Research Topics

World mental health day key drivers of risk to mental health services and innovative solutions 2022

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World mental health day 2022: Key drivers of risk to mental health services and innovative solutions

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Editorial: World mental health day 2022: key drivers of risk to mental health services and innovative solutions

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mental health, health services, innovation, socio-cultural adaptation, biopyschosocial model, COVID-19, human-centred design

Editorial on the Research Topic
World mental health day 2022: key drivers of risk to mental health services and innovative solutions

Introduction

The COVID-19 pandemic triggered a global mental health crisis, increasing stress and fueling anxiety and depressive disorders (1). In a world where already one in eight people are living with a mental disorder globally, the pandemic has put more strain on services, skills, and funding available for mental health. The pandemic has also had dire consequences in low and middle-income countries (LMICs), where the treatment gap, that is the number of people who need care actually get the required care, for mental health conditions has expanded (2).

We launched this special topic to coincide with World Mental Health Day 2022, to showcase the latest multidisciplinary research and insights into the global situation of mental health services during and post-pandemic. Our goal was to identify the key drivers of risk to mental health services, and innovations in service delivery modes that improve accessibility or coordination.

There were four strong themes embodied across the submissions received. First there were discussions of the impact of COVID-19 on service utilization and those providing care. The second theme spoke to the importance of attending to contextual differences and acknowledging cultural adaptations to different health services. The third theme focuses on the role of engaging patients and people with lived experience in designing services. The final group of papers underscore the significance of the biopsychosocial model, which sees mental health issues as a part of the larger holistic landscape of health, rather than as a clinical practice separate and apart.

Impact of COVID-19 pandemic on service utilization and workforce

Our collection highlights the critical need for enhanced mental health support for the public and healthcare workforce during crises like the COVID-19 pandemic. In Van den Broeck et al.'s study, set in Belgium, we saw a significant rise in psychological and anxiety-related issues in out of hours consultations for psychological problems since the onset of the pandemic. These consultations remained elevated even between COVID-19 waves. This increased use of out of hours care for mental health reasons can be an indicator of the unmet mental health needs in a population.

The increased strain on healthcare workers during the pandemic cannot be overlooked as burnout was already a significant threat to the well-being of the workforce prior to the pandemic. We wanted to shine a light on this issue and acknowledge the tremendous work of our healthcare teams during this period. Eder and Meyer's work stresses the need for interventions to address these harmful coping strategies and improve working conditions for long-term care nurses. They reveal that altruistic motivations in nursing can lead to self-endangering behaviors and increased exhaustion. Similarly, Bannon et al. suggest that promoting positive psychological constructs can mitigate burnout. Targeted interventions to build resilience, particularly among younger, female, and patient-facing healthcare workers, are crucial, and they emphasize the need for healthcare systems to create supportive work environments and prioritize mental well-being to reduce burnout rates.

Leadership behavior and health policy changes are essential to create a supportive work environment and prevent burnout. As observed by Hale and Davis, fewer than 14% of medical schools in the United States adhered to the Association of American Medical College's guidelines for mental health service provision. They discuss the need to include these guidelines in accreditation standards to improve adherence, underscoring the importance of policy to enable change.

Cultural and contextual adaptations to mental health services

Alongside burnout issues, it is important to consider cultural contexts to build capacity and ensure positive mental health. For instance, in low-and-middle-income countries (LMICs), it is well-known that help-seeking for mental illness is pluralistic, and alternative sources of care, such as traditional and faith healers or lay community health workers, are viewed by many as a valued community resource, which may help fill the "treatment gap" in low- and middle-income countries (LMICs). The World Health Organization (WHO) developed the "Mental Health GAP" (mhGAP) course, which aims to upskill and train non-specialist clinical staff in basic diagnosis and treatment. In many settings, psychiatric services are scarce or unaffordable, so initiatives like the mhGAP are critical. This is evidenced in the submission by Kuule et al., who found that providing mental health care in the community—away from a hospital setting, substantially increased the number of people accessing mental health care, and providing training to health center-based staff in mhGAP contributed to this.

Help-seeking for mental illness is dynamic and diverse with common concurrent or sequential use of various forms of treatment in the search for a "cure". Respectful dialogue and mutual learning not only between lay health workers and biomedical workers, but also caregivers and people with lived experience, can identify shared understandings, as well as opportunities for questioning, discovery, and transformative change. All efforts must address existing power hierarchies and health system challenges—particularly those faced during the pandemic such as virtual working, as well as engage with the meaningful activities, understanding the intrinsic values and needs of people with lived experience and their families. This calls for a public mental health approach, in which such collaborations are embedded within communities and supported by policies and interventions to address social as well as spiritual and medical needs.

Understanding lived experience for effective innovation

There is a growing recognition that understanding experiences and perspectives is critical in developing, implementing, and adapting interventions and services tailored to the needs of those using it (3), especially as it relates to patients and individuals with lived experience. Adam et al., highlighted the importance of choice and individualized care needs in traditional inpatient treatment and novel inpatient equivalent home treatment settings in Germany (3). Their qualitative study identified choice and care needs as key elements in enhancing patient satisfaction and treatment efficacy. At an organizational and systems level, Yu et al. provides a reflection on the integration of a patient, family, and persons with lived experience lived experience team (PFLE) in shaping the development of the BrainHealth Databank (BHDB), a large data initiative to advance personalized care and research at a large academic mental health hospital in Canada. These accounts include various types of engagement across the spectrum (4), ranging from "consultation" in the development of a research and care coordination portal, "involvement" in co-designing a patient-facing trajectory dashboard, to "partnership" in the BHDB governance.

Understanding the patient experience has become increasingly important with the post-pandemic shift to virtual delivery of care, as seen in two Canadian studies. Pulia et al. used admissions data to understand the feasibility of the rapid deployment Virtual Crisis Stabilization Unit as a safe, effective and feasible mechanism to provide mental health crisis care, particularly during times when traditional service delivery is disrupted. Their findings provide insights on delivering equitable and patient-centred services in Winnipeg, Canada. Henderson et al., report on their community-based participatory research approach in successfully transitioning to a virtual delivery of the Raising the Curtain on Lived Experience of Dementia (RTC) initiative in British Columbia—a creative 5-year community-based, art-engaged project to support older adults who experience isolation, loneliness, financial challenges, and mental illness. The community collectively navigated this transition and demonstrated the potential for virtual delivery to foster a sense of community, empowerment, and well-being, all of which challenges the stigma associated with dementia and the ageist assumptions about technology use.

Embracing a biopsychosocial mindset to mental health

As with the RTC initiative, several papers in this issue encourage us to think broadly about the complexity of mental health recovery, and the dynamic interpersonal and psychological systems that shape an individual's well-being (5). This dynamic is observed in the comparative study by Padyab et al., where they found differences in the types and severity of stressors experienced by Swedish and Norwegian police officers between 2018 and 2020. Furthermore, stress levels in Sweden decreased over time whereas no change or a slight increase was observed in Norway. They hypothesize that changes in organizational structure and interventions in safety and security may have improved stress for Swedish police officers. The role of societal issues and population dynamics were also explored by Abdelhadi; they found that psychological distress adversely affects satisfaction and experiences with healthcare services of American cancer survivors. Furthermore, those with psychological distress have limited access to mental health service, with many forgoing access due to its affordability. Nakimuli-Mpungu et al. will be exploring the association between psychological interventions to improve treatment outcomes. Their protocol details a pilot randomized controlled trial to evaluate the feasibility, acceptability, and preliminary effectiveness of incorporating group support psychotherapy with antiretroviral therapy for young people living with HIV in Uganda.

This collection also saw many articles highlight the biological social interactions in the complexity of mental illnesses. Ouyang et al. saw dynamic changes in frequency and types of chief complaints to their psychological crisis hotline over the different stages of the pandemic in Jiangsu, China. This study illustrates the interplay between psychological complaints (e.g., anxiety, depression, obsessive compulsive symptoms) and social factors (e.g., quarantine measures, fear or infection), but also highlights the interactions with biological responses (e.g., physical discomfort, insomnia). These findings further the case to take an integrated biopsychosocial approach to healthcare—a concept that is neither novel nor the norm (6). This gap was seen in Tredget et al.'s service evaluation of the London Mental Health Trust in the United Kingdom, where clinical staff, service users, and careers recognized the importance of integrating physical health and community support into the healthcare experience of those with serious mental illness. However, there was variability in how physical healthcare was delivered, calling for the need for guidance and leadership on how to navigate and streamline the complexities of integrated care within the Trust. Lesson can be drawn from Cano-Prieto et al. biopsychosocial approach in their MOSAIC project, which is a social initiative that accounts for psychological well-being and social determinants of health alongside traditional medical care. Their holistic approach to treatment and recovery was meaningful in engaging individuals with severe mental illness in Catalonia (Spain), fostering social inclusion, life satisfaction, resilience, hope, and personal recovery.

Perspectives

In our special topic collection, we highlight the urgent need for innovative strategies to address the disparities experienced in healthcare and transform mental health services beyond the pandemic. This global body of work reveals a common set of challenges we face, from supporting the current workforce, to requiring capacity for care delivery in underserved areas, to the transition to digital provision of care, to the challenges in providing support tailored to the recovery needs of specific populations. However, the insights from these studies highlight the value of organizational and system leadership, systemic resiliency, cultural contexts, and lived experience as critical pieces in overcoming these challenges.

The insights generated from this collection reinforces common ideas and approaches in the mental health discourse. There is a need to prioritize a holistic multidisciplinary collaborative approach—one in which embraces the complexity of delivering health services, valuing lived experience and cultural context in designing supportive environments for the workforce and the population (7). It is evident that a dynamic, responsive biopsychosocial approach to mental health is essential in enhancing resilience, promoting positive psychological well-being, and empowering individuals to cope and adapt to a variety of complex and dynamic circumstances. We hope readers find this issue useful in mental health service innovation and advocacy. We also hope this issue contributes to the ongoing efforts in shifting the paradigm on how we frame, govern, and deliver mental health services.

Author contributions

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Conflict of interest

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

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References

1. Vindegaard N, Benros ME. COVID-19 pandemic and mental health consequences: systematic review of the current evidence. *Brain Behav Immun*. (2020) 89:531–42. doi: 10.1016/j.bbi.2020.05.048

2. World Health Organization. *World Mental Health Report: Transforming Mental Health for All*. Geneva: World Health Organization (2022). Available online at: https://iris.who.int/bitstream/handle/10665/356119/9789240049338-eng.pdf?sequence=1

3. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. A new framework for developing and evaluating complex interventions: update of medical research council guidance. *BMJ*. (2021) 374:n2061. doi: 10.1136/bmj.n2061.

4. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff*. (2013) 32(2):223–31. doi: 10.1377/hlthaff.2012.1133

5. Lehman BJ, David DM, Gruber JA. Rethinking the biopsychosocial model of health: understanding health as a dynamic system. *Soc Personal Psychol Compass*. (2017) 11(8):e12328. doi: 10.1111/spc3.12328

6. Engert V, Grant JA, Strauss B. Psychosocial factors in disease and treatment-a call for the biopsychosocial model. *JAMA Psychiatry*. (2020) 77(10):996–7. doi: 10.1001/jamapsychiatry.2020.0364

7. Shen N, Sockalingam S, Charow R, Bailey S, Bernier T, Freeland A, et al. Education programs for medical psychiatry collaborative care: a scoping review. *Gen Hosp Psychiatry*. (2018) 55:51–9. doi: 10.1016/j.genhosppsych.2018.08.009

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BRIEF RESEARCH REPORT
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Increase in Anxiety-Related Out-of-Hours Primary Care Consultations Since COVID-19: An Observational Study Using Routine Data in Flanders

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Background: Survey studies suggest that COVID-19 has had a negative impact on the population's mental well-being. Routine registration data allow a more objective way for investigating such associations, complementary to self-report measures. This study investigates the level of out of hours (OOH) consultations for psychological problems since the start of the COVID-19 pandemic in Flanders, Belgium.

Methods: The iCAREdata database is a clinical research database with routine data of OOH care, covering a large area in Flanders, Belgium. After defining the first wave and the second wave of COVID-19 in Flanders in time, we compared the number of consultations regarding psychological problems (in general, anxiety-related, depression-related, and sleep-related) between those periods, the period in between these waves, and the period before the start of COVID-19.

Results: A significant rise in OOH consultations due to psychological—and more specifically, anxiety-related—problems is observed since the start of the COVID-19 pandemic in Flanders. Elevated levels are observed until the second wave. This finding is in sharp contrast with the general pattern of lower demand for primary healthcare during this period. The majority of these supplementary consultations happened by phone. Consultations regarding depression-related problems did not change over time. Sleep disturbances in the OOH setting were more common after the first wave.

Conclusion: Despite some limitations, a large Flemish database with routine data on OOH care shows an increase in the number of consultations regarding psychological problems in general and anxiety-related problems since the start of the COVID-19-pandemic until the second wave.

Keywords: mental health, anxiety, out-of-hours medical care, organization of care, primary care

KEY POINTS

- According to routine registrations of out of hours care, consultations due to psychological problems in general and anxiety problems in particular were more common during the COVID-19 pandemic in Flanders, Belgium.
- According to routine registrations of out of hour care, consultations due to depression-related problems did not change over time during the COVID-19 pandemic in Flanders, Belgium.
- According to routine registrations of out of hour care, consultations due to sleep disturbances were more common in later phases of the COVID-19 pandemic in Flanders, Belgium.
- The use of routine registration data may be complementary to self-report measures to detect trends in the population's mental well-being—which is important to react accordingly—in critical times, e.g., during a pandemic.

INTRODUCTION

Many survey studies have shown that COVID-19 and the measures to control the pandemic have (had) a strong and negative impact on the population's mental well-being (1–3). Moreover, it has been suggested that fluctuations in mental well-being correspond with the strengthening and the relaxation of the measures, which is generally in accordance with the severity of the pandemic locally (3, 4). Previous research concerning the first COVID-19 wave in Belgium revealed an increase in diagnoses related to mental health and a decrease in the demand for primary care consultations unrelated to COVID-19 (5).

In contrast to survey-based research, in which often voluntary respondents are questioned about their well-being, routine registration data allow us to more objectively study the prevalence of (mental) health problems on a regular basis in a large share of citizens, and how fluctuations in health problems are related to the evolution of the COVID-19 pandemic. The aim of this study is to describe the demand for care regarding mental health problems during out of hours (OOH) care before and during the COVID-19 pandemic in Flanders, Belgium.

The first wave of COVID-19 in Belgium began at the beginning of March 2020, peaked on March 28th (with 642 admissions daily) and ended by May 4th. During that period, Belgium went in lockdown. Non-essential businesses were closed since March 18th, and citizens were requested to work from home and to limit interpersonal contacts. Non-urgent medical appointments were adjourned and patients showing symptoms of COVID-19 were asked to contact their GP by phone. Triage stations were set up. Though citizens were still requested to limit their contacts and to work from home if possible, schools reopened and social life was gradually resumed by the beginning of May, as was non-urgent care. Figures dropped in summer but rose again at the end of September—a second wave began, following an exponential curve from October 10th. Again, more stringent measures were implemented. Restaurants and professional salons were closed, and non-essential shops could only be visited on request or to take out pre-ordered objects. Schools, however, did not close, although pupils of 14 years and older and students were obliged to follow (a part of) their lessons online. The autumn holidays were extended with an additional week, after which the number of infections declined again, but the second wave was followed by a high plateau phase.

We hypothesize that the severity of the COVID-19 pandemic in Flanders is reflected in the number of patients that visit a practitioner for psychological problems OOH. More specifically, we expect that routine registrations referring to psychological problems in general, and to anxiety-, depression-, and sleep-related problems in particular, will be more prevalent in the registry during the two COVID-19 waves, compared to the period before COVID-19 and the period in between the waves.

