)	144 (7.2)	86 (4.3)	288 (14.4)
	SD	0 (0.0)	10 (0.5)	2 (0.1)	38 (1.9)	10 (0.5)	0 (0.0)	12 (0.6)	56 (2.8)	0 (0.0)	1 (0.1)	33 (1.7)	1 (0.1)	1 (0.1)	0 (0.0)	5 (0.3)	9 (0.5)	18 (0.9)
	p-value	<0.001					<0.001				<0.001							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q5.	SA	10 (0.5)	22 (1.1)	38 (1.9)	162 (8.1)	36 (1.8)	2 (0.1)	30 (1.5)	160 (8.0)	76 (3.8)	7 (0.4)	127 (6.4)	7 (0.4)	14 (0.7)	1 (0.1)	27 (1.4)	10 (0.5)	75 (3.8)
	A	78 (3.9)	134 (6.7)	232 (11.6)	665 (33.3)	285 (14.2)	98 (4.9)	322 (16.1)	437 (21.9)	537 (26.9)	43 (2.2)	664 (33.2)	42 (2.1)	99 (5.0)	82 (4.1)	125 (6.3)	91 (4.6)	248 (12.4)
	U	2 (0.1)	0 (0.0)	4 (0.2)	30 (1.5)	14 (0.7)	2 (0.1)	14 (0.7)	16 (0.8)	18 (0.9)	2 (0.1)	23 (1.2)	2 (0.1)	3 (0.2)	4 (0.2)	3 (0.2)	3 (0.2)	10 (0.5)
	D	14 (0.7)	24 (1.2)	16 (0.8)	118 (5.9)	30 (1.5)	2 (0.1)	62 (3.1)	66 (3.3)	72 (3.6)	16 (0.8)	85 (4.3)	18 (0.9)	8 (0.4)	12 (0.6)	28 (1.4)	2 (0.1)	33 (1.7)
	SD	2 (0.1)	10 (0.5)	10 (0.5)	44 (2.2)	20 (1.0)	8 (0.4)	4 (0.2)	16 (0.8)	34 (1.7)	4 (0.2)	39 (2.0)	5 (0.3)	7 (0.4)	3 (0.2)	4 (0.2)	6 (0.3)	18 (0.9)
	<i>p</i> -value	<0.001					<0.001				<0.001							
Q6.	SA	10 (0.5)	30 (1.5)	42 (2.1)	178 (8.9)	44 (2.2)	8 (0.4)	32 (1.6)	170 (8.5)	94 (4.7)	11 (0.5)	141 (7.0)	11 (0.5)	20 (1.0)	5 (0.3)	24 (1.2)	13 (0.7)	7 (4.0)
	A	76 (3.8)	122 (6.1)	220 (11.0)	625 (31.3)	274 (13.7)	96 (4.8)	320 (16.0)	399 (20.0)	502 (25.1)	39 (2.0)	629 (31.5)	37 (1.9)	90 (4.5)	83 (4.2)	127 (6.4)	83 (4.2)	229 (11.5)
	U	0 (0.0)	2 (0.1)	8 (0.4)	34 (1.7)	4 (0.2)	8 (0.4)	2 (0.1)	12 (0.6)	26 (1.3)	2 (0.1)	22 (1.1)	3 (0.2)	3 (0.2)	1 (0.1)	5 (0.3)	1 (0.1)	11 (0.5)
	D	18 (0.9)	24 (1.2)	18 (0.9)	122 (6.1)	47 (2.4)	0 (0.0)	62 (3.1)	96 (4.8)	71 (3.6)	16 (0.8)	99 (5.0)	18 (0.9)	12 (0.6)	10 (0.5)	25 (1.3)	8 (0.4)	41 (2.1)
	SD	2 (0.1)	12 (0.6)	12 (0.6)	60 (3.0)	16 (0.8)	0 (0.0)	16 (0.8)	42 (2.1)	44 (2.2)	4 (0.2)	47 (2.4)	5 (0.3)	6 (0.3)	3 (0.2)	6 (0.3)	7 (0.4)	24 (1.2)
	<i>p</i> -value	<0.001					<0.001				0.001							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q7.	SA	2 (0.1)	8 (0.4)	10 (0.5)	28 (1.4)	16 (0.8)	4 (0.2)	4 (0.2)	30 (1.5)	26 (1.3)	4 (0.2)	28 (1.4)	5 (0.3)	5 (0.3)	2 (0.1)	2 (0.1)	4 (0.2)	14 (0.7)
	A	14 (0.7)	22 (1.1)	18 (0.9)	92 (4.6)	37 (1.9)	8 (0.4)	62 (3.1)	56 (2.8)	57 (2.9)	14 (0.7)	78 (3.9)	16 (0.8)	11 (0.5)	8 (0.4)	21 (1.1)	5 (0.3)	30 (1.5)
	U	2 (0.1)	0 (0.0)	12 (0.6)	48 (2.4)	22 (1.1)	2 (0.1)	40 (2.0)	18 (0.9)	24 (1.2)	3 (0.2)	39 (2.0)	4 (0.2)	5 (0.3)	10 (0.5)	6 (0.3)	4 (0.2)	13 (0.7)
	D	82 (4.1)	148 (7.4)	248 (12.4)	815 (40.8)	296 (14.8)	94 (4.7)	314 (15.7)	555 (27.8)	626 (31.3)	50 (2.5)	754 (37.7)	48 (2.4)	108 (5.4)	8 (0.4)	151 (7.6)	89 (4.9)	307 (15.4)
	SD	6 (0.3)	12 (0.6)	12 (0.6)	36 (1.8)	14 (0.7)	4 (0.2)	12 (0.6)	60 (3.0)	4 (0.2)	1 (0.1)	39 (2.0)	1 (0.1)	2 (0.1)	0 (0.0)	7 (0.4)	10 (0.5)	20 (1.0)
	<i>p</i> -value	0.049					<0.001				<0.001							
Q8.	SA	14 (0.7)	26 (1.3)	36 (1.8)	172 (8.6)	36 (1.8)	2 (0.1)	26 (1.3)	170 (8.5)	86 (4.3)	4 (0.2)	138 (6.9)	4 (0.2)	20 (1.0)	5 (0.3)	22 (1.1)	14 (0.7)	77 (3.9)
	A	66 (3.3)	116 (5.8)	230 (11.5)	633 (31.7)	288 (14.4)	92 (94.6)	330 (16.5)	393 (19.7)	518 (25.9)	47 (2.4)	629 (31.5)	46 (2.3)	91 (4.6)	78 (3.9)	122 (6.1)	85 (4.3)	235 (11.8)
	U	0 (0.0)	12 (0.6)	2 (0.1)	32 (1.6)	8 (0.4)	10 (0.5)	2 (0.1)	24 (1.2)	18 (0.9)	6 (0.3)	21 (1.1)	6 (0.3)	0 (0.0)	6 (0.3)	3 (0.2)	2 (0.1)	10 (0.5)
	D	24 (1.2)	28 (1.4)	22 (1.1)	126 (6.3)	33 (1.7)	8 (0.4)	66 (3.3)	82 (4.1)	77 (3.9)	11 (0.5)	106 (5.3)	13 (0.7)	13 (0.7)	11 (0.5)	33 (1.7)	6 (0.3)	40 (2.0)
	SD	2 (0.1)	8 (0.4)	10 (0.5)	56 (2.8)	20 (1.0)	0 (0.0)	8 (0.4)	50 (2.5)	38 (1.9)	4 (0.2)	44 (2.2)	5 (0.3)	7 (0.4)	2 (0.1)	7 (0.4)	5 (0.3)	22 (1.1)
	<i>p</i> -value	<0.001					<0.001				<0.001							
Q9.	SA	2 (0.1)	12 (0.6)	14 (0.7)	48 (2.4)	14 (0.7)	0 (0.0)	8 (0.4)	48 (2.4)	34 (1.7)	5 (0.3)	40 (2.0)	6 (0.3)	4 (0.2)	1 (0.1)	5 (0.3)	5 (0.3)	24 (1.2)
	A	16 (0.8)	34 (1.7)	16 (0.8)	166 (8.3)	47 (2.4)	10 (0.5)	88 (4.4)	82 (4.1)	99 (5.0)	25 (1.3)	122 (6.1)	20 (1.0)	16 (0.8)	14 (0.7)	35 (1.8)	10 (0.5)	37 (1.9)

(Continued)



TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q10.	U	10 (0.5)	12 (0.6)	18 (0.9)	50 (2.5)	30 (1.5)	10 (0.5)	74 (3.7)	22 (1.1)	14 (0.7)	6 (0.3)	54 (2.7)	7 (0.4)	11 (0.5)	11 (0.5)	6 (0.3)	6 (0.3)	19 (1.0)
	D	76 (3.8)	120 (6.0)	248 (12.4)	717 (35.9)	284 (14.2)	92 (4.6)	254 (12.7)	517 (25.9)	582 (29.1)	36 (1.8)	689 (34.4)	41 (2.1)	99 (5.0)	76 (3.8)	133 (6.7)	83 (4.2)	288 (14.4)
	SD	2 (0.1)	12 (0.6)	4 (0.2)	38 (1.9)	10 (0.5)	0 (0.0)	8 (0.4)	50 (2.5)	8 (0.4)	0 (0.0)	33 (1.1)	0 (0.0)	1 (0.1)	0 (0.0)	8 (0.4)	8 (0.4)	16 (0.8)
	p-value	<0.001					<0.001				<0.001							
	SA	6 (0.3)	8 (0.45)	16 (0.8)	60 (3.0)	16 (0.8)	0 (0.0)	12 (0.6)	50 (2.5)	44 (2.2)	7 (0.4)	46 (2.3)	10 (0.5)	5 (0.3)	1 (0.1)	5 (0.3)	4 (0.2)	28 (1.4)
Q11.	A	14 (0.7)	18 (0.9)	18 (0.9)	100 (5.0)	32 (1.6)	6 (0.3)	68 (3.4)	58 (2.9)	50 (2.5)	11 (0.5)	80 (4.0)	12 (0.6)	10 (0.5)	11 (0.5)	27 (1.4)	4 (0.2)	27 (1.4)
	U	0 (0.0)	6 (0.3)	14 (0.7)	44 (2.2)	10 (0.5)	2 (0.1)	50 (2.5)	14 (0.7)	8 (0.4)	1 (0.1)	36 (1.8)	1 (0.1)	8 (0.4)	5 (0.3)	7 (0.4)	4 (0.2)	12 (0.6)
	D	78 (3.9)	142 (7.1)	246 (12.3)	771 (38.6)	307 (15.4)	102 (5.1)	292 (14.6)	531 (26.6)	619 (31.0)	52 (2.6)	730 (36.5)	50 (2.5)	104 (5.2)	84 (4.2)	140 (7.0)	88 (4.4)	296 (14.8)
	SD	8 (0.4)	16 (0.8)	6 (0.3)	44 (2.2)	20 (1.0)	2 (0.1)	10 (0.5)	66 (3.3)	16 (0.8)	1 (0.1)	46 (2.3)	1 (0.1)	4 (0.2)	1 (0.1)	8 (0.4)	12 (0.6)	21 (1.1)
	p-value	0.020					<0.001				<0.001							
	SA	8 (0.4)	18 (0.9)	32 (1.6)	144 (7.2)	24 (1.2)	2 (0.1)	26 (1.3)	146 (7.3)	52 (2.6)	1 (0.1)	112 (5.6)	1 (0.1)	9 (0.5)	3 (0.2)	22 (1.1)	10 (0.5)	68 (3.4)
Q11.	A	70 (3.5)	128 (6.4)	218 (10.9)	665 (33.3)	298 (14.9)	96 (4.8)	288 (14.4)	441 (22.1)	554 (27.7)	49 (2.5)	650 (32.55)	46 (2.3)	100 (5.0)	80 (4.0)	127 (6.4)	87 (4.4)	240 (12.0)
	U	4 (0.2)	12 (0.6)	16 (0.8)	48 (2.4)	10 (0.5)	8 (0.4)	32 (1.6)	28 (1.4)	22 (1.1)	4 (0.2)	41 (2.1)	6 (0.3)	4 (0.2)	7 (0.4)	7 (0.4)	4 (0.22)	17 (0.9)
	D	18 (0.9)	22 (1.1)	16 (0.8)	104 (5.2)	37 (1.9)	6 (0.3)	74 (3.7)	60 (3.0)	57 (2.9)	13 (0.7)	86 (4.3)	15 (0.8)	10 (0.5)	6 (0.3)	24 (1.2)	6 (0.3)	37 (1.9)
	SD	6 (0.3)	10 (0.5)	18 (0.9)	58 (2.9)	16 (0.8)	0 (0.0)	12 (0.6)	44 (2.2)	52 (2.6)	5 (0.3)	49 (2.5)	6 (0.3)	8 (0.4)	6 (0.3)	7 (0.4)	5 (0.3)	22 (1.1)
	p-value	<0.001					<0.001				<0.001							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q12.	SA	6 (0.3)	8 (0.4)	12 (0.6)	60 (3.0)	18 (0.9)	0 (0.0)	8 (0.4)	46 (2.3)	50 (2.5)	5 (0.3)	47 (2.4)	8 (0.4)	5 (0.3)	3 (0.2)	6 (0.3)	4 (0.2)	26 (1.3)
	A	18 (0.9)	30 (1.5)	18 (0.9)	150 (7.5)	39 (2.0)	10 (0.5)	76 (3.8)	84 (4.2)	85 (4.3)	27 (1.4)	108 (5.4)	20 (1.0)	14 (0.7)	11 (0.5)	34 (1.7)	7 (0.4)	34 (1.4)
	U	4 (0.2)	8 (0.4)	10 (0.5)	34 (1.7)	18 (0.9)	6 (0.3)	40 (2.0)	16 (0.8)	12 (0.6)	2 (0.1)	35 (1.8)	3 (0.2)	7 (0.4)	5 (0.3)	1 (0.1)	5 (0.3)	16 (0.8)
	D	76 (3.8)	130 (6.5)	248 (12.4)	737 (36.9)	300 (15.0)	96 (4.8)	300 (15.0)	525 (26.3)	570 (28.5)	37 (1.9)	711 (35.6)	42 (2.1)	101 (5.1)	82 (4.1)	141 (7.0)	87 (4.4)	290 (14.5)
	SD	2 (0.1)	14 (0.7)	12 (0.6)	38 (1.9)	10 (0.5)	0 (0.0)	8 (0.4)	48 (2.4)	20 (1.0)	1 (0.1)	37 (1.9)	1 (0.1)	4 (0.2)	1 (0.1)	5 (0.3)	9 (0.5)	18 (0.9)
	p-value	0.002					<0.001				<0.001							
Q13.	SA	10 (0.5)	10 (0.5)	12 (0.6)	66 (3.3)	14 (0.7)	0 (0.0)	8 (0.4)	54 (2.7)	50 (2.5)	5 (0.3)	51 (2.6)	8 (0.4)	5 (0.3)	5 (0.3)	7 (0.4)	5 (0.3)	26 (1.3)
	A	12 (0.6)	22 (1.1)	28 (1.4)	124 (6.2)	29 (1.5)	10 (0.5)	72 (3.6)	68 (3.4)	65 (3.3)	13 (0.7)	95 (4.8)	13 (0.7)	13 (0.7)	10 (0.5)	30 (1.5)	7 (0.4)	34 (1.7)
	U	2 (0.1)	18 (0.9)	2 (0.1)	34 (1.7)	26 (1.3)	2 (0.1)	32 (1.6)	12 (0.6)	36 (1.8)	19 (1.7)	29 (1.9)	13 (0.7)	6 (0.3)	4 (0.2)	1 (0.1)	0 (0.0)	10 (0.5)
	D	80 (4.0)	128 (6.4)	246 (12.3)	743 (37.2)	302 (15.1)	100 (5.0)	312 (15.6)	529 (26.5)	558 (27.9)	34 (1.4)	718 (35.9)	39 (2.0)	103 (5.1)	82 (4.1)	142 (7.1)	90 (4.5)	291 (14.6)
	SD	2 (0.1)	12 (0.6)	12 (0.6)	52 (2.6)	14 (0.7)	0 (0.0)	8 (0.4)	56 (2.8)	28 (1.4)	1 (0.1)	45 (2.3)	1 (0.1)	4 (0.2)	1 (0.1)	7 (0.4)	10 (0.5)	23 (1.2)
	p-value	<0.001					<0.001				<0.001							
Q14.	SA	6 (0.3)	4 (0.2)	16 (0.8)	36 (1.8)	12 (0.6)	0 (0.0)	8 (0.4)	42 (2.1)	24 (1.2)	4 (0.2)	33 (1.7)	6 (0.3)	3 (0.2)	0 (0.0)	4 (0.2)	3 (0.2)	21 (1.1)
	A	10 (0.5)	20 (1.0)	12 (0.6)	100 (5.0)	16 (0.8)	4 (0.2)	64 (3.2)	46 (2.3)	44 (2.2)	11 (0.5)	68 (93.4)	12 (0.6)	6 (0.3)	9 (0.5)	25 (1.3)	3 (0.2)	24 (1.2)
	U	0 (0.0)	4 (0.2)	10 (0.5)	26 (1.3)	20 (1.0)	6 (0.3)	26 (1.3)	12 (0.6)	16 (0.8)	1 (0.1)	29 (1.5)	3 (0.2)	7 (0.4)	4 (0.2)	1 (0.1)	1 (0.1)	14 (0.7)
	D	86 (4.3)	144 (7.2)	250 (12.5)	807 (40.4)	313 (15.7)	94 (4.7)	326 (16.3)	551 (27.6)	629 (31.5)	55 (2.8)	755 (37.8)	52 (2.6)	109 (5.5)	88 (4.4)	147 (7.4)	93 (4.7)	301 (15.1)
	SD	4 (0.2)	18 (0.9)	12 (0.6)	50 (2.5)	24 (1.2)	8 (0.4)	8 (0.4)	68 (3.4)	24 (1.2)	1 (0.1)	53 (2.7)	1 (0.1)	6 (0.3)	1 (0.1)	10 (0.5)	12 (0.6)	24 (1.2)
	p-value	<0.001					<0.001				<0.001							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q15.	SA	10 (0.5)	24 (1.2)	28 (1.4)	138 (6.9)	28 (1.4)	2 (0.1)	22 (1.1)	138 (6.9)	66 (3.3)	0 (0.0)	114 (5.7)	0 (0.0)	12 (0.6)	4 (0.2)	19 (1.0)	11 (0.5)	68 (3.4)
	A	64 (3.2)	110 (5.5)	204 (10.2)	503 (25.2)	252 (12.6)	74 (3.7)	166 (8.3)	409 (20.5)	484 (24.2)	40 (2.0)	536 (26.8)	35 (1.8)	74 (3.7)	60 (3.0)	113 (5.7)	76 (3.8)	199 (10.0)
	U	2 (0.1)	14 (0.7)	22 (1.1)	158 (7.9)	44 (2.2)	18 (0.9)	152 (7.6)	30 (1.5)	40 (2.0)	9 (0.5)	111 (5.6)	12 (0.6)	22 (1.1)	25 (1.3)	17 (0.9)	7 (0.4)	37 (1.9)
	D	20 (1.0)	34 (1.7)	30 (1.5)	146 (7.3)	40 (2.0)	14 (0.7)	76 (3.8)	94 (4.7)	86 (4.3)	18 (0.9)	117 (5.9)	21 (1.1)	14 (0.7)	9 (0.5)	30 (1.5)	10 (0.5)	51 (2.6)
	SD	10 (0.5)	8 (0.4)	16 (0.8)	74 (3.7)	21 (1.1)	4 (0.2)	16 (0.8)	48 (2.4)	61 (3.1)	5 (0.3)	60 (3.0)	6 (0.3)	9 (0.5)	4 (0.2)	8 (0.4)	8 (0.4)	29 (1.5)
	<i>p</i> -value	<0.001					<0.001				<0.001							
Q16.	SA	6 (0.3)	10 (0.5)	16 (0.8)	54 (2.7)	19 (1.0)	6 (0.3)	4 (0.2)	52 (2.6)	43 (2.2)	4 (0.2)	49 (2.5)	6 (0.3)	3 (0.2)	3 (0.2)	9 (0.5)	6 (0.3)	25 (1.3)
	A	14 (0.7)	32 (1.6)	12 (0.6)	126 (6.3)	50 (2.5)	4 (0.2)	80 (4.0)	76 (3.8)	74 (3.7)	14 (0.7)	103 (5.1)	15 (0.8)	17 (0.9)	14 (0.7)	27 (1.4)	7 (0.4)	37 (1.9)
	Un	6 (0.3)	0 (0.0)	4 (0.2)	20 (1.0)	0 (0.0)	6 (0.3)	6 (0.3)	14 (0.7)	4 (0.2)	2 (0.1)	13 (0.7)	3 (0.2)	0 (0.0)	2 (0.1)	2 (0.1)	1 (0.1)	7 (0.4)
	D	78 (3.9)	134 (6.7)	260 (13.0)	789 (39.5)	298 (14.9)	96 (4.8)	334 (16.7)	527 (26.4)	602 (30.1)	51 (2.6)	738 (36.9)	49 (2.5)	109 (5.5)	83 (4.2)	141 (7.0)	90 (4.5)	298 (14.9)
	SD	2 (0.1)	14 (0.7)	8 (0.4)	30 (1.5)	18 (0.9)	0 (0.0)	8 (0.4)	50 (2.5)	14 (0.7)	1 (0.1)	35 (1.8)	1 (0.1)	2 (0.1)	0 (0.0)	8 (0.4)	8 (0.4)	17 (0.9)
	<i>p</i> -value	<0.001					<0.001				0.042							

(Continued)

TABLE 6 (Continued)