METHODS

Data Collection

The iCAREdata database (Improving Care And Research Electronic Data Trust Antwerp) is a central, clinical research database on OOH care that is provided to a large population of inhabitants (all ages) in Flanders, Belgium (6, 7). Every weekend, routine data of general practitioner (GP) cooperatives are added to the database, respecting privacy regulations and ethical considerations. In 2019, the area covered by the participating health care professionals / units counted 1.914.541 inhabitants; additional partnerships were added in 2020, resulting in an area that covers 3.162.345 inhabitants (48% of the Flemish population, representative for the entire Flemish population).

All consultations during weekends and bank holidays (further referred to as weekends) in 2019 and 2020 were included. Patients without a Belgian national insurance number were excluded. The exact number of exclusions is unknown but below five percent. GPCs need this number for billing to the obliged national health insurance so they will obtain this number whenever possible. The weekend of 18/09/2020 was excluded because of a data collection problem.

The receptionists of the GPCs registered the type of contact (telephone contact, physical contact or home visit). GPs had to register a diagnosis by selecting a single clinical label out of a Belgian list which is linked to the International Classification of Primary Care, 2nd edition (ICPC-2). Due to software limitations, it was not possible to register several diagnoses. GPs were asked to use specific codes for consultations regarding a proven or suspected case of COVID-19, a close contact of a proven case, for COVID-19 testing only and for fear of COVID-19 (which should be interpreted as questions about the disease, concerns about being infected, … but not as anxiety or phobia). All these COVID-19-related consultations were excluded from the analyses. In case a patient had multiple consultations within a 6-hour timeframe, only the first physical consultation was studied if available, else the first telephone consultation was studied.

Following the evolution of COVID-19 and its associated measures in Flanders, we defined the "Pre-COVID-19" era (69 weekends and holidays; between the start of 2019 and until March 9th 2020), the "First wave" (7 weekends; between March 13th and April 27th 2020), the "Second wave" (9 weekends; between

October 9th and November 30th, 2020), and the period between and after the waves (29 weekends; between May 1st and October 8th 2020 and between December 4th and December 31st 2020).

Analysis

The following variables were included in the analyses: type of contact (home visit, physical consultation or telephone consultation), timing (day, hours and minutes), age (years), sex (male or female), and diagnosis (ICPC-2 coded).

Patients with a COVID-19 specific diagnosis were excluded. We computed the number of patients requesting OOH care for any non-COVID-19 problem and for psychological problems (all P-scores of ICPC-2) per 100.000 inhabitants per weekend for each of the defined periods, and compared them using ANOVA. If significant, Fisher's Least Significant Difference (LSD) *post-hoc* tests were used to explore the differences between the time periods. We repeated this procedure for anxiety (P01 + P74 + P79, with P01 = "feeling anxious/nervous/tense"; P74 = "anxiety disorder/anxiety state"; P79 = "phobia/compulsive disorder"), depression (P03 + P76, with P03 = "feeling depressed"; P76 = "depressive disorder") and sleep disturbances (P06), to investigate which issues in particular were affected. The incidences were plotted for illustration. All data were analyzed using JMP Pro 15.

Ethical approval for this study was obtained from the ethics committee of Antwerp University Hospital (approval number B3002020000058).

RESULTS

General Overview

The database contains 357.710 eligible consultations. The mean age of the consulting patients is 34 years ($SD = 23$) and 54.82% is female. **Figure 1** shows the evolution of all OOH consultations over time per 100.000 inhabitants in 2019 and 2020, divided by type of contact. At the beginning of the pandemic, OOH care dropped dramatically. Especially physical consultations declined, but were partly compensated by the increase in consultations by phone, which were recommended during the pandemic. The sum of physical consultations, telephone consultations and home visits shows a net decrease in non-COVID-19 related healthcare seeking behavior.

The Prevalence of OOH Encounters Due to Psychological Problems During COVID-Times

A total of 8.990 consultations (2.52% of all consultations; 95% CI 2.47–2.57) were coded for psychological diagnoses (ICPC-2 chapter P). **Figure 2** displays the sum of OOH home visits, physical consultations and telephone consultations due to psychological problems (all ICPC-2 P-codes) per 100.000 inhabitants over time in 2019 and 2020. Remarkably, about half of all contacts due to psychological problems (52%) during the first wave were by phone. In between the two waves, 36% of contacts due to psychological problems were by phone.

The descriptive statistics of the level of consultations before and during COVID-19 are reported in **Table 1**. The demand for care regarding psychological problems increased from 2.69/100.000 before COVID-19 to 5.24/100.000 during the first wave, and dropped again to 3.77/100.000 and 3.27/100.000 in between waves 1 and 2 and during the second wave, respectively. This evolution was significant, $F(3, 111) = 17.03$, $p < 0.0001$. Fisher's LSD *post-hoc* analysis was used to investigate the size and significance of the differences between the different time frames. The results of the *post-hoc* tests are presented in **Table 2**. No significant difference was found between the number of contacts in between waves 1 and 2 and those registered during wave 2, nor between the number of contacts during the pre-COVID-19 era and those registered in wave 2. However, all other differences in contact volume do differ significantly with $t = 1.98$, $p < 0.05$ or less.

The Pre-valence of OOH Encounters Due to Anxiety- or Depression-Related Problems and Sleep Disturbances

It was further explored what kind of psychological problems added to the observed pattern. To investigate the evolution of anxiety-related problems, all consultations which were registered with P01, P74, or P79 were taken into account. Whereas before COVID-19, anxiety problems accounted for 23.19% of all psychological problems, this share rose to 45.27% during the first wave. After that first wave, still about one third of all psychological problems are anxiety-related.

The evolution of anxiety is similar to that of psychological problems in general (**Table 1**). Significant changes were observed between the time periods, $F(3,110) = 55.31$, $p < 0.0001$. A rise from 0.62/100.000 consultations for anxiety-related problems before COVID-19 to 2.37/100.000 consultations during the first wave was observed. This figure decreased to 1.14/100.000 and 1.00/100.000 in between waves and during the second wave, respectively. The results of the *post-hoc* analysis are presented in **Table 2**. All differences between the time periods are significant with $t = 1.98$ and $p < 0.005$ or less, except the difference of anxiety-related contacts in between the waves and in the second wave.

To investigate depression-related problems, all consultations that were coded with P03 or P76 were taken into account. Remarkably, before COVID-19, depression accounts for 7.22% of all OOH consultations on psychological problems. During the first wave, only 4.39% of the consultations on psychological distress were related to depression. No significant differences were observed when comparing the prevalence rates of depression related consultations between the different periods in the light of the COVID-pandemic, $F(3,110) = 0.71$, n.s.

Finally, we investigated sleep disturbances (P06). Before COVID-19, sleep disturbances accounted for 4.35% of all OOH consultations on psychological problems. During the first wave, 2.67% of all consultations on mental problems were on sleep problems. Analyses revealed significant differences regarding the demands on sleep disturbances in OOH over time, $F(3, 110) = 2.80$, $p < 0.05$. Especially the period in between waves seemed critical, as the number of

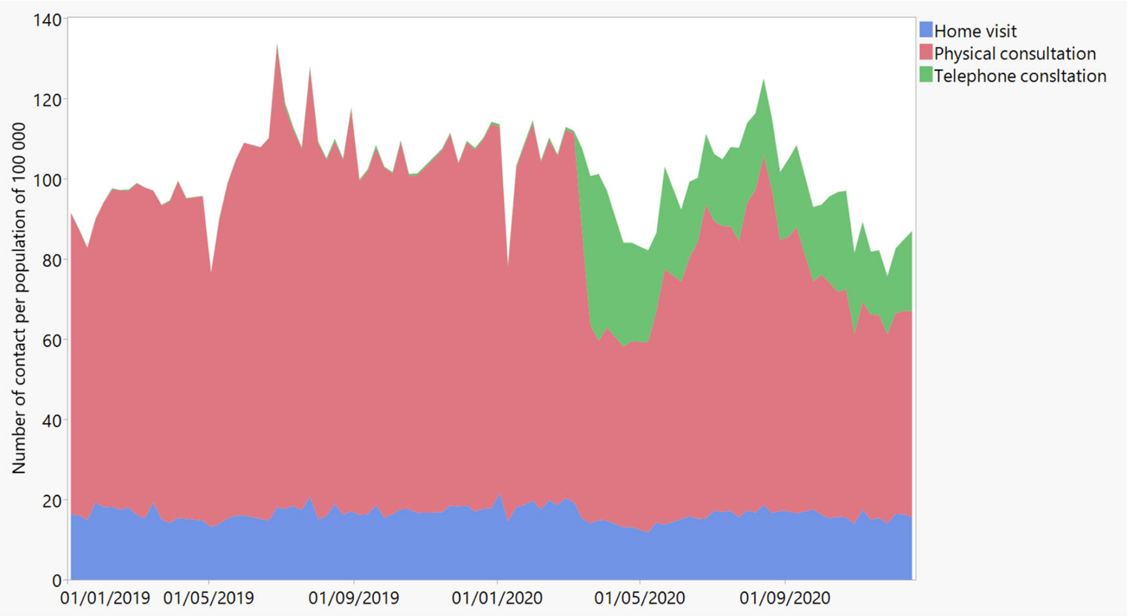

FIGURE 1 | Evolution of all physical consultations (in red), consultations by phone (in green), and home visits (in blue) over time in 2019 and 2020 as registered by iCAREdata, regardless the diagnosis.

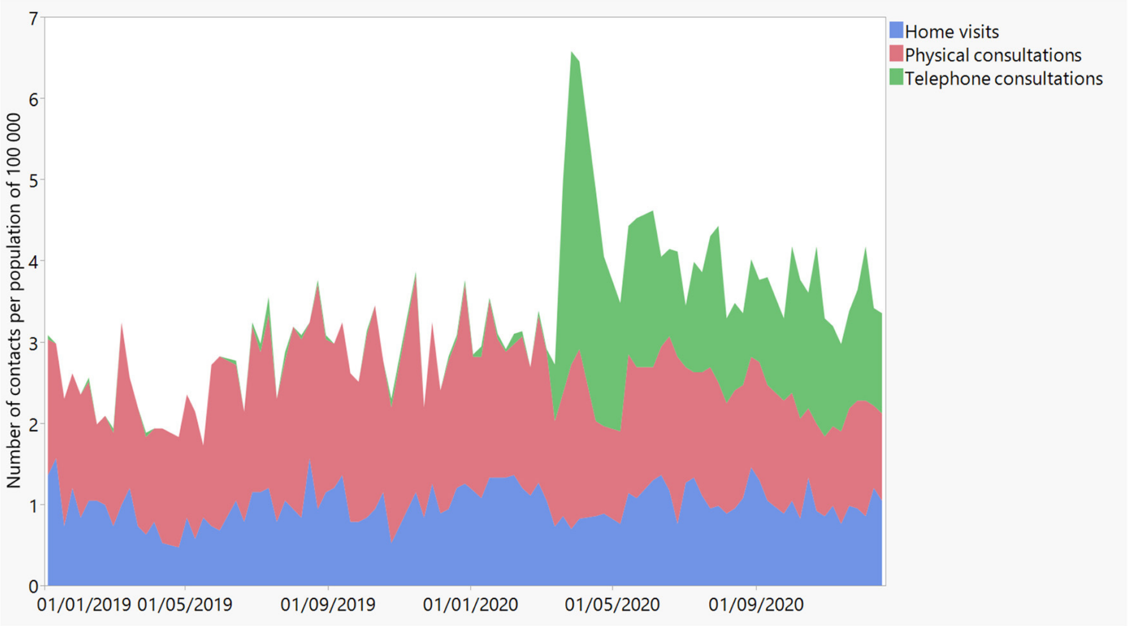

FIGURE 2 | Evolution of physical consultations (in red), consultations by phone (in green), and home visits (in blue) for psychological reasons (i.e., all P-codes of ICPC-2) over time in 2019 and 2020 as registered by iCAREdata.

request in this period was significantly higher compared to both the period before COVID-19 and the second wave, with $t = 1.98$, $p < 0.05$. No further differences were found.

DISCUSSION

To our knowledge, this study is the first that explored the prevalence and evolution of psychological problems against

TABLE 1 | Descriptive statistics of the levels of consultations due to psychological problems in general, anxiety-related problems, depression-related problems and sleep-related problems before COVID, during the first and second wave, and between the waves.

	Period	Mean incidence per 100.000	SD	95% CI
All psychological consultations	Pre-COVID	2.69	0.86	2.48–2.89
	First wave	5.24	1.55	3.81–6.67
	Between waves	3.77	1.37	3.26–4.28
	Second wave	3.27	0.78	2.67–3.87
Anxiety-related consultations	Pre-COVID	0.62	0.25	0.55–0.68
	First wave	2.37	0.94	1.50–3.25
	Between waves	1.14	0.39	0.99–1.29
	Second wave	1.01	0.35	0.74–1.28
Depression-related consultations	Pre-COVID	0.19	0.12	0.17–0.22
	First wave	0.23	0.13	0.11–0.35
	Between waves	0.23	0.11	0.19–0.27
	Second wave	0.19	0.10	0.12–0.27
Sleep-related consultations	Pre-COVID	0.12	0.08	0.10–0.14
	First wave	0.14	0.04	0.10–0.18
	Between waves	0.16	0.10	0.12–0.20
	Second wave	0.07	0.05	0.04–0.11

TABLE 2 | Results of the pairwise comparisons of the *post-hoc* analysis using the Fisher's Least Significant Difference (LSD) test.

	Comparison	Difference
General	Pre-COVID—First wave	−2.55***
	Pre-COVID—Between waves	−1.08***
	Pre-COVID—Second wave	−0.58
	First wave—Between waves	1.47*
	First wave—Second wave	1.97**
	Between waves—Second wave	0.50
Anxiety-related	Pre-COVID—First wave	−1.75***
	Pre-COVID—Between waves	−0.52***
	Pre-COVID—Second wave	−0.39*
	First wave—Between waves	1.23***
	First wave—Second wave	1.36***
	Between waves—Second wave	0.13
Sleep-related	Pre-COVID—First wave	0.02
	Pre-COVID—Between waves	0.04*
	Pre-COVID—Second wave	0.04
	First wave—Between waves	0.02
	First wave—Second wave	0.07
	Between waves—Second wave	0.08*

***$p < 0.0001$; **$p < 0.0005$; *$p < 0.0050$.

the background of the COVID-19-pandemic using a large database containing systematically collected clinical routine data of OOH care, including the diagnoses. A first finding is that OOH consultations in general decreased during the pandemic, while consultations specifically for psychological problems increased. The number of physical consultations also decreased, while telephone contacts increased. These general trends were described by Morreel et al. (5).

Our analyses revealed a significant rise in consultations due to psychological problems in general, and in anxiety-related problems in particular, since the start of the COVID-19-pandemic in Flanders. A peak during the first wave is observed. Although there was no (significant) rise during the second wave compared to the period in between waves, the demand for OOH care regarding anxiety-related problems remained elevated after the first wave compared to the period before COVID-19. Furthermore, consultations for sleep disturbances were more common in the weeks between the two waves compared to the pre-COVID-19 era or the second wave. In contrast, depression-related problems did not show any fluctuations over time.

These findings contrast with the general pattern of a decline in healthcare seeking behavior for primary and acute care during this phase of the pandemic, in Belgium as in the rest of the world (5, 8–10). While contacts for general health or emergency care declined, the number of OOH contacts for mental health problems rose. This trend was also found for emergency department visits in the US, where various mental health problems as well as social problems (e.g., overdoses) were higher in March through October 2020 as compared to the same period in 2019 (11). Interestingly, a study on primary care-recorded mental health problems suggested that the incidence of primary care- recorded depression and anxiety first declined significantly in English general practices, but returned to expected levels in September (12). These findings suggest that the decrease in regular mental health care reflects missed opportunities for care, and is compensated by the increased use of OOH care and emergency care. Missed care opportunities ultimately lead to an increase of the severity and the accumulation of mental health needs. The increased use of OOH care for mental health reasons can therefore also be seen as an indication of unmet mental health needs in the population.