Questions (Item numbers) (see Appendix)		Education N (%)					Household income (Rs.) N (%)				States N (%)							
		Uneducated	Secondary	Higher secondary	Graduate	PG	<50,000	50,001– 1.5 lac	1.6– 2.5 lac	>2.6 lac	AP	As	Mn	Mg	Mz	Ng	Sk	Tr
Q17.	SA	6 (0.3)	20 (1.0)	26 (1.3)	94 (4.7)	33 (1.7)	8 (0.4)	24 (1.2)	74 (3.7)	73 (3.7)	6 (0.3)	84 (4.2)	9 (0.5)	12 (0.6)	9 (0.5)	16 (0.8)	7 (0.4)	36 (1.8)
	A	16 (0.8)	18 (0.9)	8 (0.4)	114 (5.7)	26 (1.3)	2 (0.1)	72 (3.6)	68 (3.4)	40 (2.0)	10 (0.5)	81 (4.1)	10 (0.5)	10 (0.5)	6 (0.3)	27 (1.4)	8 (0.4)	30 (1.5)
	U	0 (0.0)	0 (0.0)	0 (0.0)	10 (0.5)	0 (0.0)	0 (0.0)	4 (0.2)	6 (0.3)	8 (0.4)	0 (0.0)	9 (0.5)	0 (0.0)	2 (0.1)	1 (0.1)	0 (0.0)	0 (0.0)	6 (0.3)
	D	76 (3.8)	122 (6.1)	224 (11.2)	114 (5.7)	269 (13.5)	88 (4.4)	320 (16.0)	483 (24.2)	489 (24.5)	56 (2.8)	643 (32.2)	55 (2.8)	95 (4.8)	69 (3.5)	120 (6.0)	72 (3.6)	270 (13.5)
	SD	8 (0.4)	30 (1.5)	42 (2.1)	112 (5.6)	49 (2.5)	14 (0.7)	12 (0.6)	88 (4.4)	127 (6.4)	0 (0.0)	121 (6.1)	0 (0.0)	12 (0.6)	17 (0.9)	24 (1.2)	25 (1.3)	42 (2.1)
	<i>p</i> -value	<0.001					<0.001				0.002							
Q18.	SA	12 (0.6)	26 (1.3)	42 (2.1)	150 (7.5)	38 (1.9)	6 (0.3)	30 (1.5)	160 (8.0)	72 (3.6)	2 (0.1)	132 (6.6)	2 (0.1)	19 (1.0)	2 (0.1)	25 (1.3)	12 (0.6)	74 (3.7)
	A	72 (3.6)	122 (6.1)	226 (11.3)	663 (33.2)	280 (14.0)	96 (4.8)	322 (16.1)	425 (21.3)	520 (26.0)	49 (2.5)	642 (32.1)	48 (2.4)	89 (4.5)	87 (4.4)	121 (6.1)	89 (4.5)	238 (11.9)
	U	0 (0.0)	4 (0.2)	2 (0.1)	16 (0.8)	16 (0.8)	0 (0.0)	12 (0.6)	8 (0.4)	18 (0.9)	2 (0.1)	17 (0.9)	2 (0.1)	4 (0.2)	1 (0.1)	3 (0.2)	0 (0.0)	9 (0.5)
	D	20 (1.0)	30 (1.5)	20 (1.0)	138 (6.9)	37 (1.9)	10 (0.5)	64 (3.2)	78 (3.9)	93 (4.7)	15 (0.8)	108 (5.4)	17 (0.9)	15 (0.8)	10 (0.5)	29 (1.5)	7 (0.4)	44 (2.2)
	SD	2 (0.1)	8 (0.4)	10 (0.5)	52 (2.6)	14 (0.7)	0 (0.0)	4 (0.2)	48 (2.4)	34 (1.7)	4 (0.2)	39 (2.0)	5 (0.3)	4 (0.2)	2 (0.1)	9 (0.5)	4 (0.2)	19 (1.0)
	<i>p</i> -value	<0.001					<0.001				<0.001							

\*SA, Strongly Agree; A, Agree; U, Uncertain; D, Disagree; SD, Strongly Disagree; AP, Arunachal Pradesh; As, Assam; Mn, Manipur; Mg, Meghalaya; Mz, Mizoram; Ng, Nagaland; Sk, Sikkim; Tr, Tripura. Bold values are indicates all the statistically significant *p* values.

TABLE 7 Bivariate analysis: examining the impact of hospital type and stay duration on patient satisfaction.\*

Questions (Item numbers) (see Appendix)		Type of hospital			Duration of stay in the hospital				
		Government	Private	Semi- government	<1 week	1 week	2 weeks	3 weeks	>3 weeks
Q1.	SA	186 (9.3)	65 (3.3)	10 (0.5)	54 (2.7)	75 (3.8)	84 (4.2)	44 (2.2)	4 (0.2)
	A	863 (43.2)	485 (24.3)	34 (1.7)	536 (26.8)	359 (18.0)	248 (12.4)	185 (9.3)	54 (2.7)
	U	26 (1.3)	14 (0.7)	0 (0.0)	12 (0.6)	8 (0.4)	14 (0.7)	4 (0.2)	2 (0.1)
	D	128 (6.4)	64 (3.2)	10 (0.5)	74 (3.7)	50 (2.5)	22 (1.1)	46 (2.35)	10 (0.5)
	SD	101 (5.1)	12 (0.6)	2 (0.1)	39 (2.0)	30 (1.5)	32 (1.6)	14 (0.7)	0 (0.0)
	p-value	<0.001			<0.001				
Q2.	SA	200 (10.0)	62 (3.1)	10 (0.5)	72 (3.6)	72 (3.6)	82 (4.1)	42 (2.1)	4 (0.2)
	A	837 (41.9)	512 (25.6)	36 (1.8)	522 (26.1)	368 (18.4)	252 (12.6)	189 (9.5)	54 (2.7)
	U	40 (2.0)	4 (0.2)	0 (0.0)	14 (0.7)	10 (0.5)	14 (0.7)	2 (0.1)	4 (0.2)
	D	136 (6.8)	56 (2.8)	8 (0.4)	68 (3.4)	50 (2.5)	30 (1.5)	44 (2.2)	8 (0.4)
	SD	91 (4.6)	6 (0.3)	2 (0.1)	39 (2.0)	22 (1.1)	22 (1.1)	16 (0.8)	0 (0.0)
	p-value	<0.001			<0.001				
Q3.	SA	204 (10.2)	54 (2.7)	16 (0.8)	78 (3.9)	70 (3.5)	84 (4.2)	38 (1.9)	4 (0.2)
	A	811 (40.6)	508 (25.4)	30 (1.5)	504 (25.2)	368 (18.4)	236 (11.8)	185 (9.3)	56 (2.8)
	U	38 (1.9)	8 (0.4)	0 (0.0)	16 (0.8)	10 (0.5)	12 (0.6)	4 (0.2)	4 (0.2)
	D	157 (7.9)	60 (3.0)	8 (0.4)	81 (4.1)	50 (2.5)	36 (1.8)	52 (2.6)	6 (0.3)
	SD	94 (4.7)	10 (0.5)	2 (0.1)	36 (1.8)	24 (1.2)	32 (1.6)	14 (0.7)	0 (0.0)
	p-value	<0.001			<0.001				
Q4.	SA	82 (4.1)	12 (0.6)	2 (0.1)	26 (1.3)	30 (1.5)	20 (1.0)	20 (1.0)	0 (0.0)
	A	158 (7.9)	76 (3.8)	12 (0.6)	62 (3.1)	86 (4.3)	44 (2.2)	50 (2.5)	4 (0.2)
	U	90 (4.5)	32 (1.6)	4 (0.2)	40 (2.0)	42 (2.1)	22 (1.1)	20 (1.0)	2 (0.1)
	D	936 (46.8)	496 (24.8)	32 (1.6)	581 (29.1)	350 (17.5)	280 (14.0)	191 (9.6)	62 (3.1)
	SD	38 (1.9)	24 (1.2)	6 (0.3)	6 (0.3)	14 (0.7)	34 (1.7)	12 (0.6)	2 (0.1)
	p-value	<0.001			<0.001				
Q5.	SA	198 (9.9)	52 (2.6)	18 (0.9)	60 (3.0)	72 (3.6)	86 (4.3)	46 (2.3)	4 (0.2)
	A	866 (43.3)	502 (35.0)	28 (1.4)	525 (26.3)	366 (18.3)	250 (12.5)	199 (10.0)	54 (2.7)
	U	38 (1.9)	10 (0.5)	2 (0.1)	18 (0.9)	12 (0.6)	14 (0.7)	2 (0.1)	4 (0.2)
	D	128 (6.4)	68 (3.4)	6 (0.3)	70 (3.5)	56 (2.8)	30 (1.5)	38 (1.9)	8 (0.4)
	SD	74 (3.7)	10 (0.5)	2 (0.1)	42 (2.1)	16 (0.8)	20 (1.0)	8 (0.4)	0 (0.0)
	p-value	<0.001			<0.001				
Q6.	SA	210 (10.5)	78 (3.9)	16 (0.8)	86 (4.3)	76 (3.8)	90 (4.5)	44 (2.2)	8 (0.4)
	A	821 (41.1)	470 (23.5)	26 (1.3)	492 (24.6)	360 (18.0)	236 (11.8)	177 (8.9)	52 (2.6)
	U	28 (1.4)	14 (0.7)	6 (0.3)	20 (1.0)	8 (0.4)	12 (0.6)	4 (0.2)	4 (0.2)
	D	157 (7.9)	64 (3.2)	8 (0.4)	73 (3.7)	66 (3.3)	34 (1.7)	50 (2.5)	6 (0.3)
	SD	88 (4.4)	14 (0.7)	16 (0.8)	44 (2.8)	12 (0.6)	28 (1.4)	18 (0.9)	0 (0.0)
	p-value	<0.001			<0.001				
Q7.	SA	52 (2.6)	10 (0.5)	2 (0.1)	28 (1.4)	16 (0.8)	14 (0.7)	6 (0.3)	0 (0.0)
	A	99 (5.0)	74 (3.7)	10 (0.5)	65 (3.3)	54 (2.7)	30 (91.5)	30 (1.5)	4 (0.2)
	U	62 (3.1)	20 (1.0)	2 (0.1)	36 (1.8)	20 (1.0)	22 (1.1)	0 (0.0)	2 (0.1)
	D	1,045 (52.3)	508 (25.4)	36 (1.8)	578 (28.9)	408 (20.4)	308 (15.4)	2,379 (11.9)	58 (2.9)
	SD	46 (2.3)	28 (1.4)	6 (0.3)	8 (0.4)	24 (1.2)	26 (1.3)	20 (1.0)	6 (0.3)
	p-value	<0.001			<0.001				

(Continued)



TABLE 7 (Continued)