Anxiety-related problems, including panic reactions, very well-fit the situation of the COVID-19 pandemic. A new and unknown virus obviously evokes a lot of stress responses. While some people may be afraid of getting ill or losing a loved one due to COVID-19, other factors such as financial hardship or fear of losing one's job may also play a role. Measures inducing social isolation, however, would be more likely to evoke feelings of loneliness or depression. Yet, regarding anxiety, social isolation may limit one's coping opportunities to effectively deal with anxiety as well-potentially enlarging the demands for help for anxiety-related problems. In regular (i.e., not OOH) primary care, the most common psychological diagnoses in Flanders are depression, acute stress, sleeping disturbances and "feeling anxious", respectively (13). The finding that depression and sleeping problems are less common in OOH care compared to non-OOH care while anxiety is more often a main theme in OOH care, may also mean that anxiety feels more urgent and pressing to patients, causing them to contact a physician outside the regular hours.

Our results show that, although possible mental health issues were addressed at times in the media in Belgium (messages focussing on staying fit, going outside for a walk, ...), this was not enough to compensate for the multiple stresses communities experience during the pandemic. Moreover, regular registration systems nor surveys might not be able to capture all problems. Therefore, governments need to think about advanced mental health infrastructures and systems that address well-being on a population level to better deal with these problems (14, 15).

One of the limitations of this study is that practitioners are unable to register more than one reason for encounter per consultation. This leads to underregistration when the patient also presents with a physical complaint. As psychological problems may be present as co-morbid problems next to a more prominent physical question during a consultation, our data might be underestimations of reality. Also, it should be noted that the data we used are collected on OOH care. This means that practitioners see patients they are not familiar with. Complex problems, like depressive state, might be more difficult to diagnose by doctors that do not know the patient when the patient does not clearly outline his emotional state. Additional data on regular care, delivered by familiar GP's, might add to the picture. It should be noted that, although our database covers a large area, the number of consultations regarding psychological problems are rather limited. Patients without a national insurance number were excluded so we do not have data on this vulnerable population. Finally, the findings should be carefully translated to other contexts, in particular to other countries where other forms of OOH care may be used.

Nevertheless, despite these limitations, our study shows the importance of a complementary use of routine registrations for managing (mental) health crises for policy makers and the organization of care.

DATA AVAILABILITY STATEMENT

The data analyzed in this study is subject to the following licenses/restrictions: The iCAREdata dataset is used. Researchers can consult the database after applying for access. Due to privacy rules, iCAREdata is only allowed to provide aggregated data. Requests to access these datasets should be directed to https://www.uantwerpen.be/en/projects/icaredata/icaredata-project.

ETHICS STATEMENT

Ethical approval for this study was obtained from the ethics committee of Antwerp University Hospital (Approval No. B3002020000058). Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

AUTHOR CONTRIBUTIONS

KVdB, SM, IG, VV, ER, and HP equally developed the research question and the research plan. SM prepared the data and conducted the analyses. KVdB wrote the different drafts of the manuscript. All other authors commented the drafts and added equally to an improvement of the manuscript.

REFERENCES

1. Indegaard N, Benros ME. COVID-19 pandemic and mental health consequences: systematic review of the current evidence. *Brain Behav Immun.* (2020) 89:531–42. doi: 10.1016/j.bbi.2020.05.048
2. Xiong J, Lipsitz O, Nasri F, Lui LM, Gill H, Phan L, et al. Impact of COVID-19 pandemic on mental health in the general population: a systematic review. *J Affect Disord.* (2020) 277:55–64. doi: 10.1016/j.jad.2020.08.001
3. Van Hoof E, De Laet H, Résibois M, Gérard S, Dekeyser S, Loix E, et al. *Living Document I: Belgian Mental Health (Care) Data Repository*. Brussels: Belgian Superior Health Council (2021). p. 36. doi: 10.5281/zenodo.4966026
4. Lades LK, Laffan K, Daly M, Delaney L. Daily emotional well-being during the COVID-19 pandemic. *Br J Health Psychol.* (2020) 25:902–11. doi: 10.1111/bjhp.12450
5. Morreel S, Philips H, Verhoeven V. Organisation and characteristics of out-of-hours primary care during a COVID-19 outbreak: a real-time observational study. *PLoS ONE.* (2020) 15:e0237629. doi: 10.1371/journal.pone.0237629
6. Colliers A, Bartholomeeusen S, Remmen R, Coenen S, Michiels B, Bastiaens H, et al. Improving care and research electronic data trust antwerp (iCAREdata): a research database of linked data on out-of-hours primary care. *BMC Res Notes.* (2016) 9:1–7. doi: 10.1186/s13104-016-2055-x
7. Bartholomeeusen S, Philips H, Van Royen P, Remmen R, Coenen S. *iCAREdata: Improving Care and Research Electronic Data Trust Antwerp*. Antwerp: University of Antwerp (2017). doi: 10.5281/zenodo.823697
8. Verhoeven V, Tsakitzidis G, Philips H, Van Royen P. Impact of the COVID-19 pandemic on the core functions of primary care: will the cure be worse than the disease? A qualitative interview study in Flemish GPs. *BMJ Open.* (2020) 10:e039674. doi: 10.1136/bmjopen-2020-039674
9. Imlach F, McKinlay E, Kennedy J, Pledger M, Middleton L, Cumming J, et al. Seeking healthcare during lockdown: challenges, opportunities and lessons for the future. *Int J Health Policy Manag.* (2021). doi: 10.34172/ijhpm.2021.26
10. Nab M, van Vehmendahl R, Somers I, Schoon Y, Hesselink G. Delayed emergency healthcare seeking behaviour by Dutch emergency department visitors during the first COVID-19 wave: a mixed

methods retrospective observational study. *BMC Emerg Med.* (2021) 21:56. doi: 10.1186/s12873-021-00449-9

11. Holland KM, Jones C, Vivolo-Kantor AM, Idaikkadar N, Zwald M, Hoots B, et al. Trends in US emergency department visits for mental health, overdose, and violence outcomes before and during the COVID-19 pandemic. *JAMA Psychiatry.* (2021) 78:372–9. doi: 10.1001/jamapsychiatry.2020.4402
12. Carr MJ, Steeg S, Webb RT, Kapur N, Chew-Graham CA, Abel KM, et al. Effects of the COVID-19 pandemic on primary care-recorded mental illness and self-harm episodes in the UK: a population-based cohort study. *Lancet Public Health.* (2021) 6:e124–e35. doi: 10.1016/S2468-2667(20)30288-7
13. Truyers C, Bartholomeeusen S, Buntin F. Geestelijke gezondheidsproblemen in de huisartsenpraktijk. Incidenties op basis van Integoregistraties. *Huisarts Nu*. (2012) 41:25–6.
14. Lestari R. Setyawan FEBJJoPHR. Mental health policy: protecting community mental health during the COVID-19 pandemic. *J Public Health Res*. (2021) 10:2231. doi: 10.4081/jphr.2021.2231
15. Ashcroft R, Donnelly C, Dancey M, Gill S, Lam S, Kourgiantakis T, et al. Primary care team's experiences of delivering mental health care during the COVID-19 pandemic: a qualitative study. *BMC Fam Pract.* (2021) 22:1–12. doi: 10.1186/s12875-021-01496-8

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Dynamic observation and qualitative analysis of a psychological crisis hotline during the COVID-19 pandemic

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Objective: The aim of this study was to analyze the chief complaints of psychological crisis hotlines during the coronavirus disease 2019 (COVID-19) pandemic in Jiangsu, China, and to summarize the psychological characteristics of the public during the different stages of COVID-19.

Methods: The chief complaints of calls to the psychological crisis hotline from 27 January 2020 to 30 June 2020. A total of 578 calls were extracted and grouped using thematic analysis into categories. After statistical analysis, the monthly and three-period trends were observed dynamically to determine whether there were statistical differences in the proportion of specific chief complaints over the phases.

Results: There were a total of 495 cases of psychological problems or physical discomfort, accounting for 85.64% of the total sample number of hotline calls related to the pandemic. The numbers of callers with anxiety, depression, obsessive-compulsive symptoms, illness anxiety, insomnia, and physical discomfort were 370 (64.01%), 103 (17.99%), 33 (5.71%), 36 (6.23%), 51 (8.82%), and 72 (12.46%), respectively, and 83 (14.36%) callers consulted other problems. The monthly main complaints showed a fluctuating trend, and each main complaint peaked at different stages. The main complaints during the three stages had distinct features, respectively, and the proportions of calls for the specific complaints differed statistically over the phases.

Conclusion: Dynamic observation and qualitative analysis of psychological crisis hotline data might indicate dynamic changes and accordingly provide guidance for online crisis intervention when other public health crises occur.

KEYWORDS

COVID-19, psychological crisis hotline, dynamic observation, qualitative analysis, public

Introduction

Coronavirus disease 2019 (COVID-19) has been the focus of attention since December 2019. It has widely and rapidly spread in China and several other countries, causing an outbreak of acute infectious pneumonia. The increasing numbers of patients, suspected cases, and outbreak-affected provinces and countries have elicited public worry about becoming infected (1). Anxiety, depression, stress, and sleep problems were commonly reported among the public during the pandemic, and higher suicidal risk at population level was one of the most important concerns (2). In the face of COVID-19, which is highly contagious and requires quarantine measures, hotlines have become the most convenient and feasible first choice for psychological assistance. The National Health Commission immediately issued guidelines for emergency psychological crisis intervention for people affected by COVID-19 (3) and subsequently announced the establishment of a psychological crisis hotline (4). Online psychological crisis intervention for the public was opened in all provinces across China. The internet hospital gradually opened up more service resources to provide psychological counseling and clinical diagnosis and treatment for patients, their family members, and other people affected by the epidemic. The Nanjing Crisis Intervention Center is the first domestic professional institution for crisis intervention and suicide prevention established on 1 July 1991. The crisis intervention center has a psychological crisis intervention clinic and a psychological crisis intervention hotline. The Jiangsu Provincial Psychological Crisis Intervention Hotline was established in 2007, and the hotline was linked to the Nanjing Crisis Intervention Center. At the same time, since 2012, we can also get help by dialing Nanjing Health 12,320 hotline, realizing three-line integration. Subsequently, a 24-h psychological hotline was set up to provide professional psychological crisis intervention services to prevent psychological stress due to the epidemic. Individuals in different age groups were psychologically affected by different tendencies at different stages of the epidemic. Therefore, by analyzing the main complaints of the three psychological crisis hotlines during the COVID-19 epidemic, this study dynamically observed the public's psychological response under specific crisis situations. It will provide guidance for psychological crisis intervention hotline work in the future, particularly for similar public health issues.

Methods

Study setting

Starting from 27 January 2020, the hotline services have been provided from 8:00 to 18:00, and it was established for 24-h operation on 7 February 2020. Approximately 100 psychiatrists, psychological consultants, and psychotherapy professionals from the Jiangsu Psychological Crisis Center in Nanjing Brain Hospital affiliated with Nanjing Medical University participated in the hotline work as volunteers. At the outset, they received uniform or standardized training and supervision to record callers' complaints, as well as monthly group supervision.

Inclusion and exclusion criteria

Only calls where the caller specifically referenced COVID-19 or the pandemic were included. Calls related to emotional problems, marital problems, children's education, family problems, psychological crisis, mental illness medication, etc., where COVID-19 was not discussed as a factor, were excluded. The following calls were also excluded: (1) the caller's main purpose was not seeking psychological services and (2) "null" calls (i.e., silence, harassing, or hoax calls). For repeat calls from the same caller, only the first call was included in the analysis.

Qualitative analysis

Dynamic records of the psychological hotline for epidemic prevention were updated over 5 months from 27 January to 30 June 2020 and extracted from the Jiangsu Psychological Crisis Center in Nanjing Brain Hospital affiliated with Nanjing Medical University. Based on previous studies, the theme analysis was adopted to extract the key information of the main complaints from the call records to determine the content and meaning. Classification analysis was used to classify the callers into the following categories: (1) psychological problems such as anxiety, depression, obsessive-compulsive symptoms, illness anxiety, and insomnia; (2) physical discomfort; and (3) other problems, including pandemic-related quarantine, registration, drug procurement, local policy consultation, etc. Words with obvious emotional indications such as worry, nervousness, and fear in the call records were classified as anxiety; calls regarding fear of infection or suspicion of suffering from a certain disease or sequelae were classified as illness anxiety; emotional depression, moodiness, pessimism, feelings of unfairness, and suicidal thoughts were classified as depression; fear of getting dirty, repetitive handwashing and checking, and disinfection were classified as obsessive-compulsive symptoms; poor sleep and difficulty in falling asleep were classified as insomnia; self-reported symptoms such as low-grade fever, cough, and chest pain without any evidence of COVID-19 infection were classified as physical discomfort. Categories were not mutually exclusive. All categories we defined as appeared in each call.

Dynamic observation

We divided the period from 27 January to 30 June into three phases according to the dynamic changes in the COVID-19 epidemic in China, namely, the peak period (27 January to– 29 February) when the majority of Chinese people were quarantined at home during the peak of COVID-19 infection; the prerelease period (1 March to 30 April) before quarantine release and resumption; and the resumption period (1 May to 30 June) when most workplaces and schools were gradually reopened. The statistical products and services solution (IBM SPSS 25.0) was used for quantitative analysis, such as calculating the proportion of each category to the total calls. The monthly and three-period trends were dynamically observed by plotting. Finally, the chi-square test was used to determine whether the proportions of calls for the specific complaints differed statistically over the phases.

Results

A total of 4,319 psychological hotline calls were received from 27 January to 30 June 2020. A total of 1,180 call records were related to the epidemic, 602 repeated or harassing calls were excluded, and a total of 578 were finally included in the data analysis. Among them, 495 were about psychological problems or physical discomfort, and 83 were simply about consulting other problems.

General information

Some information, including name, gender, age, education, and job, was missing because some callers were unwilling to provide private information. A total of 489 individuals disclosed their sex in this analysis sample, including 215 women (43.97%) and 274 men (56.03%). A total of 310 individuals provided specific ages, including 4 participants (1.29%) from 0 to 18 years old, 247 participants (79.68%) from 19 to 45 years old, 47 participants (15.16%) from 46 to 60years old, and 12 participants (3.87%) >60 years old. The results showed that the proportion of male callers was slightly higher than that of female callers, and the majority of callers were 19–45 years old. Specific medical history was provided in 139 cases (24.05%), mainly including mental disorders such as depression, bipolar disorder, anxiety disorder, schizophrenia, insomnia, and somatic diseases such as hypertension, diabetes, chronic pharyngitis, and Parkinson's disease. There were 141 callers (24.39%) with a medication history, of which 57 (9.86%) provided specific medications, mainly lorazepam, sertraline, escitalopram, olanzapine, and fluoxetine. Overall, there were a total of 495 callers that had psychological problems or physical discomfort, accounting for 85.64% of the total sample number of hotline calls related to the epidemic.

Consultation content

The main results were as follows: (1) psychological problems: anxiety (n = 370, 64.01%), depression (n = 103, 17.99%), obsessive-compulsive symptoms (n = 33, 5.71%), illness anxiety (n = 36, 6.23%), and insomnia (n = 51, 8.82%); (2) physical discomfort (n = 72, 12.46%); and (3) other problems (n = 83, 14.36%).

Multiple psychological problems

As shown in Table 1, some callers reported having both psychological problems. Anxiety was still the main complaint, and most callers were nervous and worried because of the fear of contacting or getting infected with the new coronavirus. A small number also reported three or more symptoms, most of which included anxiety and insomnia. Obsessive-compulsive symptoms are also common co-symptoms. Other symptoms were mainly physical discomfort, depression, and illness anxiety.