Questions (Item numbers) (see Appendix)		Type of hospital			Duration of stay in the hospital				
		Government	Private	Semi- government	<1 week	1 week	2 weeks	3 weeks	>3 weeks
Q8.	SA	188 (9.4)	78 (3.9)	18 (0.9)	80 (4.0)	70 (3.5)	82 (4.1)	44 (2.2)	8 (0.4)
	A	835 (41.8)	472 (23.6)	26 (1.3)	478 (23.9)	364 (18.2)	256 (12.8)	185 (9.3)	50 (2.5)
	U	36 (1.8)	18 (0.9)	0 (0.0)	26 (1.3)	14 (0.7)	8 (0.4)	0 (0.0)	6 (0.3)
	D	159 (8.0)	64 (3.2)	10 (0.5)	89 (4.5)	54 (2.7)	32 (1.6)	52 (2.6)	6 (0.3)
	SD	86 (4.3)	8 (0.4)	2 (0.1)	42 (2.1)	20 (1.0)	22 (1.1)	12 (0.6)	0 (0.0)
	<i>p</i> -value	<0.001			<0.001				
Q9.	SA	78 (3.9)	10 (0.5)	2 (0.1)	36 (1.8)	22 (1.1)	24 (1.2)	8 (0.4)	0 (0.0)
	A	185 (9.3)	86 (4.3)	8 (0.4)	99 (5.0)	76 (3.8)	36 (1.8)	62 (3.1)	6 (0.3)
	U	108 (5.4)	12 (0.6)	0 (0.0)	36 (1.8)	44 (2.2)	28 (1.4)	6 (0.3)	6 (0.3)
	D	893 (44.7)	512 (25.6)	40 (2.0)	540 (27.0)	362 (18.1)	288 (14.4)	199 (10.0)	56 (2.8)
	SD	40 (2.0)	20 (1.0)	6 (0.3)	4 (0.2)	18 (0.9)	24 (1.2)	18 (0.9)	2 (0.1)
	<i>p</i> -value	<0.001			<0.001				
Q10.	SA	88 (4.4)	14 (0.7)	4 (0.2)	40 (2.0)	28 (1.4)	22 (1.1)	14 (0.7)	2 (0.1)
	A	114 (5.7)	62 (3.1)	6 (0.3)	62 (3.1)	52 (2.6)	30 (1.5)	36 (1.8)	2 (0.1)
	U	60 (3.0)	14 (0.7)	0 (0.0)	28 (1.4)	22 (1.1)	14 (0.7)	8 (0.4)	2 (0.1)
	D	1,000 (50.0)	504 (25.2)	40 (2.0)	557 (27.9)	402 (20.1)	306 (15.3)	221 (11.1)	58 (2.9)
	SD	42 (2.1)	46 (2.3)	6 (0.3)	28 (1.4)	18 (0.9)	28 (1.4)	14 (0.7)	6 (0.3)
	<i>p</i> -value	<0.001			0.206				
Q11.	SA	160 (8.0)	52 (2.6)	14 (0.7)	54 (2.7)	54 (2.7)	78 (3.9)	34 (1.7)	6 (0.3)
	A	877 (43.9)	476 (23.8)	26 (1.3)	512 (25.6)	370 (18.5)	244 (12.2)	197 (9.9)	56 (2.8)
	U	58 (2.9)	24 (1.2)	8 (0.4)	30 (1.5)	30 (1.5)	18 (0.9)	12 (0.6)	0 (0.0)
	D	121 (6.1)	68 (3.4)	8 (0.4)	63 (3.2)	52 (2.6)	34 (1.7)	40 (2.0)	8 (0.4)
	SD	88 (4.4)	20 (1.0)	0 (0.0)	56 (2.8)	16 (0.8)	26 (1.3)	10 (0.5)	0 (0.0)
	<i>p</i> -value	<0.001			<0.001				
Q12.	SA	9 (4.5)	8 (0.4)	6 (0.3)	34 (1.7)	34 (1.7)	22 (1.1)	12 (0.6)	2 (0.1)
	A	173 (8.6)	78 (3.9)	4 (0.2)	99 (5.0)	64 (3.2)	34 (1.7)	54 (2.7)	4 (0.2)
	U	58 (2.9)	16 (0.8)	0 (0.0)	18 (0.9)	28 (1.4)	22 (1.1)	4 (0.2)	2 (0.1)
	D	937 (46.9)	514 (25.7)	40 (2.0)	550 (27.5)	378 (18.9)	294 (14.7)	209 (10.5)	60 (3.0)
	SD	46 (2.3)	24 (1.2)	6 (0.3)	14 (0.7)	18 (0.9)	28 (1.4)	14 (0.7)	2 (0.1)
	<i>p</i> -value	<0.001			<0.001				
Q13.	SA	96 (4.8)	12 (0.6)	4 (0.2)	46 (2.3)	26 (1.3)	24 (1.2)	14 (0.7)	2 (0.1)
	A	143 (7.2)	62 (3.1)	10 (0.5)	77 (3.9)	50 (2.5)	34 (1.7)	50 (2.5)	4 (0.2)
	U	62 (3.1)	20 (1.0)	0 (0.0)	26 (1.3)	42 (2.1)	6 (0.3)	8 (0.4)	0 (0.0)
	D	945 (47.3)	518 (25.9)	36 (1.8)	538 (26.9)	382 (19.1)	310 (15.5)	207 (10.4)	62 (3.1)
	SD	58 (2.9)	28 (1.4)	6 (0.3)	28 (1.4)	22 (1.1)	26 (1.3)	14 (0.7)	2 (0.1)
	<i>p</i> -value	<0.001			<0.001				
Q14.	SA	66 (3.3)	4 (0.2)	4 (0.2)	18 (0.9)	16 (0.8)	26 (1.3)	12 (0.6)	2 (0.1)
	A	102 (5.1)	52 (2.6)	4 (0.2)	56 (2.8)	34 (1.7)	22 (1.1)	42 (2.1)	4 (0.2)
	U	34 (1.7)	20 (1.0)	6 (0.3)	22 (1.1)	30 (1.5)	4 (0.2)	2 (0.1)	2 (0.1)
	D	1,042 (52.1)	522 (26.1)	36 (1.8)	579 (29.0)	422 (21.1)	316 (15.8)	223 (11.2)	60 (3.0)
	SD	60 (3.0)	42 (2.1)	6 (0.3)	40 (2.0)	20 (1.0)	32 (1.6)	14 (0.7)	2 (0.1)
	<i>p</i> -value	<0.001			<0.001				

(Continued)

TABLE 7 (Continued)

Questions (Item numbers) (see Appendix)		Type of hospital			Duration of stay in the hospital				
		Government	Private	Semi- government	<1 week	1 week	2 weeks	3 weeks	>3 weeks
Q15.	SA	166 (8.3)	50 (2.5)	12 (0.6)	56 (2.8)	60 (3.0)	76 (3.8)	34 (1.7)	2 (0.1)
	A	675 (33.8)	430 (21.5)	28 (1.4)	456 (22.8)	254 (12.7)	204 (10.2)	169 (8.5)	50 (2.5)
	U	190 (9.5)	48 (2.4)	2 (0.1)	58 (2.9)	108 (5.4)	44 (2.2)	20 (1.0)	10 (0.5)
	D	164 (8.2)	92 (4.6)	14 (0.7)	88 (4.4)	76 (3.8)	48 (2.4)	50 (2.5)	8 (0.4)
	SD	109 (5.5)	20 (1.0)	0 (0.0)	57 (2.9)	24 (1.2)	28 (1.4)	20 (1.0)	0 (0.0)
	<i>p</i> -value	<0.001			<0.001				
Q16.	SA	87 (4.4)	14 (0.7)	4 (0.2)	43 (2.2)	22 (1.1)	26 (1.3)	12 (0.6)	2 (0.1)
	A	154 (7.7)	74 (3.7)	6 (0.3)	88 (4.4)	60 (3.0)	32 (1.6)	48 (2.4)	6 (0.3)
	U	26 (1.3)	4 (0.2)	0 (0.0)	14 (7.0)	12 (0.6)	4 (0.2)	0 (0.0)	0 (0.0)
	D	999 (50.0)	520 (26.0)	40 (2.0)	552 (27.6)	414 (20.7)	314 (15.7)	219 (11.0)	60 (3.0)
	SD	38 (1.9)	28 (1.4)	6 (0.3)	18 (0.9)	14 (0.7)	24 (1.2)	14 (0.7)	2 (0.1)
	<i>p</i> -value	<0.001			0.002				
Q17.	SA	141 (7.0)	32 (1.6)	6 (0.3)	81 (4.1)	40 (2.0)	40 (2.0)	14 (0.7)	4 (0.2)
	A	118 (5.9)	60 (3.0)	4 (0.2)	42 (2.1)	48 (2.4)	32 (1.6)	58 (2.9)	2 (0.1)
	U	12 (0.6)	6 (0.3)	0 (0.0)	6 (0.3)	6 (0.3)	2 (0.1)	0 (0.0)	4 (0.2)
	D	892 (44.6)	45 (22.5)	38 (1.9)	484 (24.2)	372 (18.6)	282 (14.1)	190 (9.5)	52 (2.6)
	SD	141 (7.0)	92 (4.6)	8 (0.4)	102 (5.1)	56 (2.8)	44 (2.2)	31 (1.6)	8 (0.4)
	<i>p</i> -value	0.005			<0.001				
Q18	SA	182 (9.1)	72 (3.6)	14 (0.7)	78 (3.9)	62 (3.1)	86 (4.3)	36 (1.8)	6 (0.3)
	A	851 (42.6)	480 (24.0)	32 (1.6)	500 (25.0)	364 (18.2)	248 (12.4)	195 (9.8)	56 (2.8)
	U	32 (1.6)	6 (0.3)	0 (0.0)	16 (0.8)	6 (0.3)	10 (0.5)	4 (0.2)	2 (0.1)
	D	159 (8.0)	76 (3.8)	10 (0.5)	81 (4.1)	78 (3.9)	34 (1.7)	46 (2.3)	6 (0.3)
	SD	80 (4.0)	6 (0.3)	0 (0.0)	40 (2.0)	12 (0.6)	22 (1.1)	12 (0.6)	0 (0.0)
	<i>p</i> -value	<0.001			<0.001				

\*SA, Strongly Agree; A, Agree; U, Uncertain; D, Disagree; SD, Strongly Disagree. Bold values are indicates all the statistically significant *p* values.

## 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 University of Amity Institutional Review Board (IRB No. AUUP/IEC/MAY/2023/4). 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

SS: Conceptualization, Writing – original draft. FN: Methodology, Writing – original draft. KK: Formal analysis, Writing – original draft. SR: Writing – review & editing. MS: Writing – review & editing. HS: Supervision, 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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## Appendix 1

### Question (Item numbers).

- Q1. Doctors are good about explaining the reason for medical tests.
- Q2. I think my doctor's office has everything needed to provide complete medical care.
- Q3. The medical care I have been receiving is just about perfect.
- Q4. Sometimes doctors make me wonder if their diagnosis is correct.
- Q5. I feel confident that I can get the medical care I need without being set back financially.
- Q6. When I go for medical care, they are careful to check everything when treating and examining me.
- Q7. I have to pay for more of my medical care than I can afford.
- Q8. I have easy access to the medical specialists I need.
- Q9. Where I get medical care, people have to wait too long for emergency treatment.
- Q10. Where I get medical care, people have to wait too long for emergency treatment.
- Q11. My doctors treat me in a very friendly and courteous manner.
- Q12. Those who provide my medical care sometimes hurry too much when they treat me.
- Q13. Doctors sometimes ignore what I tell them.
- Q14. I have some doubts about the ability of the doctors who treat me.
- Q15. Doctors usually spend plenty of time with me.
- Q16. I find it hard to get an appointment for medical care right away.
- Q17. I am dissatisfied with some things about the medical care I receive.
- Q18. I am able to get medical care whenever I need it.



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# Improving patient-centered mental health promotion in primary care in vulnerable communities through mindfulness training in Rio de Janeiro, Brazil

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**Introduction:** Brazilian Primary Health Care (PHC) is responsible for all-sanitary actions for a community-based population, including health promotion and mental health care. Mindfulness Based Health Promotion (MBHP) is an intervention that can promote self-care and psychosocial support in PHC.

**Objective:** To discuss the effects of mindfulness based psychosocial group interventions for health promotion in primary care units in Rio de Janeiro, Brazil.

**Methods:** The intervention was based on the MBHP model adapted for SUS. Nine groups were held in Rio de Janeiro. A quali-quantitative research was held with two parts: (a) quantitative study, pre and after the 8 weeks intervention, evaluating the effect on mindfulness and self-compassion and their association with levels of anxiety, depression, and quality of life. (b) Qualitative research using Focus Groups with the participants to investigate their experience at the end of the mindfulness groups.

**Results and discussion:** Sixty-two participants finished the 9 groups where 86% were women, mostly between 30 and 59 years of age and low income, and around 80% under regular medical care in PHC in SUS. In the studied sample 80% had at least one chronic health condition under treatment, including 42% with anxiety and 35% with depression. The effects included significant improvement in Anxiety and Depression and in Quality of Life, mainly in the psychological but also in the physical and interrelation domains. The qualitative study showed that most patients joined the group on the recommendation of health professionals for managing physical and mental health symptoms. Patients reported being able to use the practices taught in the sessions to manage symptoms such as



insomnia and emotionally distressing situations in their daily lives. Including family members in mindfulness practices was a strategy to negotiate not only a space at home to meditate, but also to obtain a different approach to health problems. Participants pointed to mindfulness as a complementary therapeutic option to medication and psychotherapy.

**Conclusion:** Mindfulness-Based Intervention have shown to be a feasible, well-accepted and efficacious method of offering psychosocial support and promoting well-being for low-income patients in primary care in LAMIC.

#### KEYWORDS

mindfulness, public health, primary care, mental health promotion, vulnerable populations

## 1 Introduction

Common mental disorders (CMD), including anxious-depressive syndromes, are present in more than 50% of the population attended by Primary Health Care (PHC) units in Brazil (1), especially being associated with vulnerable social economic conditions such as violence, unemployment, and extreme poverty. CMD are frequently presented through medically unexplained symptoms, especially pain symptoms, and related to chronic diseases such as hypertension, obesity, and diabetes. They are directly associated with low self-esteem and disempowerment, indirectly associated with a strong social support network, and significantly reduce quality of life. The historical absence of psychosocial mental health interventions in PHC in the Brazilian National Health System (SUS-Sistema Único de Saúde) have led to long-lasting inadequate treatment based mainly in the prescription of benzodiazepines and the presence of important levels of treatment gap for mental disorders, such as more than 75% for depression (2). Given this situation, initiatives for scalable and cost-effective interventions are being developed in the SUS to reduce the chronic burden of CMD, promote empowerment, self-esteem, well-being and peer support.

The SUS is the largest universal public health system in the world and provides direct free health care for approximately 100% of the Brazilian population, estimated at 203 million people, although 30% also have private health insurance (3). However, SUS faces many challenges as Brazil is one of the most unequal countries in the world (4). PHC at SUS is provided by Family Health Teams (FHT), encompassing a physician, a nurse, a nurse technician and up to 6 community health workers that are responsible for all-sanitary actions for a community-based population up to 4,500 people, involving health promotion, preventive actions and solving 80% of health problems, including mental health. These teams work through a model of collaborative care work defined as matrix support (Matriciamento, or matrix support, is the Brazilian term for mental health collaborative care (MHCC) in primary health care), with other professionals such as psychologist, psychiatrist, social worker, physiotherapist, and physical educators, in an interdisciplinary work process. They are responsible for providing self-care and psychosocial support in communities cared for by the FHT, such as Community Therapy, Peer Support Groups, Handcraft Women's groups, Music Therapy Group and Mindfulness Based Health Promotion (MBHP) interventions.

Since the pandemic of COVID-19 emotional distress has increased, demanding provision of primary mental health care, including financing and training of health professionals, with an extra focus on the mental health condition of the professionals (5). Given that Brazil was one of the countries hardest hit by COVID-19 in terms of the number of deaths, increased levels of anxiety and depression symptoms and a significant decrease in quality of life was observed (6). Even before the pandemic, the number of years with disability (YLDs) due to mental disorders accounted for the largest number of years of healthy life lost in Brazil resulting in 4.9 million YLDs across all age groups and corresponding to 18.8% of all YLDs in the country. Anxiety and depressive disorders represent almost one third of all non-fatal disease-related burden, which is a common scenario in low-income and middle-income countries (LAMICs) (7). The Brazilian prevalence of CMD varies from 17 to 50%, being more common in women, the elderly, people living in social isolation and at greater social vulnerability and people with other chronic health conditions (8). In the SUS, CMD cases should be managed at primary care. Due to the structural vulnerability and poverty presented by the population attending at the PHC, CMD rates among them are even higher than in the general Brazilian population: reaching up to 60% of patients in these units (9).

It is necessary, therefore, to offer non-pharmacological treatments, not only psychotherapy and supervised physical activities, but also group interventions as previously presented. The development of group interventions in PHC has been a promising strategy in the care and promotion of mental health, as it develops "safe spaces" for social inclusion and empowerment, expanding social support networks and increasing the patient's ability to cope with adversity. Among these interventions, mindfulness has proven to be effective in PHC worldwide, both with users and health professionals experiencing burnout (10–12). In Brazilian PHC, this cost-effective intervention can offer empowerment and increase in self-esteem, as well as support from a peer group can help promote wellbeing and reduce the chronic burden of common mental disorders (13, 14).

This article examines an experience of implementation of mindfulness groups, designed especially for SUS, in PHC units in Rio de Janeiro, Brazil. Our aims are to discuss the health effects perceived by patients when participating in these mindfulness groups, identifying the challenges and facilities presented by their implementation regarding beliefs, values, expressions, experiences, and religiosity.

## 2 Materials and methods

### 2.1 Type of study

This research was designed to evaluate the effects of developing mindfulness-based interventions in primary care settings, in a “quasi experimental study (15, 16).” The first aim of the research was to train mental health and primary health care professionals in order to study the usefulness of a psychosocial group intervention based in Mindfulness Practices as part of non-pharmacological care.

To enrich our understanding of the intervention’s multifaceted impact, we employed a convergent parallel mixed-methods design, pre-post evaluation study, on the effects of the implementation of a mindfulness-based program for patients in PHC in Brazil. The research was carried out in two parts: (a) quantitative study, assessing variables pre and post the 8-week intervention with patients, (b) qualitative research using focus groups evaluating the patients experience with the program. The integration of these two parts was achieved by juxtaposing quantitative outcomes with qualitative insights (experiences and perceptions), facilitating a holistic interpretation of the intervention’s efficacy.

### 2.2 Intervention

The intervention was based on the MBHP Program designed by the Mente Aberta (Open Mind) team of Federal University of São Paulo (Unifesp) together with the State University of Rio de Janeiro (UERJ) team. It is a secular and evidence-based mindfulness training protocol, created and adopted by the “Mente Aberta” Center – Mindfulness Brazil in 2011, and has been improved over time by its general and clinical use, and by the contribution of several collaborators (17–19). The MBHP is inspired by Jon Kabat-Zinn’s original model – “Mindfulness Based Stress Reduction” (MBSR) but adapted to the context of Health Promotion and Quality of Life. In addition to MBSR, the United Kingdom Breathworks Institute, the MBCT (“Mindfulness-Based Cognitive Therapy”) and the MBRP (“Mindfulness-Based Relapse Prevention”) are the main sources of inspiration for the MBHP protocol. The program was created and designed for the Brazilian and Latin-American context, and, in particular, for its application in public policies in the areas of health, education and organizations, having as principles accessibility, didactics and simplicity, and as an objective the secular and scientific development of metacognitive awareness, providing a more conscious and healthy life, and promoting autonomy and self-care in health (17).

The groups were held at five PHC units in the city of Rio de Janeiro from 2015 till 2018, being facilitated by health professionals working in primary care units, either from the Family Health Teams or from Matrix Support Teams, under the supervision of researchers from Unifesp and UERJ. The instructors were professionals working in these units that participated in the 18 months specific training described above to work with the MBHP protocol. The groups took place in weekly meetings lasting an average of 1 h and a half to 2 h, in selected spaces in each PHC unit, organized by the instructors. The population taking part in the groups was the usual PHC clientele, referred to by the FHT that considered these patient’s needs and who could benefit from a support group intervention. Patients with severe mental health disorders such as psychotic disorders, Dementia and

suicidal ideas and plans were recommended not to participate in the groups.

The patients who took part in the groups were tested with standardized instruments before and immediately after the 8-week MBHP Protocol course.

The following instruments were used in the quantitative evaluation:

### 2.3 Quantitative instruments

#### 2.3.1 Socio-demographic questionnaire and information on health status

The questionnaire aims to assess subjects’ socio-demographic data, including gender, age, if the person is only attended in the SUS or have private insurance (which is a measure of better economic status), but also asking about the existence of a chronic illness, treatments that are being currently used, including use of medication.

#### 2.3.2 Hospital Anxiety and Depression Scale

The Hospital Anxiety and Depression Scale (HADS) was developed to detect depression and anxiety in hospital environments. However, it has been shown that it has the same psychometric properties when used with the general population, especially in PHC (20). The HADS scale contains 14 questions and is subdivided into two subscales: one for anxiety and another for depression. Each subscale has seven (7) questions, the answers to which range from 0 to 3. The cutoff score of 8/9 was considered for anxiety and depression.

#### 2.3.3 World Health Organization abbreviated quality of life instrument brief

The instrument was constructed by the World Health Organization Quality of Life Group (WHOQOL Group), of the World Health Organization (WHO), for this purpose and validated in Portuguese (21). It measures, through 26 questions, quality of life in four domains - physical, psychological, social relationships and environment. The physical domain assesses pain and discomfort, energy and fatigue, sleep and rest; the psychological domain, positive feelings, thinking, learning, memory and concentration, self-esteem, body image, negative feelings; the social relations domain inquiries about personal relationships, social support and sexual activity; while the environment domain asks about the physical safety and security, home environment, financial resources, health and social care, opportunity to acquire information and skills, opportunities for recreation and leisure, physical environment and locomotion. The WHOQOL - abbreviated questions were formulated to a Likert-type response scale, with a scale ranging from 1 to 5 in intensity (nothing - extremely), capacity (nothing - completely), frequency (never - always) and assessment (very dissatisfied - very satisfied; very bad - very good).

#### 2.3.4 Full attention and consciousness scale (MAAS)

The Mindfulness and Attention Scale (MAAS) is one of the most popular scales for Mindfulness. The scale allows the measurement of the construct “being attentive” based on a 15-item self-administered questionnaire to be answered with a Likert scale that varies between

1 (almost always) and 6 (almost never) and which evaluates cognitive, emotional, physical, interpersonal, and general domains (22).

### 2.3.5 Self compassion

The Self-Compassion Scale, developed by Kristin Neff, is a psychological concept assessment tool that involves treating oneself with humility, kindness and understanding, in the same way one would treat a close friend when faced with difficulties, failures or suffering. The scale is made up of several statements that explore different aspects of self-compassion and its underlying components (23). The scale is structured around the three main components of self-compassion: self-judgment vs. self-kindness; social isolation vs. notion of shared humanity, and over-identification vs. mindfulness. Studies report positive evidence in the adaptation, validation and reliability of the use of the Self-Compassion Scale in the Brazilian population (24, 25). It has 26 items, quantifiable from “almost never” (1) to “almost always” (5).

## 2.4 Qualitative approach

Nine focus groups were held with patients by pairs of trained researchers, in the roles of moderator and observer, using a script created especially for this research. The script included questions about the participants' expectations of the groups and their experience during the process, as well as asking about their impressions of the implementation of mindfulness-based interventions in PHC. The focus groups took place at the end of the mindfulness courses in each health unit. The groups were audio-recorded and later transcribed.

## 2.5 Data analyses

Our study involved a triangulation of methods including quantitative and qualitative methodologies. We integrated these data streams by mapping qualitative themes onto quantitative results, thereby gaining a nuanced understanding of how and why the intervention was effective. This methodological synergy allowed for a comprehensive understanding of patient outcomes beyond what could be gleaned from numerical data alone.

In the statistical analysis of the data, the paired t-test was applied to check whether there was a statistically significant difference, at the 5% level, in the scores studied between the patients' responses before and after the intervention for all the outcomes to be assessed, namely:

- Four domains of the quality-of-life scale (WHOQOL - domains: physical, psychological, social relations and environment).
- Screening scales for anxiety (HAD-Anxiety) and screening for depression (HAD-Depression) were evaluated in terms of percentage of positive screening and on a continuous scale via the average of the sum of the scores on the scale items.
- Mindfulness and Awareness Scale (MAAS) assessed by the sum of the scores on the scale items.
- Self-Compassion Scale (SC) assessed by the average of the scores on the scale items.

In addition, this evaluation of the effectiveness of the intervention via the paired t-test was also replicated according to each of the

sociodemographic and health variables investigated in the study, in order to better characterize the groups where this occurred differently.

Statistical tests were performed using SPSS Statistical software version 22 (IBM).

The qualitative material from the focus groups was analyzed based on the transcripts and the researchers' notes, aiming for a thematic analysis. Thematic content analysis is a research method that seeks the subjective interpretation of text content through systematic classification and the identification of themes and patterns. The words used, meanings attributed by the group and ideas that emerged from the group were taken into account. The script of questions from the focus groups acted as a framework that also supported this analysis. The transcripts were read independently by the researchers in order to immerse themselves in the material. The themes and patterns identified by each researcher were listed and then discussed as a group, looking for similarities and discrepancies. Based on the identification of themes, they were categorized and the categories that emerged will be discussed below (26).

## 2.6 Procedures

The groups were facilitated by health professionals working in PHC units, under the supervision of university teams. The groups took place in weekly meetings lasting an average of one hour and thirty to two hours, in selected spaces in each PHC unit, organized by the instructors.

Nine groups were held with PHC patients in the city of Rio de Janeiro. The patients who took part in the groups were tested with standardized instruments before and after the 8-week MBHP Protocol course. A total of 144 patients started the groups, but only 62 patients completed both questionnaires (pre and post), allowing an assessment of the immediate effect of the practices implemented in the groups.