Dynamic changes in chief complaints

Monthly trend

As shown in Table 2, the proportion of callers with anxiety as the chief complaint remained high throughout the epidemic period, and the highest proportion (81.58%) occurred in March; the proportion of callers with physical discomfort and insomnia was only obvious in February and declined during the later period; the proportion of callers with depression and obsessive-compulsive symptoms was low in the early stage and increased significantly in March and April, reaching as high as 35 and 21% in April, and then gradually decreasing in the later period. Generally, a fluctuating trend was shown (Figure 1), and each main complaint peaked at different stages.

Three-phase trend

As shown in Table 3; Figure 1, the main complaints during the three stages also had distinct features, respectively. During the peak of COVID-19 infection, the number of national newly diagnosed COVID-19 cases increased rapidly. To curb the spread of the epidemic, the government took measures to control the population flow. Correspondingly, anxiety was the main complaint of callers. Most callers were worried about the new coronavirus. Callers with anxiety complaints had more physical discomfort and insomnia symptoms, but some calls were mainly related to consultation on quarantine

TABLE 1 Two kinds of symptoms.

Complaint N	Illness anxiety	Anxiety	OC symptoms	Depression	Physical discomfort
Anxiety	16	-	-	-	-
OC symptoms	0	29	-	-	-
Depression	3	38	14	-	-
Physical discomfort	5	66	11	6	-
Insomnia	0	41	3	8	9

OC, obsessive-compulsive.

TABLE 2 Monthly changes in chief complaints.

		Total	Illness anxiety	Anxiety	OC symptoms	Depression	Physical discomfort	Insomnia	Other problems
Jan 27th-Feb 29th	N	281	2	156	3	26	46	28	35
	%		0.71%	55.52%	1.07%	9.25%	15.37%	9.96%	12.46%
Mar 1st-Mar 31th	N	76	4	62	3	24	8	10	11
	%		5.26%	81.58%	3.95%	31.58%	10.53%	13.16%	14.47%
Apr 1st -Apr 30th	N	100	10	64	21	35	12	4	15
	%		10.00%	64.00%	21.00%	35.00%	12.00%	4.00%	15.00%
May 1st-May 31th	N	82	15	62	3	16	6	5	10
	%		18.29%	75.61%	3.66%	19.51%	7.32%	6.10%	12.20%
Jun 1st-Jun 30th	N	39	5	26	3	3	0	4	12
	%		12.82%	66.67%	7.69%	7.69%	0.00%	10	30.77%

Other problems include consulting about quarantine, registration, medicine purchase, and local policy.

policies and registration of drugs. The proportion of callers with depression and obsessive-compulsive symptoms was not high during this period. The spread of the epidemic was basically blocked in the middle period, and the number of patients with new coronary pneumonia in hospitals across the country decreased. The proportion of callers with anxiety remained high, while the proportion with depression and compulsion increased significantly; the proportion with illness anxiety gradually increased, and the proportion with physical discomfort and insomnia declined. Compulsions mainly manifested as repeated medical examinations and repeated disinfection and washing for the fear of illness. During the resumption period, epidemic prevention and control entered into normalization, and almost full work resumption occurred. The proportion of callers with anxiety as the main complaint remained high, but the proportion of callers with depression and obsessive-compulsive behavior declined. At the same time, more calls concerned consultation on resumption of work and local epidemic prevention policies, and the proportion of callers with illness anxiety gradually increased. For example, callers with a negative nucleic acid test were still worried about the sequelae of the new coronary pneumonia. At the same time, we also found a statistical difference in the proportion of calls for specific complaints over the phases (Table 4).

Discussion

According to the dynamic observation results and qualitative analysis of the information extracted from the detailed records of the psychological crisis hotline in this study, we found that the proportion of male callers was slightly higher than that of female callers during the COVID-19 outbreak period. However, studies have found that women are more likely than men to develop psychological stress responses, which may be related to their own susceptibility factors, including physical, psychological, and social factors (5, 6), but it is possible that women are more resilient than men. During the COVID-19 outbreak, we applied Zung's Self-Rating Anxiety Scale, Zung's Self-Rating Depression Scale, the Connor–Davidson resilience scale, and Simplified Coping Style Questionnaire to 3,180 people and finally found that individuals with a higher level of mental resilience and active coping styles had a lower level of anxiety and depression (7). In addition, hotline callers were mainly young and middle-aged people aged 19–45 years, which may be related to young people being more receptive to online smart services. To date, several online psychological self-help intervention systems have been developed for online psychoeducation and psychotherapy, including

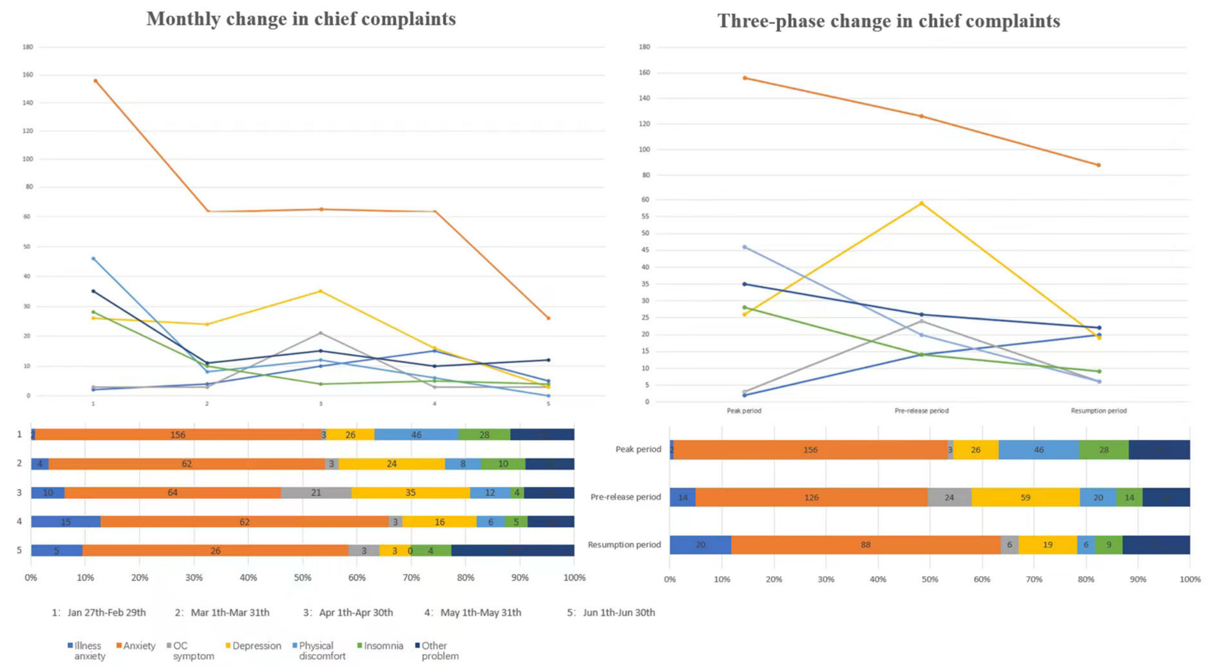

FIGURE 1
The monthly and three-phase changes in chief complaints of the psychological hotline from 27 January to 30 June 2020. Anxiety was the main complaint, and its proportion was significantly higher than that of other complaints. Overall, calls regarding anxiety, insomnia, physical discomfort, and other problems showed a downward trend, and calls regarding anxiety exhibited a plateau period from March to May. In particular, calls regarding illness anxiety increased. In addition, calls regarding depression and obsessive-compulsive symptoms exhibited a small peak in April, which was during the prerelease period. Other problems include consulting about quarantine, registration, medicine purchase, and local policies.

TABLE 3 Proportions of chief complaints during the three-phase period.

		Total	Illness anxiety	Anxiety	OC symptoms	Depression	Physical discomfort	Insomnia	Other problems
Peak period	N	281	2	156	3	26	46	28	35
	%		0.71%	55.52%	1.07%	9.25%	15.37%	9.96%	12.46%
Prerelease period	N	176	14	126	24	59	20	14	26
	%		7.95%	71.59%	13.64%	33.52%	11.36%	7.95%	14.77%
Resumption period	N	121	20	88	6	19	6	9	22
	%		16.53%	72.72%	4.96%	15.75	4.96%	7.44%	18.18

cognitive behavioral therapy or supportive therapy for depression, anxiety, and insomnia. Several artificial intelligence techniques and applications have also been put into use as interventions for psychological crises during the epidemic (8). Meanwhile, publicity efforts should be increased to raise public awareness and make it easier for the public to get professional help themselves.

According to the overall trend, we found that calls regarding anxiety, insomnia, physical discomfort, and other problems showed a downward trend in the monthly and three-phase analysis, mainly in the early stage. The main manifestations of anxiety were nervousness, worry, and fear of contracting or getting infected with the new coronavirus, accompanied by dizziness, palpitation, cough, and other physical symptoms, as well as insomnia. This is a common early psychological response under a stressful epidemic state, and the fear of the uncertainty may also be present. Psychological stress is an interactive dynamic balance "system" composed of an individual's life events, cognitive evaluation, coping style, social support, personality characteristics, and psychosomatic response. When the system is out of balance under the stressful conditions, the individual will experience a state

TABLE 4 Proportions of calls for specific complaints differed statistically over the phases.

	Illness Anxiety +OC symptoms	Anxiety	Depression	Physical discomfort	Insomnia	Other problems	Statistical test	*p*-value
Peak period	5 (1.7%)	156 (52.7%)	26 (8.8%)	46 (15.5%)	28 (9.5%)	35 (11.8%)	$\chi^2 = 74.94$	<0.001
Prerelease period	38 (13.4%)	126 (44.5%)	59 (20.8%)	20 (7.1%)	14 (4.9%)	26 (9.2%)		
Resumption period	26 (15.3%)	88 (51.8%)	19 (11.2%)	6 (3.5%)	9 (5.3%)	22 (12.9%)		

of psychological stress. Moderate psychological stress may motivate individuals to actively face catastrophic events, but excessive psychological stress response may cause individuals to experience hypersensitivity, difficulty concentrating, impaired memory, decreased judgment ability, anxiety and depression, panic and irrational behaviors, and even serious psychological problems such as post-traumatic stress disorder (PTSD). One study conducted five follow-up visits of SARS survivors over a period of 4 years and found that the prevalence of PTSD exceeded 40% (9). In addition, studies have shown that in the early stages of an outbreak lack of information from official channels, misleading information from social media, and fear of the uncertainty can also increase public anxiety (10). According to other hotline reports, during the peak of the epidemic, the "Xinxinyu" hotline of Wuhan Mental Health Center received a total of 2,653 calls from 4 February to 24 February. Among them, 33.5% of callers reported anxiety, 10.1% expressed depressive symptoms, and 5.5% had sleep problems (11). In addition, the crisis hotline of the Brain Hospital affiliated with Guangzhou Medical University received 1,973 calls related to the COVID-19 epidemic from 23 January to 26 March. A total of 523 (26.5%) calls concerned emotional problems directly caused by anxiety, fear, worry, and hypochondriasis symptoms (5, 6). This is also consistent with our observations. We found that complaints of anxiety and physical discomfort accounted for a high proportion of hotline calls during the peak of the epidemic, followed by depression (12). Therefore, psychological crisis intervention in the early stage of the new coronary pneumonia epidemic may have effectively reduced or alleviated the occurrence of related psychological problems or mental disorders. Regarding the early response, psychological intervention mainly focused on normalizing the anxiety response, mainly using core listening skills and providing support to soothe the panic caused by the caller's psychological imbalance, guiding them to normalize and accept the anxiety response, and understand the progress of prevention and control of the epidemic.

In particular, one interesting point was that calls regarding illness anxiety showed a modest upward trend. This may have occurred because the public was overly nervous about information related to the epidemic. If the epidemic is not thoroughly controlled, it will fluctuate periodically. Illness anxiety can be defined as a constant, excessive, and irrational worry that is present despite an absence of physical or psychological disease. COVID-19 causes anxiety because it affects people's lives negatively and brings many uncertainties to society. Since the virus has a high rate of spreading from person to person, it causes pressure in personal relationships, and the anxiety increases due to uncertainties regarding how long the pandemic will last and how long its effects will continue. This is also consistent with our results. Previous studies have found that female gender, accompanying chronic disease, and previous psychiatric history were found as risk factors for illness anxiety (13). In subsequent studies, we can further verify and carry out early prevention for high-risk groups.

We also found that calls regarding depression and obsessive-compulsive symptoms showed a small spike in April. As the quarantine period becomes longer, public mental health will worsen. Individuals with any physical symptoms that may be related to the infection will become repeatedly worried, and some obvious compulsive behaviors will be shown; additionally, people will be quarantined for a long time. Prolonged quarantine often leads to feelings of boredom, depression, and isolation, resulting in significantly higher post-traumatic stress and depression symptoms (14). Moreover, long-term quarantine at home without income causes great economic pressure for families. During this period, psychological intervention should mainly involve providing various types of psychological support. Although population movement is prohibited during an epidemic, this does not mean self-isolation. The public can be encouraged to use mobile phones and the internet to communicate with family and friends and not let themselves fall into a state of self-isolation. If effective adjustments cannot be made for a long time, the public should be advised to seek professional psychological assistance. Second, the most important psychological intervention during this period should be the popularization of psychological science, to inform the public of self-help methods for psychological crises, combined with internet services and smartphones, so that the public can find a sense of self-control, reduce their anxiety level, and increase their sense of security (15). There may be additional social support for people who are isolated, people with low family incomes, and people who have lost income due to the epidemic (14). The study also found that the proportion of callers who consulted about drug purchase, registration, resumption of work in other places, and local epidemic prevention policies was also relatively high, accounting for a considerable proportion during each period. This is mainly because prolonged quarantine will cause difficulties in purchasing drugs and medical treatment, financial difficulties due to lack of work, and lack of knowledge about official policies. Therefore, it is necessary to explore the psychological hotlines (16) and online medical treatment models of internet hospitals (17). To help prevent and alleviate the psychological distress caused by the epidemic, the National Health Commission has launched a national psychological assistance hotline inquiry service, and crisis hotlines across the country will successively provide 24-h free psychological services (18).

In short, based on the guiding principles of psychological crisis intervention during the COVID-19 epidemic, active prevention should be performed while slowing down and trying to control the psychosocial impact caused by the epidemic according to the different psychological characteristics of the public during different periods. Additionally, healthcare professionals should be alert to the various psychological effects and mental disorders after the epidemic, such as post-traumatic stress, persistent depression, anxiety and somatization reactions, persistent obsessive-compulsive disorder, and insomnia. In fact, the number of hotline consultations has increased rapidly in the wake of the COVID-19 outbreak, which may be due to the use of new media to promote mental health knowledge and improve the public's psychological preparation for the crisis. However, the public's demand for psychological services has increased the professional requirements for hotline operators, who need to have corresponding professional qualifications and rich experience in helping others. Therefore, efforts should be made in the following aspects: (1) establish a talent pool; usually, the psychological hotline operators have basic psychological knowledge and basic counseling skills; (2) improve the supervision and training system for professionals; and (3) form clear management system and service standard for the operation of psychological hotline. When other public health crises occur, work on the psychological crisis intervention hotline by different groups can be targeted and adapted as appropriate (19). In addition, in the next step, the caller's psychological changes and mental state can be tracked after the epidemic, and the impact of crisis events on the public can be explored to identify positive response measures.