## 3 Results

### 3.1 Quantitative results

Nine groups were held with PHC patients in the city of Rio de Janeiro. A total of 144 patients started the groups, but only 62 patients completed both questionnaires (pre and post), allowing an assessment of the immediate effect of the practices implemented in the groups. 85.5% were women, mostly between 30 and 59 years of age (56.4%) and around 77% under regular medical care in PHC. The cohort analyzed (pre and post) consisted mainly of patients from middle or low middle class, with a majority without private health insurance (83.5%) indicating low income (in Brazil 73.7% of the population, mainly middle and low income classes, do not have private health insurance) (27), and were treated only in the Unified Health System. Most of them (77%) had at least one chronic health condition under treatment, including 41.9% with anxiety and 35.5% with depression, although 50% referred to suffering from depression. Meaning that 22.6% of them are not undergoing regular treatment. Although many were being treated (“taking medication”) for chronic health conditions such as hypertension, diabetes and obesity, anxiety and depression represent the second and third most frequent chronic conditions.

Also 50% of patients use medication daily. We will discuss the issue of depression and anxiety below. As already described in the methodology, we evaluated the impact of mindfulness interventions especially concerning the development of mindfulness and self-compassion, but also its effects on quality of life and in the presence and intensity of depression and anxiety.

As shown in Table 1, regarding mindfulness and self-compassion skills, the interventions had a more significant effect on self-compassion. There was a significant increase in mindfulness among women with depression who, despite improving, persisted with significant depressive symptoms. However, when we evaluated the effects in terms of self-compassion, we see significant improvements

TABLE 1 Evaluation of the mindful attention and awareness scale (MAAS), self-compassion, screening for anxiety and depression, before and after intervention, in patients of the city of Rio de Janeiro/RJ, Brazil.

Questions	Before and after	MAAS			Self-compassion		
		Before	After	Paired t-teste	Before	After	Paired t-teste
	(n)	(Sum)	(Sum)	p-value	(Mean)	(Mean)	p-value
All patients	62	52.7	56.3	0.031	2.8	3.1	0.000
Gender (Male)	9	59.9	61.2	0.772	3.1	3.2	0.385
(Female)	53	51.5	55.4	0.028	2.7	3.0	0.000
Age groups (18–29 years)	6	45.2	49.5	0.353	2.5	3.1	0.017
(30–59 years)	35	50.3	53.9	0.107	2.7	3.0	0.003
(60+ years)	17	61.2	62.6	0.644	3.0	3.1	0.245
Do you have health insurance?							
Yes	11	51.0	57.9	0.060	2.6	3.0	0.064
No	51	53.0	55.9	0.124	2.8	3.1	0.000
Do you have a chronic illness?							
Yes	30	54.6	55.7	0.640	2.8	2.9	0.072
No	27	51.2	55.5	0.069	2.9	3.2	0.000
Do you receive regular medical care for the treatment of any ongoing or chronic health problem?							
Yes	47	51.3	55.0	0.067	2.7	3.0	0.000
No	14	56.4	61.1	0.060	3.1	3.2	0.067
Do you receive regular medical care for the treatment of anxiety?							
Yes	26	48.8	54.0	0.057	2.6	3.1	0.000
No	36	55.5	57.9	0.249	3.0	3.1	0.108
Do you receive regular medical care for the treatment of depression?							
Yes	22	47.3	53.0	0.074	2.5	3.0	0.000
No	40	55.7	58.1	0.208	3.0	3.1	0.037
Do you have depression?							
Yes	29	46.8	52.7	0.019	2.5	3.0	0.000
No	29	56.6	59.0	0.321	3.0	3.1	0.268
Do you take medication daily?							
Yes	48	52.5	56.2	0.060	2.7	3.0	0.000
No	12	51.1	53.7	0.467	2.9	3.2	0.064
Screening for anxiety							
Negative before and after	14	66.4	68.9	0.397	3.3	3.3	0.876
Improved after intervention	11	52.8	60.3	0.059	3.0	3.4	0.009
Positive before and after	37	47.5	50.3	0.220	2.5	2.9	0.000
Screening for depression							
Negative before and after	19	61.5	65.6	0.177	3.3	3.3	0.797
Improved after intervention	12	56.6	59.2	0.613	2.8	3.3	0.010
Positive before and after	28	44.7	48.9	0.054	2.4	2.8	0.000

In red bold p-value < 5%.



for women, adults up to the age of 60, especially those with lower incomes, without chronic illness (the presence of chronic illness only indicates a tendency to improve -  $p = 0.077$ ), and in those who receive regular monitoring for chronic illnesses including anxiety and depression. In these patients the impact of the practices was felt both in those undergoing treatment and also in those without treatment. It is important to remember that the increase in self-compassion accompanied all levels of improvement in symptoms of both anxiety and depression, even when the mental disorder was not considered to be cured.

It is important to remember that studies have shown that in primary health care the predominant condition is an association of symptoms of anxiety and depression, described as anxious depression in the ICD-11-AP proposal (28). In this way, these symptoms were evaluated together, and it was found that the effect of the intervention was positive. There was a significant reduction in the intensity of the conditions in both men and women in terms of anxiety and in women, those under 60, and those on lower incomes also in terms of the intensity of depression. There was a significant positive effect for those with depression, whether they were being treated or not. But the improvement was more significant among those who were not being treated for anxiety, regardless of whether they had chronic illnesses or not. In general, there was an association with an improvement in anxiety in general, including those associated with the presence of depression, which also reduced in intensity, even if it did not disappear completely (Table 2).

The effect of the intervention also included a significant improvement in Quality of Life, mainly of the physical domain but also in the psychological and environmental ones. Quality of life is an important outcome in evaluating the effect of mindfulness practices as a health promotion intervention. Its greatest effect, as expected, was in increasing quality of life in the psychological domain, which was more significant among women and people under 60, with lower incomes, no chronic illnesses, and who did not receive regular medical care. In these groups, there is also an improvement in quality of life in physical terms. We noticed that the intervention is also significantly associated with improvement of quality of life in those with anxiety and depression, whether they were being treated or not, having a positive impact even on those who still have symptoms after the intervention. Interestingly, there was no such significant impact in the areas of social relationships and the environment. Only in those who do not face specific difficulties, i.e., have a better income, do not have a chronic illness and do not take medication regularly, improvements in the social relationships' domain were found, associated with a reduction in the presence of anxious symptoms. This confirms another positive effect of these practices as forms of health promotion (Table 3).

## 3.2 Qualitative results

The following thematic categories emerged from the qualitative analysis of the focus groups: access to mindfulness groups and motivations for seeking this type of intervention, opportunity to experience mindfulness, daily life experiences that influence adherence, coping strategies for difficulties and challenges, benefits of the mindfulness group on emotional suffering, changes in perception

about mindfulness and meditation. There were also themes related to the benefits of participating in groups in general, as well as changes in self-perception. These themes are discussed below.

### 3.2.1 Access to the groups - motivations and references

When the qualitative study is considered, most users reported joining the group because of referrals from the unit's professionals, generally related to stress management, anxiety, or depression symptoms, or even support for people with chronic pain. Exceptions were people who join the group based on referrals from other family members, friends, and neighbors. The engagement of patients in the groups fundamentally involves pre-established bonding and trust with the FHT.

I'm 53 years old. I came because the physiotherapist mentioned that there was going to be a meditation group and I was curious. I've always really enjoyed learning, for me too as I'm now entering menopause, I have insomnia, and a lot of headaches.

### 3.2.2 A long-awaited opportunity

Mindfulness groups in SUS also caters for a portion of the population who are curious and want to try it out but cannot afford private groups in which participation fees are charged. Some statements show the gap in public policies and the importance of the availability of free secular mindfulness meditation spaces. Some users reported looking for mindfulness courses or groups and finding them unaffordable. This shows that, despite its popularity and the existence of a large number of courses, workshops, teaching materials and apps, mindfulness is still inaccessible to a significant portion of the Brazilian population, especially those who use the SUS as their main source of care.

I thought I had to pay, because I've always been interested in other meditation courses, but I couldn't afford them. So, I've always been interested, and knowing that we now have a meditation group at the family health unit was good.

### 3.2.3 Family stress, family solutions

Analysis of the focus groups showed that several patients who took part in the mindfulness groups are caregivers of family members with chronic illnesses or disabilities. The motivation to take part in the mindfulness groups came from their perception of the emotional suffering related to tending to their loved ones. Among these patients involved in the daily care of their families, the strategy was to incorporate the family as co-participants in the mindfulness practices carried out at home. At their homes, where people often have little or no privacy, if they are to have a brief pause to practice mindfulness, it needs to be shared, so that it makes sense to their peers.

My home it's a problem for me, until I get out of there, I don't think I'll ever get better. And my family says that what I have is spiritual, but I'm completely sure that it's not spiritual. Then,



TABLE 2 Screening for anxiety (HAD-Anx) and depression (HAD-Dep), before and after intervention, in patients of the city of Rio de Janeiro/RJ, Brazil.

Questions	Before and after	HAD-Anx (categorical % positive cases)			HAD-Dep (categorical % positive cases)		
		Before	After	Paired t-teste	Before	After	Paired t-teste
	(n)	(%)	(%)	p-value	(%)	(%)	p-value
All patients	62	<b>0.77</b>	<b>0.60</b>	<b>0.001</b>	<b>0.65</b>	<b>0.50</b>	<b>0.019</b>
Gender (Male)	9	0.56	0.56	1.000	0.56	0.56	1.000
(Female)	53	0.81	0.60	<b>0.001</b>	0.66	0.49	<b>0.011</b>
Age groups (18–29 years)	6	1.00	0.50	0.076	0.67	0.50	0.363
(30–59 years)	35	0.89	0.77	<b>0.044</b>	0.77	0.57	<b>0.017</b>
(60+ years)	17	0.47	0.29	0.083	0.41	0.41	1.000
<b>Do you have health insurance?</b>							
Yes	11	0.82	0.64	0.167	0.82	0.55	0.082
No	51	0.76	0.59	<b>0.002</b>	0.61	0.49	0.083
<b>Do you have a chronic illness?</b>							
Yes	30	0.83	0.73	0.083	0.60	0.53	0.423
No	27	0.70	0.44	<b>0.006</b>	0.70	0.44	<b>0.017</b>
<b>Do you receive regular medical care for the treatment of any ongoing or chronic health problem?</b>							
Yes	47	0.89	0.74	<b>0.007</b>	0.68	0.57	0.096
No	14	0.43	0.14	<b>0.040</b>	0.57	0.21	<b>0.019</b>
<b>Do you receive regular medical care for the treatment of anxiety?</b>							
Yes	26	0.96	0.85	0.077	0.77	0.65	0.185
No	36	0.64	0.42	<b>0.000</b>	0.56	0.39	0.057
<b>Do you receive regular medical care for the treatment of depression?</b>							
Yes	22	1.00	0.91	0.083	0.91	0.77	0.083
No	40	0.65	0.43	<b>0.003</b>	0.50	0.35	0.083
<b>Do you have depression?</b>							
Yes	29	0.97	0.90	0.162	0.90	0.72	0.057
No	29	0.66	0.38	<b>0.002</b>	0.48	0.31	0.057
<b>Do you take medication daily?</b>							
Yes	48	0.83	0.67	<b>0.004</b>	0.69	0.54	<b>0.033</b>
No	12	0.67	0.42	0.082	0.58	0.42	0.339
<b>Screening for anxiety</b>							
Negative before and after	14	0.00	0.00	-	0.29	0.21	0.583
Improved after intervention	11	1.00	0.00	-	0.36	0.18	0.167
Positive before and after	37	1.00	1.00	-	0.86	0.70	0.057
<b>Screening for depression</b>							
Negative before and after	19	0.53	0.16	<b>0.005</b>	0.00	0.00	-
Improved after intervention	12	0.83	0.67	0.166	1.00	0.00	-
Positive before and after	28	0.93	0.86	0.161	1.00	1.00	-

(Continued)

TABLE 2 (Continued)