There are some limitations to this study. The dynamic observation of psychological hotlines combined with qualitative and quantitative analysis can help understand the public's psychological state in a timely manner during an epidemic. The disadvantage of the study is that the sample size is limited, and the study is restricted by the region, with certain regional characteristics. In the future, we can expand publicity and unite with various provinces and even psychological hotline centers across the country to perform this work. In addition, approximately a quarter of the callers had a detailed history of illness, mainly including some common mental disorders and chronic physical diseases. Most of the drugs being taken are psychotropic. We cannot differentiate between the worsening of a preexisting condition and a specific psychological response to the epidemic. Most of the people seeking help were middle-aged and young people who were willing to actively seek help. They can only represent a small number of people, not the whole. Therefore, to fully understand the public's psychological state, the data should be supplemented in other ways.

Data availability statement

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

Ethics statement

The studies involving human participants were reviewed and approved by the Institutional Review Board of the affiliated Nanjing Brain Hospital of Nanjing Medical University. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

MO and SS contributed to the writing of this article and the statistical analysis of this article. NL led the whole study, including putting forward this study, and carrying out the study. NZ contributed suggestions on revision after review of the manuscript. JLe and HY contributed to the preparation of the psychological crisis hotline. HM, PZ, and CT collected data. HO and JLi contributed to quality control. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

Publisher's note

References

1. Bao Y, Sun Y, Meng S, Shi J, Lu L.nCoV epidemic: address mental health care to empower society. *Lancet*. (2020) 395:e37–8. doi: 10.1016/S0140-6736(20)30309-3

2. Gunnell D, Appleby L, Arensman E, Hawton K, John A, Kapur N, et al. Suicide risk and prevention during the COVID-19 pandemic. *Lancet Psych*. (2020) 7:468–471. doi: 10.1016/S2215-0366(20)30171-1

3. National Health Commission of China. A notice on the issuance of guidelines for emergency psychological crisis intervention in pneumonia for novel coronavirus infections. (2020). Available online at: http://www.nhc.gov.cn/xcs/zhengcwj/202001/6adc08b966594253b2b791be5c3b9467.shtml

4. National Health Commission of China. A notice on the issuance of guidelines for the psychological assistance hotline during the prevention and control of the new coronavirus pneumonia epidemic. (2020). Available online at: http://www.nhc.gov.cn/xcs/zhengcwj/202002/f389f20cc1174b21b981ea2919beb8b0.shtml

5. Wang C, Pan R, Wan X, Tan Y, Xu L, Ho CS, et al. Immediate psychological responses and associated factors during the initial stage of the 2019 coronavirus disease (COVID-19) epidemic among the general population in China. *Int J Environ Res Public Health.* (2020) 17:1729. doi: 10.3390/ijerph17051729

6. Wang J, Wei H, Zhou L. Hotline services in China during COVID-19 pandemic. *J Affect Disord.* (2020) 275:125–6. doi: 10.1016/j.jad.06030

7. Song S, Yang X, Yang H, Zhou P, Ma H, Teng C, et al. Psychological resilience as a protective factor for depression and anxiety among the public during the outbreak of COVID-19. *Front Psychol.* (2021) 11:618509. doi: 10.3389/fpsyg.2020.618509

8. Liu S, Yang L, Zhang C, Xiang YT, Liu Z, Hu S, et al. Online mental health services in China during the COVID-19 outbreak. *Lancet Psych.* (2020) 7:e17–8. doi: 10.1016/S2215-0366(20)30077-8

9. Hong X, Currier GW, Zhao X, Jiang Y, Zhou W, Wei J, et al. Posttraumatic stress disorder in convalescent severe acute respiratory syndrome patients: a 4-year follow-up study. *General Hospital Psych.* (2009) 31:546–54. doi: 10.1016/j.genhosppsych.06008

10. Torales J, O'Higgins M, Castaldelli-Maia JM, Ventriglio A. The outbreak of COVID-19 coronavirus and its impact on global mental health. *Int J Soc Psychiatry.* (2020) 66:317–20. doi: 10.1177/0020764020915212

11. Li WT, Yang Y, Tong J, Li Y, Liu L, Liu C, et al. Trend analysis of calls of wuhan 'xinxinyu' psychological hotline from february 4 to february 24 in 2020. *Psychol Commun*. (2020) 1:24–7. (In Chinese).

12. Song S, Li J, Ma H, Leng J, Chen J, Teng C, et al. Analysis of jiangsu psychological crisis intervention hotline during the peak of outbreak of covid-19. *J Clin Psych*. (2020) 30:365–7. (In Chinese).

13. Özdin S, Bayrak Özdin S. Levels and predictors of anxiety, depression and health anxiety during COVID-19 pandemic in Turkish society: the importance of gender. *Int J Soc Psychiatry.* (2020) 66:504–11. doi: 10.1177/0020764020927051

14. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet.* (2020) 395:912–20. doi: 10.1016/S0140-6736(20)30460-8

15. Xiang YT, Zhao N, Zhao YJ, Liu Z, Zhang Q, Feng Y, et al. An overview of the expert consensus on the mental health treatment and services for major psychiatric disorders during COVID-19 outbreak: China's experiences. *Int J Biol Sci.* (2020) 16:2265–70. doi: 10.7150/ijbs.47419

16. Xiang YT, Yang Y, Li W, Zhang L, Zhang Q, Cheung T, et al. Timely mental health care for the 2019 novel coronavirus outbreak is urgently needed. *Lancet Psych.* (2020) 7:228–9. doi: 10.1016/S2215-0366(20)30046-8

17. He D, Gu Y, Shi Y, Wang M, Lou Z, Jin C, et al. COVID-19 in China: the role and activities of internet-based healthcare platforms. *Glob Health Med.* (2020) 2:89–95. doi: 10.35772/ghm.2020.01017

18. National Health Commission of China. Psychological assistance hotline enquiry service. (2020). Available online at: http://bmfw.www.gov.cn/xxgzbdfyxlyzrxcx/index.html

19. Duan L, Zhu G. Psychological interventions for people affected by the COVID-19 epidemic. *Lancet Psych.* (2020) 7:300–2. doi: 10.1016/S22150366(20)30073-0

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Psychological wellbeing and the association with burnout in a cohort of healthcare workers during the COVID-19 pandemic

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Burnout, depression, and anxiety are prevalent among healthcare workers (HCWs) during the COVID-19 pandemic and have been previously shown to contribute to poor health outcomes and reduced quality of care. Positive psychological constructs such as positive affect and meaning and purpose are related to resilience in the face of significant stress. No studies have examined these associations among a cohort of HCWs during this pandemic. The purpose of this study was to examine the association of depression, anxiety, positive affect, and meaning and purpose with burnout among HCWs during the COVID-19 pandemic. We utilized data from a cross-sectional survey conducted between September 29-December 8, 2021, among a cohort of 2,411 HCWs from a large, tertiary academic health care system in the Chicago area. We employed the Patient-Reported Outcomes Measurement Information System (PROMIS) measures for depression, anxiety, positive affect, and meaning and purpose and burnout was measured by the Oldenburg Burnout Inventory (OLBI). The majority (80.88%) of HCWs in this study identified as White, Non-Hispanic race/ethnicity, female sex (82.37%), and roughly one third were between ages 30–39 years old (30.98%). Registered nurses (26.96%) accounted for the largest single occupation group. The mean burnout score was 36.87 (SD = 7.65), with 53.38% of participants classified as having burnout, and registered nurses demonstrating the highest proportions of burnout (63.54%). Higher depression (coef = 0.15, SE = 0.03, $p < 0.001$) and anxiety (coef = 0.25, SE = 0.02, $p < 0.001$) scores were associated with higher burnout in multivariable linear regression models. Increased positive affect (coef= −0.19, SE= 0.02, $p < 0.001$) and meaning and purpose (coef= −0.12, SE= 0.01, $p < 0.001$) scores were significantly associated with reduced burnout. Positive affect and meaning and purpose were inversely associated with burnout among a cohort of HCWs during the COVID-19 pandemic. Previous studies of positive affect and meaning and purpose suggest the potential buffering effect that these indices may have on burnout. Future research is needed to examine the effect of positive affect and meaning and purpose on mitigating the negative impacts of burnout, depression, and anxiety among HCWs as they cope with the stress of the COVID-19 pandemic and beyond.

KEYWORDS

healthcare worker (HCW), burnout—professional, positive psychology, depression, anxiety, cohort study

Introduction

Burnout is an ongoing, significant threat to healthcare worker (HCW) well-being and to health systems' abilities to deliver quality, people-centered care (1–4). Burnout is characterized by emotional exhaustion (feeling emotionally drained by contact with patients), depersonalization (extreme detachment from patients), and lack of personal accomplishment (feelings of incompetence and lack of job success) (5–7). Burnout has been linked to poor health outcomes for HCWs- including depression, cardiometabolic risk behaviors (e.g. reduced physical activity, cigarette smoking), increased alcohol consumption, and sleep disruptions (8–11)—and the work environment and patients they care for, such as through increased medical errors, absenteeism, and poor quality of care (12–15).

Studies of burnout have highlighted the severe mental health impacts to HCWs amid the COVID-19 pandemic (16–18). Several literature reviews and meta-analyses have noted increased prevalence of depression, anxiety, sleep disturbances, post-traumatic stress, and other psychological disorders among HCWs since the start of the pandemic (19–24). However, studies have less frequently examined domains of positive psychological wellbeing and their associations with HCW burnout. Additionally, there are few evidence-based interventions to reduce burnout, anxiety, and depression among HCWs. Of available evidence-based interventions for HCWs, these interventions largely focus on mindfulness or meditation-based interventions rather than broader psychological domains of wellbeing (25–28).

Growing evidence from groups experiencing a variety of types of significant life stress, suggests that the ability to maintain positive psychological wellbeing in the context of stress may be protective against mental and physical health consequences of stress and burnout (29–32). Psychological wellbeing has traditionally been conceptualized to include both hedonic, or feelings of positive affect, and eudaimonic, or a sense meaning and purpose in life, domains (33–35). Among HCWs, positive affect has been associated with increased creative problem solving and job satisfaction, and these aspects of psychological wellbeing may help to buffer the stress of the COVID-19 pandemic and reduce the likelihood of burnout (36–38). To that end, a focus on wellbeing has recently been prioritized by the U.S. Surgeon General, as health systems must promote meaning and purpose in work to reduce burnout as HCWs provide life-saving care (39).

In the present study, we examine the associations of depression, anxiety, positive affect, and meaning and purpose with burnout among a cohort of HCWs in the US during the COVID-19 pandemic. We hypothesize that burnout will be positively associated with depression and anxiety, and inversely associated with positive affect and meaning and purpose. We will also examine the extent to which demographic factors (e.g. age, biological sex), occupational role, degree of patient contact, and occupational COVID-19 exposure, provide insights into the association between psychological health and burnout.

Methods

Study design and participants

This was an analysis of data from the Northwestern Medicine Healthcare Worker SARS-CoV-2 Serology Study, a prospective cohort study of healthcare workers from a large, tertiary academic health care system. The study is described in more detail elsewhere but briefly, includes HCWs from 10 hospitals, 18 immediate care centers, and 325 outpatient practices in the Chicago area and surrounding Illinois suburbs (40–42). From May 28 to June 30, 2020, 38,127 Northwestern Medicine HCWs were invited in to participate in an employer-sponsored benefit that provided free SARS-CoV-2 serological testing, for which all HCWs were eligible. A total of 18,985 (49.8%) participated in the employer-sponsored serological benefit. HCWs enrolled in the benefit included 79.6% women and 74.9% non-Hispanic White, 9.7% Asian, 7.3% Hispanic, and 3.1% non-Hispanic Black workers, with a mean age was of 40.6 (SD:12.0) years old, and nurses represented the largest occupational group ($n = 1794$) (41). Those that attended the serologic testing were recruited to enroll in the Northwestern Medicine Healthcare Worker SARS-CoV-2 Serology Study, a 1-year cohort study, which included monthly, self-administered, online surveys related to COVID-19 exposures, testing, symptoms, and vaccine intentions. In the original 1-year cohort study, 6,510 HCWs enrolled in the study. In June 2021, cohort participants were recruited to continue in an extension cohort study in which 3,538 consented to enroll in the ongoing extension cohort. This present analysis was conducted on psychological health and burnout data collected from the participants who enrolled in the extension and completed a self-administered, online survey between September 29 and December 8, 2021.

Measures

Descriptive variables

Participants were asked to report demographics (e.g. race/ethnicity, age, and sex), household size, and occupation (e.g. registered nurse, physician, phlebotomist, administration, etc.). We also asked about patient contact, exposure to procedures, place of work (including home) and self-reported COVID-19 infection. A total of 19 categorizations of occupational roles were included and can be viewed in Supplemental Table 1. For the main analyses, we collapsed occupations into four categories of registered nurse, physician, administrative roles, or other healthcare workers.

Burnout

Burnout was measured using the Oldenburg Burnout Inventory (OLBI), a validated 16–item inventory which measures two core dimensions of burnout: exhaustion and disengagement (from work) (43) and has strong validity and reliability among English-speaking workers in the United States (44). Responses to OLBI items range from 1 (totally disagree) to 4 (totally agree), and total scores range from 16 to 64. Consistent with work by Peterson et al. (45) we dichotomized burnout for descriptive analyses such that participants who had an average disengagement score of 2.1 or greater and an average exhaustion score of 2.25 or greater, were classified as having burnout. For our multivariable linear regression analysis, the OLBI score was kept continuous.

Psychological health

We utilized several measures from the Patient-Reported Outcomes Measurement Information System (PROMIS) computer adaptive tests (CAT) for measurement of psychological health, including anxiety, depression, positive affect, and meaning and purpose measures (46–49). All of the selected PROMIS psychological measures are examined as T-scores ($M = 50$, $SD = 10$) of the general population (50). We utilized cut points (e.g. high, average, low, etc.) to interpret the clinical significance of T-scores. For the PROMIS depression and anxiety measures, the cut points for normal limits of anxiety or depression are T-score values below 55, mild from 55 to 60, moderate from 60 to 70, and severe above 70. For PROMIS positive affect and meaning and purpose, T-score value cut points for very high scores greater than 70, high from 60 to 70, average from 40 to 60, low from 30 to 50, and very low with values less than 30. See Supplemental Figure 2 for interpretation of these measures. For all PROMIS measures, 3 T-score units can be interpreted as a meaningful difference in T-score values (51, 52).

Statistical analyses

We completed univariate analyses of all study data, including indices of central tendency (mean, median, 95% CI, etc.). T-tests for comparison of mean values of continuous demographic and health characteristics and chi-squared tests for comparisons of proportions for categorical characteristics were used to assess burnout as a dichotomous variable for descriptive analysis and to guide selection of covariates for our linear regression model. For the main analysis, OLBI scores were analyzed as a continuous outcome measure in a multivariable linear regression model to assess the association between depression, anxiety, positive affect, and meaning and purpose on burnout with selected covariates so that our analysis was sufficiently powered. Variables were included in the model based on the literature or significance at the $p < 0.05$ level in unadjusted analyses. The most parsimonious model was selected and reported. Moreover, respondents to the psychological health and burnout survey were compared to non-respondents among the 3,538 participants, to determine whether there were any significant differences in demographic characteristics and occupation. All analyses were conducted using Stata/IC (StataCorp) version 15 (53).

IRB

This study was approved by the Northwestern University Review board (STU00212515) prior to recruitment of HCWs, and all participants provided written informed consent at study enrollment.

Results

A total of 2,619 of 3,538 (74%) individuals in the cohort study responded to the online survey, with 19 of respondents missing baseline data (e.g. age, gender, and occupation).

Compared to non-respondents, survey respondents were significantly older, and more likely to identify as female sex and White race. Survey respondents also were significantly more likely to work in administrative roles and less likely to work as a physician or registered nurse. After removing participants who had missing data on burnout and key independent variables (e.g. age, gender, and PROMIS measures), a total of 2,411 participants were included in the current analyses (data flow diagram in Supplemental Figure 1). Table 1 contains demographic and work-related characteristics of the sample. The majority (n = 1,950, 80.88%) of HCWs in this study identified as White, Non-Hispanic race, and female sex (n = 1,986, 82.37%), and roughly one third (n = 747, 30.98%) were between ages 30–39 years old. Registered nurses (n = 650, 26.96%) accounted for the largest single occupation of HCWs, followed by physicians (n = 431, 17.88%) and administrators (n = 416, 17.25%). The mean score of burnout as measured by the OLBI was 36.87 (SD = 7.65), with 53.38% participants classified as having burnout based on cutoff scores. The highest proportion of HCWs with burnout were registered nurses (63.54%), followed by physicians (53.60%) and other healthcare occupations (53.28%). The proportion of HCWs experiencing burnout also varied by age, sex, and self-reported COVID-19 infection and exposure (Table 1). For instance, a significantly greater proportion of HCWs reported burnout identified as female sex (n = 1,098, 55.29%, $p < 0.001$) than those who identified as male sex (n = 189, 44.47%). Further, 71% (n = 251) of HCWs ages 18–29 years old were classified as having burnout, and the proportion of HCWs with burnout were significantly lower among 50–59 years-old (n = 203, 42.74%) and HCWs ages 60 and above (n = 73, 28.63%, $p < 0.001$). HCWs within single-person households also demonstrated the highest proportion of burnout (60.73%), with fewer individuals reporting burnout among two or more person households. Individuals with self-reported history of COVID-19 infection (n = 207, 58.81%) were significantly more likely to report burnout than those who did not report any history of COVID-19 infection (n = 1,080, 52.45%, $p < 0.001$).

A total of 359 respondents (14.89%) had a PROMIS-depression score more than one standard deviation above the mean, as well as 346 (14.35%) for the PROMIS-anxiety. Additionally, 14.35% (n = 346) of respondents scored one standard deviation below the mean for the PROMIS-positive affect, and 16.47% (n = 397) scored a standard deviation below the mean for the PROMIS-meaning and purpose score (see Supplemental Figure 2 for PROMIS measure distributions and cut-point descriptions).

In our multivariable linear regression model (Table 2) higher depression (coef = 0.15, SE= 0.03, $p < 0.001$) anxiety (coef = 0.25, SE = 0.02, $p < 0.001$) and lower positive affect (coef = −0.19, SE = 0.02, $p < 0.001$) and meaning and purpose (coef = −0.12, SE= 0.01, $p < 0.001$) scores were significantly associated with increased burnout scores. In addition, HCWs ages 60 years or older had lower burnout scores (coef = −3.25, SE = 0.46, $p < 0.001$) compared to individuals who were 18-29 years old; registered nurses (coef = 2.37, SE = 0.38, $p < 0.001$) and physicians (coef = 1.46, SE = 0.43, p = 0.001) reported greater burnout scores than individuals with administrative roles; and female respondents (coef = 1.07, SE = 0.25, $p < 0.001$) reported greater burnout scores than males. We also completed a logistic regression analysis which did not find any difference in factors associated with burnout as a dichotomous outcome (see Supplemental Table 1). Each unit increase in positive affect was associated with a 6% decrease in reported burnout (OR: 0.94, SE: 0.01, $p < 0.001$), and each increase in meaning and purpose was associated with a 5% decrease in burnout (OR: 0.95, SE: 0.01, $p < 0.01$).

Discussion

We found that among a cohort of HCWs who had been working since prior to the COVID-19 pandemic, higher scores on depression and anxiety were significantly associated with higher burnout. In contrast, positive affect and meaning and purpose were inversely associated with burnout scores. These statistically significant associations were stable even with the adjustment for other independent factors associated with burnout in our cohort (including age, female sex, occupational role, and patient contact, and COVID-19 exposure). We noted that burnout was prevalent (53.38%) in this cohort of HCWs at the time of data collection. Our findings also highlight the intersections of age, occupation, and sex in experienced depression, anxiety, positive affect, and meaning and purpose in association with burnout, with individuals with lower age, female sex, and occupational role as a physician or nurse with greater burnout.

Numerous studies have characterized the extent of burnout amid the COVID-19 pandemic and factors associated with higher rates of burnout. Our findings indicated that half of our participants were classified as having burnout as measured by the OLBI, (45) consistent with other estimates of burnout during the pandemic (54–57). For instance, Denning et al. (56) noted that 67% of HCWs in United Kingdom, Poland, and Singapore reported burnout based on the OLBI. Other studies reported even higher levels of burnout in HCWs, ranging from 75 to 79% (55, 57). These higher rates may be due to slightly different definitions of burnout or measurement at different points in the pandemic. Our findings are also consistent with other studies in that demographic and work characteristics associated with higher burnout scores included female sex (54), being a nurse, physician, or other patient-facing occupational role (56).

Our findings demonstrate that HCWs reported symptoms of depression and anxiety during the COVID-19 pandemic. This is not surprising as other studies have reported high

TABLE 1 Demographic characteristics of HCWs and associations with burnout.

	Burnout			
Characteristics*	**Overall**	**Yes**	**No**	***P*-value**
Age category, (*n*, %)	2,411 (100%)	1,287 (53.38%)	1,124 (46.62%)	
				<0.001
18–29 y	353 (14.64)	251 (71.10)	102 (28.90)	
30–39 y	747 (30.98)	449 (60.11)	298 (38.89)	
40–49 y	581 (24.10)	311 (53.53)	270 (46.47)	
50–59 y	475 (19.70)	203 (42.74)	272 (57.26)	
60 + y	255 (10.58)	73 (28.63)	182 (71.37)	
Sex, (*n*, %)				**<0.001**
Female	1,986 (82.37)	1,098 (55.29)	888 (44.71)	
Male	425 (17.63)	189 (44.47)	236 (55.53)	
Race/ethnicity, (*n*, %)				0.57
Asian	205 (8.50)	111 (54.15)	94 (45.85)	
Hispanic/Latino	141 (5.85)	73 (51.77)	68 (48.23)	
Multiracial	39 (1.62)	24 (61.54)	15 (38.46)	
Non-Hispanic black	50 (2.07)	23 (46.00)	27 (54.00)	
Non-Hispanic white	1,950 (80.88)	1,039 (53.28)	911 (46.72)	
Other/NA	26 (1.08)	17 (65.38)	9 (34.62)	
Household size (*n*, %) *				
1 person	303 (1.40)	184 (60.73)	119 (39.27)	**0.020**
2 persons	775 (34.36)	416 (53.68)	359 (46.32)	
3 persons	415 (18.35)	207 (49.88)	208 (50.12)	
4 persons	478 (21.13)	236 (49.37)	242 (50.63)	
≥5 persons	291 (12.86)	157 (53.95)	134 (46.05)	
Occupation (*n*, %)				**<0.001**
Administrative Role	416 (17.25)	156 (37.50)	260 (62.50)	
Physician	431 (17.88)	231 (53.60)	200 (46.40)	
Registered Nurse	650 (26.96)	413 (63.54)	237 (36.46)	
Other	914 (37.91)	487 (53.28)	427 (46.72)	
Patient contact (*n*, %)				**<0.001**
Yes	2,001 (82.99)	1,120 (55.97)	881 (44.03)	
No	410 (17.01)	167 (40.73)	243 (59.27)	
Vaccinated for COVID-19 (*n*, %)				0.14
Yes	2,358 (97.80)	1,264 (53.60)	1,094 (46.40)	
No	53 (2.20)	23 (43.40)	30 (56.60)	
COVID-19 patient exposure (*n*, %)				**<0.001**
Yes	1,045 (43.34)	644 (61.63)	401 (38.37)	
No	1,366 (56.66)	643 (47.07)	723 (52.93)	
Non-hospital COVID-19 exposure (*n*, %)				**<0.001**
Yes	2,203 (91.37)	1,167 (52.97)	1,036 (47.03)	
No	208 (8.63)	120 (57.69)	88 (42.31)	
Self-reported COVID-19 infection (*n*, %)				**0.001**
Yes	352 (14.60)	207 (58.81)	145 (41.19)	
No	2,059 (85.40)	1,080 (52.45)	979 (47.55)	
PROMIS-depression, *m* (SD)	49.23 (7.25)	52.08 (6.53)	45.96 (6.64)	**<0.001**
PROMIS-anxiety, *m* (SD)	53.67 (7.86)	56.89 (6.72)	49.99 (7.44)	**<0.001**
PROMIS-positive affect, *m* (SD)	47.24 (8.64)	43.81 (7.36)	51.16 (8.31)	**<0.001**
PROMIS-meaning and purpose, *m* (SD)	53.52 (0.20)	49.71 (9.11)	57.89 (9.19)	**<0.001**

COVID-19 exposure captured as self-reported exposure to SARS-CoV-2 during healthcare work. COVID-19 vaccination was defined as self-reported first and second doses of the COVID-19 vaccine series. *P*-values are reported for chi-squared tests for group differences in demographic characteristics by burnout. Burnout was defined as having both OLBI-Exhaustion score ≥ 2.25 and OLBI-Disengagement score ≥ 2.1, based on Peterson, Demerouti (45). PROMIS measures are examined as *T*-scores ($M = 50$, $SD = 10$) of the general population.

[*] Values are *n* (%) unless stated otherwise.

The bold values indicate the number is statistically significant ($p < 0.05$).

TABLE 2 Multivariable linear regression analyses of the association between psychological measures and burnout (OLBI) adjusted for demographic characteristics, occupational group, and COVID infection history ($n = 2,411$).

Variable	Coef	SE	*t*	*P*-value
Depression	0.15	0.03	5.86	**<0.001**
Anxiety	0.25	0.02	11.44	**<0.001**
Positive affect	−0.19	0.02	−10.48	**<0.001**
Meaning and purpose	−0.12	0.01	−8.33	**<0.001**
Patient contact (Y)	0.82	0.34	2.42	**0.016**
Age category				
18–29 years-old (ref)				
30–39 years-old	−1.01	0.35	−2.89	**0.004**
40–49 years-old	−1.53	0.37	−4.17	**<0.001**
50–59 years-old	−2.55	0.38	−6.59	**<0.001**
>60 years-old	−3.25	0.46	−7.11	**<0.001**
Occupation group				
Administrative Role (ref)				
Physicians	1.46	0.43	3.39	**0.001**
Registered Nurses	2.37	0.38	6.18	**<0.001**
Other	0.92	0.35	2.62	**0.009**
COVID-19 exposure				
No (ref)				
Yes	1.07	0.25	4.23	**<0.001**
Sex				
Male (ref)				
Female	1.11	0.31	3.64	**<0.001**

The bold values indicate the number is statistically significant ($p < 0.05$).

rates of significant psychological distress by HCWs during the COVID-19 pandemic (11, 58–64). A meta-review of 40 systematic reviews of studies of HCWs during the pandemic found that depression and anxiety were the most prevalent mental health conditions (61). In concordance with our findings, another rapid review of the psychological impact to HCWs amid the COVID-19 pandemic noted that nurses who identified as female with contact to COVID-19 patients had the highest prevalence of mental health problems (65). Notably, given that surges in COVID-19 cases are mirrored with increased levels of burnout (66), the data collection period of our study may have led to lower reports of symptoms of depression, anxiety, and burnout in our sample, given the relative lull in COVID-19 cases occurring during that period.

We found a significant inverse association of positive affect and meaning and purpose with burnout in our cohort. Several studies, some completed before the pandemic, had similar findings. For example, one study of social workers in China in May 2021 found that positive affect was inversely associated with psychological distress, while negative affect was associated with higher with psychological distress (38). A study of primary care physicians in Spain conducted in 2013 found that positive affect mediated the relationship between lower resilience, lack of development, and burnout (67). Similarly, Barnett et al. observed that meaning and purpose was significantly inversely associated with burnout prior to the COVID-19 pandemic (37). One study also conducted prior to COVID-19 examining psychological well-being among HCWs noted that nurses, who were overwhelmingly female, reported significantly lower positive affect than other healthcare professionals (68). Similar studies have not been conducted during the COVID-19 pandemic. To our knowledge, our study is the first to report the associations of positive affect and meaning and purpose with burnout scores among a large cohort of multidisciplinary HCWs during the COVID-19 pandemic. While interventions exist to increase positive affect (31, 32, 69–71), researchers have yet to assess the efficacy, feasibility, and acceptability of these targeted interventions among HCWs.

This study has several limitations. First, our study participants largely identified as White race and female sex, and worked as registered nurses, physicians, or administrators, which may limit the generalizability of our findings to HCWs who are non-White, male sex or gender-non-binary, or work in other healthcare roles including staff with patient contact (e.g. custodial staff, nursing assistants, security, etc.). Further, despite high burnout reported among individuals within single person households, we did not include household size in our regression models due to high missingness of data for this variable in our sample. More research is needed to focus on the specific experiences with burnout and psychological wellbeing for these HCWs. The initial recruitment strategies for this cohort study included a focus on COVID-19 testing at the time of data collection, which may have also biased this sample towards HCWs who require in-person work associated with their role. We also utilized online recruitment and survey methods for data collection, which may have limited our ability to reach some HCWs for recruitment and engagement in this study. Of note, our utilization of PROMIS measures has limited our ability to determine clinically significant differences in psychological health and burnout, as PROMIS measures are not diagnostic tools for psychological well-being (52). Further, our analysis was conducted utilizing cross-sectional data, which precludes any ability to determine causality and directionality in the associations between psychological health and burnout. Future studies are needed to examine causal mechanisms of burnout associated with clinically meaningful differences in psychological health, as well as examinations of effective interventions to reduce burnout among HCWs.

Conclusions

In conclusion, the prevalence of burnout, depression, and anxiety were high among HCWs during the 2nd year of the COVID-19 pandemic. However, positive affect and meaning and purpose were associated with lower levels of burnout. As we have noted in our findings, individuals who are younger, identify as female, and work in patient-facing occupational roles (e.g. RNs, MDs) were associated with higher rates of increased burnout in this study and would benefit from targeted interventions to promote resilience in these populations. Future research is needed to examine the association of specific domains of burnout- including exhaustion and disengagement- with depression, anxiety, meaning and purpose, and positive affect. Individual-level and systems-level interventional studies are needed to develop evidence-based interventions, potentially through increasing positive affect and sense of purpose, to reduce burnout and increase the resiliency and psychological wellbeing of the HCWs who are critical to providing health care before, during, and after current and future pandemics.

Data availability statement

Data are available on reasonable request from the principle investigator CE, charlesnika-evans@northwestern.edu and if in accordance with institutional guidelines.

Ethics statement

The studies involving human participants were reviewed and approved by Northwestern University Institutional Review Board (IRB). The patients/participants provided their written informed consent to participate in this study.

Author contributions

JB, LH, CE, and JM contributed to conception and design of the study. JB organized the database and performed the statistical analysis with mentorship from TV. JB wrote the first draft of the manuscript. JB, MF, CL, and JM wrote sections of the manuscript. All authors contributed to manuscript revision, read, and approved the submitted version.