Questions	Before and after	HAD-Anx (categorical % positive cases)			HAD-Dep (categorical % positive cases)		
		Before	After	Paired <i>t</i> -teste	Before	After	Paired <i>t</i> -teste
	( <i>n</i> )	Mean	Mean	<i>p</i> -value	Mean	Mean	<i>p</i> -value
All patients	62	11.2	9.3	0.000	9.4	7.9	0.001
Gender (Male)	9	9.8	7.6	0.030	8.4	7.8	0.591
(Female)	53	11.4	9.6	0.001	9.6	7.9	0.001
Age groups (18–29 years)	6	12.7	8.5	0.042	9.8	5.7	0.003
(30–59 years)	35	12.5	10.8	0.008	10.7	9.0	0.010
(60+ years)	17	8.1	7.0	0.144	7.1	6.8	0.790
Do you have health insurance?							
Yes	11	10.9	9.0	0.094	11.0	8.7	0.032
No	51	11.3	9.4	0.000	9.1	7.7	0.009
Do you have a chronic illness?							
Yes	30	12.3	11.3	0.088	9.1	8.8	0.561
No	27	9.6	7.1	0.001	9.7	6.8	0.000
Do you receive regular medical care for the treatment of any ongoing or chronic health problem?							
Yes	47	12.3	10.8	0.003	10.0	8.5	0.006
No	14	7.8	4.7	0.008	8.0	5.8	0.009
Do you receive regular medical care for the treatment of anxiety?							
Yes	26	13.2	11.9	0.077	11.0	9.2	0.016
No	36	9.8	7.4	0.000	8.3	7.0	0.028
Do you receive regular medical care for the treatment of depression?							
Yes	22	13.4	12.2	0.144	12.8	10.3	0.002
No	40	10.0	7.7	0.000	7.6	6.6	0.079
Do you have depression?							
Yes	29	13.4	11.5	0.008	12.5	10.1	0.001
No	29	9.8	7.9	0.009	7.3	6.3	0.094
Do you take medication daily?							
Yes	48	12.0	10.1	0.000	10.1	8.4	0.002
No	12	9.5	7.3	0.102	8.3	6.9	0.210
Screening for anxiety							
Negative before and after	14	4.4	4.1	0.583	5.4	5.8	0.649
Improved after intervention	11	11.0	5.2	0.000	6.8	3.9	0.004
Positive before and after	37	13.8	12.5	0.020	11.7	9.9	0.005
Screening for depression							
Negative before and after	19	7.9	5.3	0.007	4.2	3.8	0.439
Improved after intervention	12	11.7	9.1	0.068	10.4	5.6	0.000
Positive before and after	28	13.4	12.2	0.047	13.1	11.5	0.020

In red bold *p*-value < 5%.

from that day on, I started doing various (mindfulness) exercises, and I was able to take more control of the situation, which I didn't have before. I started to do the exercises and got my mother to do them. My mother wouldn't let me be quiet at home, either. I'd say Mom, look, I'm doing a meditation that goes like this, like that, right? Then I started explaining it to her. I got the CD and now I do it with her, at home. Now even my brother is doing it with us...

3.2.4 Time for myself

Another aspect valued by the participants was the possibility of having quality time to themselves. Both the time set aside to take part in the weekly group, but also the time set aside to practice at home as a moment of self-care.

The most important thing is that I've discovered, in this fast-paced life, I've learned to find time for myself. (.)This solves a lot of

TABLE 3 Evaluation of quality of life domains and screening for anxiety/depression, before and after intervention, in patients of the city of Rio de Janeiro/RJ, Brazil.

Questions	Before and after	Physical domain			Psychological domain		
		Before	After	Paired t-teste	Before	After	Paired t-teste
	(n)	Mean	Mean	p-value	Mean	Mean	p-value
All patients	62	51.9	56.6	0.002	49.2	55.5	0.002
Gender (Male)	9	56.3	63.9	0.066	61.1	63.9	0.572
(Female)	53	51.1	55.4	0.013	47.2	54.1	0.002
Age groups (18–29 years)	6	51.2	68.5	0.028	43.1	61.1	0.010
(30–59 years)	35	43.7	49.8	0.003	43.4	51.1	0.004
(60+ years)	17	67.8	65.3	0.238	60.0	59.9	0.965
<b>Do you have health insurance?</b>							
Yes	11	47.7	53.2	0.210	48.9	51.1	0.671
No	51	52.8	57.3	0.006	49.3	56.4	0.001
<b>Do you have a chronic illness?</b>							
Yes	30	48.8	50.9	0.284	49.8	50.9	0.697
No	27	57.1	64.2	0.011	50.5	60.6	0.001
<b>Do you receive regular medical care for the treatment of any ongoing or chronic health problem?</b>							
Yes	47	47.8	50.8	0.060	47.1	51.9	0.039
No	14	63.9	75.0	0.009	55.7	66.7	0.014
<b>Do you receive regular medical care for the treatment of anxiety?</b>							
Yes	26	42.7	48.7	0.003	42.9	51.7	0.012
No	36	58.5	62.3	0.095	53.7	58.3	0.069
<b>Do you receive regular medical care for the treatment of depression?</b>							
Yes	22	40.1	45.8	0.013	39.4	45.1	0.120
No	40	58.3	62.6	0.044	54.6	61.2	0.008
<b>Do you have depression?</b>							
Yes	29	39.5	46.3	0.001	37.3	47.1	0.003
No	29	61.1	65.0	0.119	57.9	62.2	0.087
<b>Do you take medication daily?</b>							
Yes	48	48.4	52.3	0.013	46.9	52.0	0.042
No	12	61.9	69.6	0.143	55.2	66.3	0.000
<b>Screening for anxiety</b>							
Negative before and after	14	74.1	75.3	0.381	68.2	69.3	0.696
Improved after intervention	11	61.0	71.8	0.069	59.8	69.7	0.137
Positive before and after	37	40.7	45.1	0.025	38.8	46.0	0.006
<b>Screening for depression</b>							
Negative before and after	19	65.6	70.9	0.107	66.9	70.6	0.291
Improved after intervention	12	49.9	57.7	0.091	46.2	61.5	0.001
Positive before and after	28	43.7	47.4	0.050	38.5	42.5	0.208

(Continued)

TABLE 3 (Continued)

Questions	Before and after	Social relationships domain			Environment domain		
		Before	After	Paired t-teste	Before	After	Paired t-teste
	(n)	Mean	Mean	p-value	Mean	Mean	p-value
All patients	62	<b>52.8</b>	<b>57.4</b>	<b>0.048</b>	<b>46.5</b>	<b>48.3</b>	<b>0.240</b>
Gender (Male)	9	56.5	64.8	0.123	54.7	57.0	0.535
(Female)	53	52.2	56.1	0.126	45.1	46.9	0.313
Age groups (18–29 years)	6	51.4	58.3	0.474	40.1	46.4	0.152
(30–59 years)	35	48.3	52.9	0.169	43.9	45.9	0.351
(60+ years)	17	60.8	62.7	0.626	52.8	50.3	0.281
<b>Do you have health insurance?</b>							
Yes	11	45.5	55.3	<b>0.019</b>	54.8	53.7	0.739
No	51	54.4	57.8	0.199	44.7	47.2	0.159
<b>Do you have a chronic illness?</b>							
Yes	30	51.1	54.2	0.397	46.6	47.8	0.634
No	27	55.0	61.7	<b>0.029</b>	47.4	51.0	0.092
<b>Do you receive regular medical care for the treatment of any ongoing or chronic health problem?</b>							
Yes	47	51.2	55.0	0.190	44.1	45.6	0.408
No	14	56.6	64.9	<b>0.025</b>	53.9	56.3	0.407
<b>Do you receive regular medical care for the treatment of anxiety?</b>							
Yes	26	46.7	51.9	0.220	44.9	49.1	0.085
No	36	57.2	61.3	0.119	47.7	47.8	0.960
<b>Do you receive regular medical care for the treatment of depression?</b>							
Yes	22	45.0	47.0	0.650	42.1	43.6	0.495
No	40	57.1	63.1	0.028	49.0	50.9	0.345
<b>Do you have depression?</b>							
Yes	29	44.5	49.1	0.203	40.7	43.9	0.141
No	29	59.5	64.1	0.175	50.2	51.6	0.555
<b>Do you take medication daily?</b>							
Yes	48	51.5	54.3	0.304	44.1	45.8	0.371
No	12	56.3	68.1	<b>0.016</b>	53.9	56.9	0.261
<b>Screening for anxiety</b>							
Negative before and after	14	65.5	70.2	0.140	59.6	59.0	0.780
Improved after intervention	11	58.3	69.7	<b>0.050</b>	46.9	54.5	0.088
Positive before and after	37	46.4	48.9	0.446	41.5	42.5	0.633
<b>Screening for depression</b>							
Negative before and after	19	64.1	71.0	0.062	54.9	56.1	0.620
Improved after intervention	12	51.4	59.7	0.119	42.6	51.7	<b>0.028</b>
Positive before and after	28	45.2	47.6	0.517	42.8	41.5	0.587

In red bold *p*-value < 5%.

problems, finding time for yourself in the midst of all the hustle and bustle solves a lot of problems. When you come here to the clinic, you get out of your day-to-day life for a special day. In everyday life, practicing is different, but I was able to do it at home too.

### 3.2.5 Focus, attention and wellbeing

The patients also reported that the effects of the mindfulness groups involved improving focus and attention, greater body awareness, greater awareness of thoughts and emotional reactions. From these experiences, they observed an improvement in emotional

regulation and a reduction in symptoms of anxiety, insomnia, and depression.

I realized that I'm still anxious, but with more inner space. I'm managing to control myself, which I used to not be able to do. Now I don't, I know when it's going to start, I can divert my thoughts, you know? I look after my mother, so I used to get very nervous, but I'm more patient with her, you know? Now I feel I have more patience. I'm managing to control my anxiety.

One thing that improved a lot was insomnia. I used to have a lot of insomnia. So, even if I wake up at night, I can meditate and I can go back to sleep. And that was great because I'm extremely anxious. Sleepless nights are horrible.

Increased body awareness changed some patients' experience of daily life, through habits such as walking and eating. The practices helped them not only to cope with unpleasant experiences but also to enjoy pleasant moments.

Dancing I could clearly feel the awareness of my movements. That's what I've felt the most, because I've improved in ballroom dancing because of the practices here. It's been very good for me. I'm very anxious. I knew how to do the step, but when it came time to do it, I wanted to run over my partner. And I'm trying to reconcile all this with my breathing, you know.

The practice of eating raisins with full attention was one that benefited me. Because of my anxiety, I eat too fast, and the technique helped me to savor the food. I started eating more slowly and I no longer feel sick to my stomach.

Throughout the intervention, participants observed changes in attitudes related to self-perception, regarding feelings, emotions and thoughts. It was possible to increase kindness towards oneself and reduce reactivity to the thoughts content in the sense of emotional self-regulation. These skills proved useful in dealing with anxiety symptoms and unpredictable or undesirable everyday events.

The instructors always said: during the practices, we should be very gentle with ourselves. That was something I also took into my life, so, when I'm doing something, if it doesn't turn out the way I wanted, I should be gentle with myself.

### 3.2.6 Another form of care

Many patients recognize group psychosocial interventions strategies as a coherent offer in PHC, complementary to individual and medication treatments. In the sample studied, mindfulness groups emerged as a possibility for managing anxiety with the expectation of reduction and even withdrawal of anxiolytic medication.

Some of the patients' motivation was associated with dissatisfaction with the usual treatments offered, such as anxiolytic medication and other types of group psychotherapy.

In group therapy you have to expose your life in front of everyone, or sit in front of a psychologist and all you have to do is talk and he'll say "keep taking the medication," the same thing with the psychiatrist. And not here, here is a group where little by little we become aware that it's not like that, and over time maybe we'll reduce the medication, because I take very strong medication for depression.

It's interesting to note that the presence of mindfulness groups as an ordinary PHC offering can set up a space in which some patients can negotiate other forms of mental health care, either as a substitute or as a complement to their usual treatment. When asked about the possible impacts of the group, in terms of benefits and difficulties, participants reported changes in their relationship with painful symptoms and the experience of illness.