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Conflict of interest

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

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frhs.2022.994474/full#supplementary-material

References

1. Leo CG, Sabina S, Tumolo MR, Bodini A, Ponzini G, Sabato E, et al. Burnout Among healthcare workers in the COVID 19 era: a review of the existing literature. *Front Public Health*. (2021) 9:1–6. doi: 10.3389/fpubh.2021.750529

2. Sullivan D, Sullivan V, Weatherspoon D, Frazer C. Comparison of nurse burnout, before and during the COVID-19 pandemic. *Nurs Clin North Am.* (2022) 57:79–99. doi: 10.1016/j.cnur.2021.11.006

3. McHugh MD, Kutney-Lee A, Cimiotti JP, Sloane DM, Aiken LH. Nurses' widespread job dissatisfaction, burnout, and frustration with health benefits signal problems for patient care. *Health Affairs.* (2011) 30:202–10. doi: 10.1377/hlthaff.2010.0100

4. Aiken LH, Sermeus W, Van den Heede K, Sloane DM, Busse R, McKee M, et al. Patient safety, satisfaction, and quality of hospital care: cross sectional surveys of nurses and patients in 12 countries in Europe and the United States. *BMJ.* (2012) 344:e1717. doi: 10.1136/bmj.e1717

5. Maslach C, Jackson SE. The measurement of experienced burnout. *J Organ Behav.* (1981) 2:99–113. doi: 10.1002/job.4030020205

6. Maslach C, Jackson SE, Leiter MP. *Maslach Burnout Inventory*. Lanham, MD: Scarecrow Education (1997).

7. Maslach C, Schaufeli WB, Leiter MP. Job burnout. *Annu Rev Psychol.* (2001) 52:397–422. doi: 10.1146/annurev.psych.52.1.397

8. Dolan N. The relationship between burnout and job satisfaction in nurses. *J Adv Nurs.* (1987) 12:3–12. doi: 10.1111/j.1365-2648.1987.tb01297.x

9. Hakanen JJ, Schaufeli WB. Do burnout and work engagement predict depressive symptoms and life satisfaction? A three-wave seven-year prospective study. *J Affect Disord.* (2012) 141:415–24. doi: 10.1016/j.jad.2012.02.043

10. Shanafelt TD, Balch CM, Dyrbye L, Bechamps G, Russell T, Satele D, et al. Special report: suicidal ideation among American surgeons. *Arch Surgery*. (2011) 146:54–62. doi: 10.1001/archsurg.2010.292

11. Melnyk BM, Hsieh AP, Tan A, Teall AM, Weberg D, Jun J, et al. Associations among nurses' mental/physical health, lifestyle behaviors, shift length, and workplace wellness support during COVID-19: important implications for health care systems. *Nurs Adm Q.* (2022) 46:5–18. doi: 10.1097/NAQ.0000000000000499

12. Tawfik DS, Scheid A, Profit J, Shanafelt T, Trockel M, Adair KC, et al. Evidence relating health care provider burnout and quality of care: a systematic review and meta-analysis. *Ann Int Med.* (2019) 171:555–67. doi: 10.7326/M19-1152

13. Parker PA, Kulik JA. Burnout, self- and supervisor-rated job performance, and absenteeism among nurses. *J Behav Med.* (1995) 18:581–99. doi: 10.1007/BF01857897

14. Shanafelt TD, Bradley KA, Wipf JE, Back AL. Burnout and self-reported patient care in an internal medicine residency program. *Ann Int Med.* (2002) 136:358–67. doi: 10.7326/0003-4819-136-5-200203050-00008

15. Peterson U, Bergström G, Demerouti E, Gustavsson P, Asberg M, Nygren A. Burnout levels and self-rated health prospectively predict future long-term sickness absence: a study among female health professionals. *J Occup Environ Med.* (2011) 53:788–93. doi: 10.1097/JOM.0b013e318222b1dc

16. Luceño-Moreno L, Talavera-Velasco B, Vázquez-Estévez D, Martín-García J. Mental health, burnout, and resilience in healthcare professionals after the first wave of COVID-19 pandemic in Spain: a longitudinal study. *J Occup Environ Med.* (2022) 64:e114–e23. doi: 10.1097/JOM.0000000000002464

17. Dobson H, Malpas CB, Burrell AJ, Gurvich C, Chen L, Kulkarni J, et al. Burnout and psychological distress amongst Australian healthcare workers during the COVID-19 pandemic. *Australas Psychiatry.* (2021) 29:26–30. doi: 10.1177/1039856220965045

18. Card AJ. Burnout and sources of stress among health care risk managers and patient safety personnel during the COVID-19 pandemic: a pilot study. *Disaster Med Public Health Prep*. (2021) 1–3. doi: 10.1017/dmp.2021.120

19. Hao Q, Wang D, Xie M, Tang Y, Dou Y, Zhu L, et al. Prevalence and risk factors of mental health problems among healthcare workers during the COVID-19 pandemic: a systematic review and meta-analysis. *Front Psychiatry.* (2021) 12:567381. doi: 10.3389/fpsyt.2021.567381

20. Bahamdan AS. Review of the psychological impact of COVID-19 pandemic on healthcare workers in Saudi Arabia. *Risk Manag Healthc Policy.* (2021) 14:4105–11. doi: 10.2147/RMHP.S324938

21. Bekele F, Mechessa DF, Sefera B. Prevalence and associated factors of the psychological impact of COVID-19 among communities, health care workers and patients in Ethiopia: a systematic review. *Ann Med Surgery*. (2021) 66:102403. doi: 10.1016/j.amsu.2021.102403

22. Benfante A, Di Tella M, Romeo A, Castelli L. Traumatic stress in healthcare workers during COVID-19 pandemic: a review of the immediate impact. *Front Psychol.* (2020) 11:569935. doi: 10.3389/fpsyg.2020.569935

23. Serrano-Ripoll MJ, Zamanillo-Campos R, Castro A. Fiol-de Roque MA, Ricci-Cabello I. Insomnia and sleep quality in healthcare workers fighting against COVID-19: a systematic review of the literature and meta-analysis. *Actas Espanolas de Psiquiatria.* (2021) 49:155–79.

24. Marvaldi M, Mallet J, Dubertret C, Moro MR, Guessoum SB. Anxiety, depression, trauma-related, and sleep disorders among healthcare workers during the COVID-19 pandemic: a systematic review and meta-analysis. *Neurosci Biobehav Rev.* (2021) 126:252–64. doi: 10.1016/j.neubiorev.2021.03.024

25. Fillion L, Duval S, Dumont S, Gagnon P, Tremblay I, Bairati I, et al. Impact of a meaning-centered intervention on job satisfaction and on quality of life among palliative care nurses. *Psycho Oncol J Psychol Soc Behav Dimen Cancer.* (2009) 18:1300–10. doi: 10.1002/pon.1513

26. Harding R, Higginson IJ. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Med.* (2003) 17:63–74. doi: 10.1191/0269216303pm667oa

27. Potter P, Deshields T, Rodriguez S. Developing a systemic program for compassion fatigue. *Nurs Adm Q.* (2013) 37:326–32. doi: 10.1097/NAQ.0b013e3182a2f9dd

28. Holmes EA, O'Connor RC, Perry VH, Tracey I, Wessely S, Arseneault L, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry.* (2020) 7:547–60. doi: 10.1016/S2215-0366(20)30168-1

29. Folkman S. Positive psychological states and coping with severe stress. *Soc Sci Med.* (1997) 45:1207–21. doi: 10.1016/S0277-9536(97)00040-3

30. Folkman S, Moskowitz JT. Positive affect and the other side of coping. *Am Psychol.* (2000) 55:647. doi: 10.1037/0003-066X.55.6.647

31. Moskowitz JT, Carrico AW, Duncan LG, Cohn MA, Cheung EO, Batchelder A, et al. Randomized controlled trial of a positive affect intervention for people newly diagnosed with HIV. *J Consult Clin Psychol.* (2017) 85:409. doi: 10.1037/ccp0000188

32. Moskowitz JT, Cheung EO, Snowberg KE, Verstaen A, Merrilees J, Salsman JM, et al. Randomized controlled trial of a facilitated online positive emotion regulation intervention for dementia caregivers. *Health Psychol.* (2019) 38:391–402. doi: 10.1037/hea0000680

33. Waterman AS. Two conceptions of happiness: Contrasts of personal expressiveness (*eudaimonia*) and hedonic enjoyment. *J Pers Soc Psychol.* (1993) 64:678. doi: 10.1037/0022-3514.64.4.678

34. Kahneman D. Objective happiness. *Wellbeing Found Hedonic Psychol.* (1999) 3:1–23.

35. Ryan RM, Deci EL. On happiness and human potentials: a review of research on hedonic and eudaimonic wellbeing. *Ann Rev Psychol.* (2001) 52:141–66. doi: 10.1146/annurev.psych.52.1.141

36. Javadi Sharif T, Hosseinzadeh M, Mahdavi N, Namdar Areshtanab H. G LD. Happiness and its relationship with job burnout in nurses of educational hospitals in Tabriz, Iran. *Inl J Commun Based Nurs Midwifery.* (2020) 8:295–304. doi: 10.30476/IJCBNM.2020.83298.1138

37. Barnett MD, Moore JM, Garza CJ. Meaning in life and self-esteem help hospice nurses withstand prolonged exposure to death. *J Nurs Manag.* (2019) 27:775–80. doi: 10.1111/jonm.12737

38. Huang C, Xie X, Cheung SP, Zhou Y. Job demands and resources, positive and negative affect, and psychological distress of social workers in China. *Front Psychiatry.* (2021) 12:752382. doi: 10.3389/fpsyt.2021.752382

39. Service PH, editor. *Addressing Health Worker Burnout*: *The U.S. Surgeon General's Advisory* on *Building* a *Thriving Health Workforce.* U.S. Department of Health and Human Services PHS, Office of the Surgeon General (2022).

40. Evans CT, DeYoung BJ, Gray EL, Wallia A, Ho J, Carnethon M, et al. COVID-19 vaccine intentions and uptake in a tertiary care healthcare system: a longitudinal study. *Infect Control Hospital Epidemiol.* (2021) 1–19. doi: 10.1017/ice.2021.523

41. Wilkins JT, Gray EL, Wallia A, Hirschhorn LR, Zembower TR, Ho J, et al., editors. "Seroprevalence and correlates of SARS-CoV-2 antibodies in health care workers in Chicago". In: *Open forum Infectious Diseases.* Cary, NC: Oxford University Press (2021). doi: 10.1101/2020.09.11.20192385

42. Wilkins JT, Hirschhorn LR, Gray EL, Wallia A, Carnethon M, Zembower TR, et al. Serologic status and SARS-CoV-2 infection over 6 months of follow up in

healthcare workers in Chicago: a cohort study. *Infect Control Hospital Epidemiol.* (2021) 43:1–9. doi: 10.1017/ice.2021.367

43. Demerouti E, Bakker AB, Vardakou I, Kantas A. The convergent validity of two burnout instruments: a multitrait-multimethod analysis. *Eur J Psychol Assess.* (2003) 19:12. doi: 10.1027//1015-5759.19.1.12

44. Halbesleben JR, Demerouti E. The construct validity of an alternative measure of burnout: investigating the English translation of the Oldenburg Burnout inventory. *Work and Stress.* (2005) 19:208–20. doi: 10.1080/02678370500340728

45. Peterson U, Demerouti E, Bergström G, Samuelsson M, Åsberg M, Nygren Å. Burnout and physical and mental health among Swedish healthcare workers. *J Adv Nurs.* (2008) 62:84–95. doi: 10.1111/j.1365-2648.2007.04580.x

46. Hahn EA, DeWalt DA, Bode RK, Garcia SF, DeVellis RF, Correia H, et al. New English and Spanish social health measures will facilitate evaluating health determinants. *Health Psychol.* (2014) 33:490. doi: 10.1037/hea0000055

47. Salsman JM, Lai JS, Hendrie HC, Butt Z, Zill N, Pilkonis PA, et al. Assessing psychological wellbeing: self-report instruments for the NIH toolbox. *Qual Life Res.* (2014) 23:205–15. doi: 10.1007/s11136-013-0452-3

48. Pilkonis PA, Choi SW, Reise SP, Stover AM, Riley WT, Cella D, et al. Item banks for measuring emotional distress from the patient-reported outcomes measurement information system (PROMIS®): depression, anxiety, and anger. *Assessment.* (2011) 18:263–83. doi: 10.1177/1073191111411667

49. Pilkonis PA Yu L, Dodds NE, Johnston KL, Maihoefer CC, Lawrence SM. Validation of the depression item bank from the patient-reported outcomes measurement information system (PROMIS®) in a three-month observational study. *J Psychiatr Res.* (2014) 56:112–9. doi: 10.1016/j.jpsychires.2014.05.010

50. PROMIS. (n.d.). Available online at: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis (accessed May 1, 2022).

51. PROMIS Score Cut Points. (n.d.). Available online at: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/promis-score-cut-points (accessed May 1, 2022).

52. Meaningful Change for PROMIS (n.d.). Available online at: https://www.healthmeasures.net/score-and-interpret/interpret-scores/promis/meaningful-change (accessed May 1, 2022).

53. StataCorp. *Stata Statistical Software: Release 15.* College Station, TX: StataCorp LLC (2017).

54. Moll V, Meissen H, Pappas S, Xu K, Rimawi R, Buchman TG, et al. The coronavirus disease 2019 pandemic impacts burnout syndrome differently among multiprofessional critical care clinicians-a longitudinal survey study. *Crit Care Med.* (2022) 50:440–8. doi: 10.1097/CCM.0000000000005265

55. Sheehan O, Sheehan M, Rau RI, Sullivan IO, McMahon G, Payne A. Burnout on the frontline: the impact of COVID-19 on emergency department staff wellbeing. *Irish J Med Sci.* (2021) 191:1–9. doi: 10.1007/s11845-021-02795-w

56. Denning M, Goh ET, Tan B, Kanneganti A, Almonte M, Scott A, et al. Determinants of burnout and other aspects of psychological well-being in healthcare workers during the Covid-19 pandemic: a multinational cross-sectional study. *PLoS ONE.* (2021) 16:e0238666. doi: 10.1371/journal.pone.0238666

57. Tan BYQ, Kanneganti A, Lim LJH, Tan M, Chua YX, Tan L, et al. Burnout and associated factors among health care workers in Singapore during the COVID-19 pandemic. *J Am Med Direct Assoc.* (2020) 21:1751–8. doi: 10.1016/j.jamda.2020.09.035

58. Rose S, Hartnett J, Pillai S. A comprehensive dataset describing nurse's emotions, perceived stressors and coping mechanisms during the first surge of the COVID-19 pandemic. *Data Brief.* (2022) 40:107814. doi: 10.1016/j.dib.2022.107814

59. Peccoralo LA, Pietrzak RH, Feingold JH, Syed S, Chan CC, Murrough JW, et al. A prospective cohort study of the psychological consequences of the COVID-19 pandemic on frontline healthcare workers in New York City. *Int Arch Occup Environ Health.* (2022) 95:1–13. doi: 10.1007/s00420-022-01832-0

60. Yu B, Barnett D, Menon V, Rabiee L, De Castro YS, Kasubhai M, et al. Healthcare worker trauma and related mental health outcomes during the COVID-19 outbreak in New York City. *PLoS ONE.* (2022) 17:e0267315. doi: 10.1371/journal.pone.0267315

61. Chutiyami M, Cheong AMY, Salihu D, Bello UM, Ndwiga D, Maharaj R, et al. COVID-19 pandemic and overall mental health of healthcare professionals globally: a meta-review of systematic reviews. *Front Psychiatry.* (2021) 12:804525. doi: 10.3389/fpsyt.2021.804525

62. Xiong N, Fritzsche K, Pan Y, Löhlein J, Leonhart R. The psychological impact of COVID-19 on Chinese healthcare workers: a systematic review and meta-analysis. *Soc Psychiatry Psychiatric Epidemiol.* (2022) 57:1–15. doi: 10.1007/s00127-022-02264-4

63. Vizheh M, Qorbani M, Arzaghi SM, Muhidin S, Javanmard Z, Esmaeili M. The mental health of healthcare workers in the COVID-19 pandemic: a systematic review. *J Diabetes Metab Disord.* (2020) 19:1–12. doi: 10.1007/s40200-020-00643-9

64. Maunder RG, Heeney ND, Kiss A, Hunter JJ, Jeffs LP, Ginty L, et al. Psychological impact of the COVID-19 pandemic on hospital workers over time: relationship to occupational role, living with children and elders, and modifiable factors. *Gen Hosp Psychiatry.* (2021) 71:88–94. doi: 10.1016/j.genhosppsych.2021.04.012