Well, I was pretty unwell when I came here, but along with these practices I went to the doctor. I took some pills that he gave me, it was only one box. He even said "Are you better?" And I said, "I am". And I did get better. Then, combining the group here with the medication, I got better.

### 3.2.7 Benefits of being in a group

The patients recognize that the benefits of the group go beyond the skills developed over the 8 weeks; they also involve socialization, networking, and mutual help.

Because for me at least, the group is welcoming. It's not just the practices themselves. Understanding that there are other people in the same situation. And that we can help each other. And that these practices help us.

### 3.2.8 Difficulties

Some participants reported difficulties in the group related to the infrastructure of the health units and the ambience.

I think one thing that had a big influence on my difficulty was the atmosphere in the clinic: every time someone knocked on the door, someone opened the door, there was a lot of noise, a lot of people talking. The accommodation itself, the benches, the low chair, the discomfort didn't allow us to relax enough to enjoy it. That was my difficulty.

### 3.2.9 Surprises and adjustments - mindfulness and patients' religious context

One of the concerns about offering mindfulness groups in the context of PHC would be the possibility of reconciling secular practices with the patients' religious context.

The participants indicated that before starting the groups, they thought that mindfulness might have a religious component, but this was not sustained when they actually attended the sessions. Some of the patients even incorporated mindfulness practices into their current religious practices in church.

I thought it was church stuff until I did the meditation.



I even practice mindfulness at church. Breathing brought changes, I felt more confident.

The highlighted excerpts point out that the construction of meaning for participation is anchored in the experience of mental suffering and in the opportunities offered by the PHC teams for their patients. Mindfulness groups then emerge as an option for relieving suffering, even if the mechanisms involved in the treatment process are not debated or made explicit to participants by professionals.

## 4 Discussion

### 4.1 Key findings

This original quali-quantitative study in the Brazilian population confirmed that mindfulness-based groups are effective as a psychosocial intervention for health promotion and to improve quality of life and mental health care. The findings of our research are compatible with review studies in primary care, which have also observed positive impacts on quality of life and mental health with mindfulness-based interventions (29). They can be held by professionals from the PHC teams and specialized professionals as part of collaborative care. The benefits of participating in the groups for the management of these complaints appeared both in the quantitative results and in the perception of the participants in the focus group reports. The patients demonstrated a significant increase in Mindfulness and Self Compassion, associated with reduction of anxiety and depression symptoms and increase of Quality of Life. Patients' motivations for taking part in the group ranged from curiosity about meditation, a desire to manage the stress of daily life, and control of symptoms such as insomnia, anxiety, and depression. The patients pointed out that the practices were helpful in self-regulating emotions, feelings, and bodily sensations. They also described the ways they assimilate the practices they had experienced at the health unit in their daily lives, adjusting and negotiating their use in new scenarios. As the practices were recommended by health professionals, they assumed a status of being a therapeutic intervention. Thus, it can be considered as a complementary intervention that will help patients develop self-esteem and empowerment, increasing wellbeing. Our study reinforces that mindfulness-based interventions can be successfully used in PHC in the National Health System in Brazil.

The study also points to the fact that a proportion of people suffering from mental health conditions find themselves without regular follow-up and treatment, even if they are regularly attending primary care, indicating a gap in mental health care, something that has been observed in other research related to mental health (2, 30). Considering the great variability of people being treated in primary care services, being able to offer different therapeutic strategies can improve access and equity for groups with different needs. Recognizing the mental health care gap and the presence of psychological distress and mental health symptoms prior to a mindfulness-based program helps to recognize the groups that can most benefit from this type of intervention. A meta-analysis investigating different interventions that can improve mental wellbeing showed that mindfulness benefits

among the general population and in clinical settings. Another meta-analysis of mindfulness programs and health promotion showed that individual characteristics related to worse mental health outcomes seem to be related to better outcomes, with a greater influence than gender and educational level (31).

Our research also indicates that it is possible to offer 8-week mindfulness groups in PHC with the involvement of health teams. Primary care services are a favorable setting for stepped care of different intensities and durations (32), but a randomized study carried out with PHC patients shows that an eight-week structured intervention has better results than brief interventions in terms of self-regulation and self-care for this clientele (33). Thus, our research helps to reinforce that, if qualified instructors are available to offer protocols adapted for PHC, it is possible to provide an intervention with real benefits for the population in question.

Although there exist few specific studies on mindfulness interventions with disadvantaged Brazilian population, there are some experiences with people in situations of vulnerability, such as immigrants, which have similar results to this research. A study carried out with Portuguese-speaking immigrants in Boston showed that a mindfulness program adapted for PHC was acceptable, feasible and culturally appropriate for this population (34). Studies with Latino/Hispanic populations show that adapted protocols have greater adherence, and significant results in reducing depressive symptoms, stress and symptoms related to chronic diseases (35, 36). Other studies carried out with overweight low-income Brazilian women show that mindfulness-based interventions can help cultivate perceived self-compassion and positively affect the participants' lives (37).

Studies in Brazilian primary care show that women are the main users of primary care services, including participating in psychosocial interventions (1). It is therefore not surprising that most of the sample in our study was made up of women. Although there is no research on mindfulness and meditation use profiles with the Brazilian population, the findings of this study are compatible with US population studies in which most people engaging in mind-body meditation practices are female (38). The manifestation of emotional distress is more frequent in women, which in our study appears to be due to the stress of being a caregiver and not having time for oneself. Mindfulness groups could be a coping strategy for these women. Qualitative studies with women in situations of extreme vulnerability in the role of family caregiver show that the quality time for oneself and emotional self-regulation promoted by mindfulness-based interventions can improve quality of life and interpersonal relationships (39). The perceptions of the participants in our research are also compatible with reviews that indicate that mindfulness-based interventions can help informal caregivers of people with chronic illnesses (40, 41).

We did not expect to find practices from a different spiritual tradition (even if it is secularized to a certain extent, as mindfulness activities are) being incorporated so easily and without conflict into users' religious practices (mostly Catholic or Neo Pentecostal) in very poor communities. This ease may have happened because Brazilian syncretism facilitates the translation of elements from a particular religious practice into another (there are many examples: Afro-Brazilian religions such as Umbanda which incorporate elements from the Catholic tradition). Brazilian culture has an enormous capacity for including elements from other cultural traditions, and this explains the acceptance of mindfulness, which may be different in other

contexts (42, 43). This finding is very promising concerning how cultural differences can be integrated within mindfulness practices.

These qualitative research results are aligned with the most recent reflections in the field of mindfulness on the need to build intercultural and interreligious competencies in order to strengthen the presence of mindfulness-based interventions as a public health care option (44). Mental health interventions must respect the patients' beliefs and values system while helping to maintain the integrity of the professionals and the fidelity of the proposed intervention (45). Mindfulness-based interventions are presented in the Global Mental Health literature as a successful example of integrating and adapting a health care strategy from a traditional system (46). Mindfulness-based programs can currently be found in more than 50 countries across the world. But there is little research into cultural influences and potential adaptations, especially in Latin-American countries, and our study did not show special resistance from the patients while highlighting the importance of professionals responsible for PHC recommending them (47, 48).

Implementation studies show that health professionals recommend therapies and treatments that they recognize as coherent and effective in their work setting (32). Bringing information and experiences about mindfulness to PHC professionals could be a way of increasing the availability of the intervention for patients. Previous research carried out in Brazilian PHC with health professionals indicates that mindfulness-based interventions are feasible (49). The research findings with Brazilian health workers are compatible with studies carried out in other countries with PHC professionals who work with vulnerable populations. The continuous offer of groups with the possibility of maintenance sessions, combined with continuity of care and the ongoing therapeutic bonds with health teams, are relevant to promote and implementing behavior activation, including changing habits and increasing self-care, in PHC.

It is important to keep on investigating how to incorporate mindfulness practices in universal health systems as the Brazilian SUS. We can point that an important aspect to be investigated involves the minimum amount of time for an intervention to last. Moreover, it is fundamental to evaluate the possibilities of developing opportunities for continuing the practices. The participants have talked about the difficulties of maintaining them within their daily routine in small and crowded homes. Including mindfulness practices in other health promotion group activities that are held at the primary care units have shown to be feasible and easily accepted. Keeping open and public mindfulness groups as a form of follow-up after the end of the protocols, even though mobile messaging apps proved to be a strategy recognized by professionals and patients as effective, but they need to be better implemented and evaluated.

## 4.2 Potential shortcomings and limitations

The paper offers novel insights into implementing mindfulness-based interventions in resource-limited settings, which is a significant contribution to the field. A special aspect of this project is that it has trained Brazilian professionals from the National Health System to use a protocol specially designed for our Health system and population – The MBHP – Mindfulness Based Health Promotion (50) which limits its scalability. On the other hand, a main limitation

of our study is the absence of follow-up for a longer period. Medium and long-term follow-up studies, participant observation of groups and other methodologies for mixed methods could contribute to a more comprehensive understanding of mindfulness-based interventions as an alternative for stress management, mental health, and well-being promotion in patients in primary health care in LAMIC. It would also have been important to analyze why patients dropped out, even these being in frequent group activities offered in PHC. A better understanding of reasons could provide new insights for both mental health services and the implementation of mindfulness groups.

Another limitation of our study is the potential for selection bias, as participants who volunteered for a mindfulness-based intervention might already have been more open to or in need of psychological support. This selection bias could limit the generalizability of our findings to the wider population of primary care patients. Deepening our knowledge of the demographic characteristics of group participants in terms of educational level, ethno-racial characteristics, and patterns of use of health services can also provide new insights into social markers of difference that can influence the demand for and potential benefits of groups for the health of the population. The fact that less than 50% of the patients participating in the groups answered the post-intervention tests demonstrates the difficulty of the analyzes of “quasi experimental studies”.

Moreover, while our findings are promising, they should be interpreted with caution due to the study's limited sample size and the absence of a control group. Future studies could address these limitations by including a larger, more diverse sample and employing a randomized controlled trial design to provide more robust evidence of the intervention's effectiveness.

Finally, the generalizability of our results to other Low and Middle-Income Countries (LAMICs) may be limited, given the unique sociocultural context of Rio de Janeiro. Subsequent research in varied geographical and cultural settings would be valuable to ascertain the wider applicability of our findings.

## 5 Conclusion

The results of the research indicate that MBHP groups are a viable option for psychosocial intervention in the primary health care scenario in Brazil's. They have shown to be a feasible, well-accepted and efficacious method of offering support and promoting well-being for a low-income population in PHC. Observations of both the patients' impressions and the results of the scales applied in the pre-and post-intervention period indicate that the groups carried out using the MBHP protocol had an effect on different spheres of the health of the population studied, both in terms of mental health promotion, quality of life increase, and the management of physical symptoms and anxiety. The findings of our study are particularly relevant for healthcare practitioners and policymakers in LAMICs, offering valuable insights into the implementation of patient-centered, mindfulness-based interventions in resource-limited settings. By demonstrating the feasibility and benefits of such interventions, this research contributes to the ongoing efforts to empower patients and foster a more patient-centered approach in global health care, particularly within vulnerable communities.

## 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 Approved by the Research Ethics Committees of State University of Rio de Janeiro (UERJ) and the Health Department of Rio de Janeiro Municipality. CAAE: 39405814.3.0000.5259. 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

DS: Conceptualization, Formal analysis, Methodology, Project administration, Writing – original draft, Writing – review & editing. SF: Formal analysis, Methodology, Project administration, Writing – original draft, Writing – review & editing. CK: Funding acquisition, Project administration, Writing – original draft. KA: Project administration, Writing – original draft. MC: Conceptualization, Formal analysis, Methodology, Writing – review & editing. AN: Writing – review & editing. FO: Methodology, Writing – review & editing. JG-C: Conceptualization, Formal analysis, Methodology, Writing – original draft. MD: Conceptualization, Formal analysis, Methodology, Project administration, 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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