65. Cabarkapa S, Nadjidai SE, Murgier J, Ng CH. The psychological impact of COVID-19 and other viral epidemics on frontline healthcare workers and ways to address it: a rapid systematic review. *Brain Behav Immun Health.* (2020) 8:100144. doi: 10.1016/j.bbih.2020.100144

66. Melnikow J, Padovani A, Miller M. Frontline physician burnout during the COVID-19 pandemic: national survey findings. *BMC Health Serv Res.* (2022) 22:365. doi: 10.1186/s12913-022-07728-6

67. Montero-Marin J, Tops M, Manzanera R, Piva Demarzo MM, Álvarez de. Mon M, García-Campayo J. Mindfulness, resilience, and burnout subtypes in primary care physicians: the possible mediating role of positive and negative affect. *Front Psychol.* (2015) 6:1895. doi: 10.3389/fpsyg.2015.01895

68. Atanes AC, Andreoni S, Hirayama MS, Montero-Marin J, Barros VV, Ronzani TM, et al. Mindfulness, perceived stress, and subjective well-being: a correlational study in primary care health professionals. *BMC Compl Altern Med.* (2015) 15:303. doi: 10.1186/s12906-015-0823-0

69. Addington EL, Cheung EO, Bassett SM, Kwok I, Schuette SA, Shiu E, et al. The MARIGOLD study: feasibility and enhancement of an online intervention to improve emotion regulation in people with elevated depressive symptoms. *J Affect Disord.* (2019) 257:352–64. doi: 10.1016/j.jad.2019.07.049

70. Bassett S, Cohn M, Cotten P, Kwok I, Moskowitz J. Feasibility and acceptability of an online positive affect intervention for those living with comorbid HIV depression. *AIDS Behav.* (2019) 23:753–64. doi: 10.1007/s10461-019-02412-z

71. Cheung EO, Cohn MA, Dunn LB, Melisko ME, Morgan S, Penedo FJ, et al. A randomized pilot trial of a positive affect skill intervention (lessons in linking affect and coping) for women with metastatic breast cancer. *Psychooncology.* (2017) 26:2101–8. doi: 10.1002/pon.4312

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A comparative study of stress experienced by Swedish and Norwegian police officers

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Introduction: Police officers work in a variable environment under different circumstances and often involves stressful situations. This include working irregular hours, ongoing exposure to critical incidents, confrontations and violence. community police officers are mainly out in the society and have daily contact with the general public. critical incidents can also consist of being criticized and stigmatized as a police officer, both from the public but also lack of support from their own organization. There is evidence on negative impacts of stress on police officers. However, knowledge about the nature of police stress and its various types is insufficient. It is assumed that there are common stress factors which are universal among all police officers in different contexts but there is a lack of comparative studies to provide empirical evidence. The aim of this study is to compare different types of stress among police officers in Norway and Sweden and how the pattern of experiencing stress has changed over time in these countries.

Methods: The study population consisted of patrolling police officers from 20 local police districts or units in all seven regions in Sweden ($n = 953$) and patrolling police officers from four police districts in Norway ($n = 678$). A 42-item Police Stress Identification Questionnaire was used to measure the stress level.

Results: The findings show differences in types of stressful events as well as its severity among police officers in Sweden and Norway. The level of stress decreased over time among Swedish police officers whereas it showed no change or even an increase among the Norwegian participants.

Discussion: The results of this study are relevant for policy-makers, police authorities and lay police officers in each country to tailor their efforts to prevent stress among police officers.

KEYWORDS

stress, police, comparative study, Sweden, Norway

1. Introduction

Police officers are exposed to emotionally demanding situations, which come with the job. These situations include not only being confronted with death and illness and dealing with crime and accident victims but also interacting with perpetrators and disturbing persons and being exposed to various types of threats (1, 2). Police work includes regular and ongoing exposure to confrontation, violence, and, at its most extreme, potential harm to the officer's life (3). Many of these situations involve vulnerable people who are expected to receive support from the police (4). Therefore, police officers are continuously exposed to critical incidents as a part of their daily work. However, these critical incidents can also involve being criticized and stigmatized by the public and receiving little support from their own organization (5). For example, in a study on citizens' decisions to complain about the police, McLean (6) showed that the likelihood of complaining increases when the citizen perceives the interaction as procedurally and distributively unfair and when the outcome is unfavorable. In addition, police officers often work irregular hours, a factor that has been seen to negatively affect their health (e.g., an increased risk of cardiovascular disease) (7).

In summary, the complexity of demanding work-related situations and the factors described above have been shown to affect the stress levels of police officers (8–10). Although many investigations in police research have indicated the role of stress in police work, little is known about the various types of police stress. Without a comparative approach, it is difficult to determine whether there are some types of stress that are common among all police officers. In this comparative study, we aim to contribute to police stress research, identify specific types of police stress in Sweden and Norway, and assess the severity of these stress factors in both countries. We argue that this issue is highly relevant to police work and the profession because the identification of specific stress factors in police work creates the opportunity to develop resilience programs aimed at preventing long-term negative psychiatric, psychological, and social consequences for police officers. Moreover, the identification of police stress contributes to self-awareness among police officers and to police education by supporting the development of theoretical and practical modules to prepare police trainees for future police work. Researchers have reported the long-term effects of stress on police officers, which include maladaptive and antisocial behaviors, such as problem drinking, hyper-aggressiveness, and violence in work and private life (11, 12).

The current study compares Norway and Sweden because of the many similarities in their criminal justice systems (13); for example, the police are unified and state-organized, and each country is divided into police districts with a considerable degree of independence (13). However, there also exist several differences, including those in the way they organize prosecution, the number of police per resident, and the regulations concerning force resources (e.g., pepper spray and firearms). Furthermore, police work is carried out differently in Sweden and Norway. Norwegian police do not carry firearms unless the situation is expected to merit it (14), this is derived from that the police adopt a philosophy of policing by consent rather than policing with the threat of force.

2. Theoretical framework

Stress is defined as human psychological and physiological adaptation to the environment (15). Coping is defined as a cognitive resource for managing stressful internal and external situations (16). The coping theory introduced by Folkman and Lazarus contributes to increasing our understanding of the relationship between human cognition and the environment through primary and secondary appraisals. In their early studies on coping, Folkman and Lazarus suggested two coping mechanisms: problem-focused and emotion-focused coping. Later, two other main mechanisms of coping, namely, meaning-focused and support-seeking coping, were presented (16). Adding John Violanti's research on police stress from the early 1990 s until now and the long-term consequences of exposure to massive stress creates an opportunity to comprehensively study the stressful work environment of police (16–22). In this article we use coping theory as our point of departure. Police work requires mental preparation before acting or managing complex threatful situations. Given that Coping theory is based on individual's appraisal, it would contribute in understanding how police officers recognize the source of stress and how they organize their policing based on their judgment of the stressful event. Stress in police work.

Many studies support the notion that police work is highly stressful (9, 23–26) and that police officers experience high levels of work-related stress relative to many other occupations (27). For example, working with traumatized victims and conducting homicide inquiries are stressors in the area of criminal investigation (28–30). Police work also involves shift work, traumatic events, staff shortages, and bureaucratic burden, all of which are considered stressful. Lucas and colleagues (31) found that killing in the line of duty, inadequate supervisor support, departmental politics, and insufficient personnel are work stressors that are rated as especially stressful; meanwhile, assignment to nonpolicing duties, demand for high morality, promotion, and boredom are not rated as especially stressful. Job dissatisfaction, workplace discrimination, lack of cooperation among coworkers, and exposure to critical incidents are associated with perceived work stress (32). Additionally, studies have addressed different stress patterns among female and male police officers (33, 34). Some studies have explored the relationship between police officers' strategies to cope with stress and police culture (10) while other studies have focused on individual factors, such as age and gender, in relation to police officers' coping strategies (35). Gershon and colleagues (32) found that avoidant or negative coping is associated with higher levels of perceived work stress and adverse health outcomes.

The present study focused on the comparison of stress levels between police officers in Sweden and Norway and the temporal changes over time.

3. Methods

3.1. Setting

This study comprises police officers from two neighboring Scandinavian countries, namely, Sweden and Norway.

3.1.1. The Swedish police

The Swedish police is a national authority with seven geographical police regions comprising 100 local police districts. In 2018, approximately 30% of 20,040 police officers were women, and the average age of all officers was 44 years. The Swedish Police Authority is led by the National Police Commissioner.

3.1.2. The Norwegian police

The Norwegian police is a national authority consisting of 12 police districts and is mainly responsible for police operations within a geographical area. There are approximately 10,000 police officers, approximately 30% of whom are women.

3.2. Data collection

Data originated from three investigations: the Mareld study (36) in Sweden and two studies aimed at evaluating conducted energy weapons (CEWs) in Sweden and Norway. A Conducted Energy Weapon (CEW) is a device that delivers low amperage electrical current into its target, temporarily impacting the sensory and motor nervous system. When properly deployed, a CEW can disable an assailant with limited risk of long term or substantial injury. Response rate was 52% in the Swedish sample and 56% in the Norwegian sample. The authors were assigned by the Stockholm Police Region to conduct a scientific investigation (Mareld) with a focus on the health and working conditions among police officers working in so-called vulnerable areas in Stockholm, a term applied by the Swedish Police to areas with high crime rates and social exclusion. The data were collected from 2017 to 2020. In addition, the authors evaluated the test periods on CEWs of the Swedish and Norwegian police forces. The Swedish test period was between 2018 and 2019, and the Norwegian test period was between 2019 and 2020. In all three investigations, data were collected annually in three phases.

All police officers present at work were eligible to take part in the study. Participation was voluntary and no incentive was given to participants. The entire sample consisted of patrolling police officers from 20 local police districts or units in all seven regions of Sweden ($n = 954$) and patrolling police officers from 4 police districts in Norway ($n = 677$).

3.2.1. Sample and data collection in the Mareld study

The researchers visited three local police districts in the Stockholm Police Region in spring 2018 and spring 2019 and personally informed them about the project and ethical issues to obtain informed consent. The project was described in a letter and a paper survey was distributed. The third data collection in spring 2020 was modified because of the COVID-19 pandemic; specifically, one appointed police officer in every three local police districts distributed and collected the paper survey and then sent it to us by mail. The project was described in an information letter provided to the respondents.

This study was approved by the Regional Ethical Review Board of Umeå University (Dnr 2017/516-31). This project was funded by the Stockholm Police Region.

3.2.2. Sample and data collection in the Swedish CEW study

The surveys and prepaid return envelopes were sent in a sealed envelope to the contact persons at each local police district or unit for distribution to police officers who could respond to the survey and return it using the prepaid return envelopes in December 2017. The project was presented to the researchers' contacts in the police authority through written and verbal descriptions. A reminder was conveyed to the contact persons through e-mail and communicated further to the police officers. This convenience sample was used because of confidentiality rules in the Swedish police organization. In November 2018 and November 2019, a link to the web survey and an information letter were distributed through e-mail to the police officers involved in the study by the contact person within the police authority. Two reminders were sent to police officers by e-mail.

This study was approved by the Swedish Ethical Review Authority (Dnr 2019-02464). This project was funded by the Swedish Police Authority.

3.2.3. Sample and data collection in the Norwegian CEW study

The dataset was based on a survey conducted among all police officers who participated in the CEW evaluation. The survey and an information letter describing the project were distributed by the National Police Directorate through e-mail and made available to all participating officers in the evaluation of CEWs. Two reminders were sent to the police officers by e-mail. Once the data were collected, they were handed over to the research team after being anonymized.

3.2.4. Instrument

A 42-item Police Stress Identification Questionnaire (11) was used to measure stress levels with the following instruction: "These questions map different types of stressors that affect you as a police officer or civil servant. Mark with a cross how strong you experienced the stress. It can be both that you experienced the event or that you experienced the risk of it happening as stressful." A numerical rating from 0 to 9 was applied, with 9 indicating the most stressful level. A previous study has reported the validity and reliability of the instrument (11). Reliability of the questionnaire was checked with internal consistency assessment methods. Consistency of the entire scale was assessed using the Cronbach's alpha coefficient which was 0.95.

To ascertain face validity, we interviewed nine police officers focusing on items provided to them and discussed them, given their personal experiences that may lead to generating new items (11). The interviewees, aged 30–60 years, had on average more than 10 years of experience in the field. They were informed about the study's aim. Each interview took approximately 30 min. The content of interviews was discussed in our authorship group using content analysis and our theoretical perspectives. Phrases identified from the content analysis were discussed in the expert panel, including one expert in the field of stress and coping and an experienced police officer, and provided the basis for modifying or rewording the items and generating new items that were not included in the preliminary list. Interview data were used to confirm concepts in the existing literature about police stress and explore new areas. The results from confirmatory factor analysis showed the highest fit for data, suggesting construct validity of the PSIQ (11).

3.2.5. Statistical methods

A random-effects ordered logistic model was adopted to analyze the data. Ordered logistic models were used to compare stress levels between police officers in Sweden and Norway as well as the temporal changes over the study period. We assessed (1) whether there is a difference between Sweden and Norway; (2) any changes in the mean score of stress items over time (three time points); and (3) the interactions between country and time point, that is, whether or not the change over time differs between Sweden and Norway. This method is designed to estimate models in the presence of a variable number of waves for each individual (37). Some individuals participated once, twice, and all three times. In this structure, repeated observations (panels) are nested within individual observations. We chose an optimal statistical method that accounts for the correlation between within-person measures repeated over time. We also estimated the predicted means in the form of average marginal effects (38) of the stress items at each measurement point for each country.

All estimations were performed using Stata version 16.1 (StataCorp, College Station, TX).

4. Results

A total of 1,631 police officers (677 from Norway and 954 from Sweden) participated in this study (73% of them were male). Their baseline ages ranged from 22 to 66 years (mean age = 35 years; SD = 8 years).

Figure 1 shows the mean scores for the stress items among the Swedish and Norwegian police officers. The police officers in both countries identified “That my colleague was suddenly shot, which led to serious injury or death” as the most stressful factor, followed by “That family members have received death threats.” Both countries identified “Regretting becoming a police officer” as the least stressful factor.

The mean score for the majority of the items (26 out of 42 items) was significantly higher among Norwegian police officers, suggesting that they experience a higher level of stress than their Swedish counterparts. Only five items were scored higher among Swedish police officers. These items are as follows:

P13. Working night shift
P24. That the law is ineffective in dealing with interventions against offenders
P33. It is hopeless to be a police officer
P34. That I feel that police work has become much more difficult than before
P38. Regretting becoming a police officer

Table 1 presents the mean scores of the 42 stress items among police officers in Sweden and Norway.

4.1. Interaction between time and country

We found an interaction between time and country for 23 items, suggesting that Sweden and Norway showed different patterns regarding changes in stress levels over time. These interactions can be classified into the following four patterns. There were 15 items that belonged to Pattern 1, 6 items to Pattern 2 and one item in each pattern 3 and 4.

FIGURE 1
Mean score for stress items among Swedish and Norwegian police officers.

TABLE 1 Mean scores for the stress items among police officers in Sweden and Norway at three measurement points.

		Norway			Sweden			*P*-value	*P*-value	*P*-value
								Comparison over time	Comparison between countries	Interaction between time and country
Item		T1	T2	T3	T1	T2	T3			
1	Condescending claims	2.8	2.7	2.5	1.8	2.0	1.8	NS	<0.001	NS
2	Verbal aggressive threats	3.6	3.5	3.7	3.1	3.1	3.0	NS	<0.001	NS
3	Threats of physical violence against someone in your own family	5.7	5.8	6.0	5.1	5.3	5.0	NS	<0.001	NS
4	Threats of physical violence	4.3	4.4	4.6	3.6	3.5	3.5	NS	<0.001	NS
5	Being physically abused during an intervention	5.4	5.3	5.4	4.5	4.4	4.1	NS	<0.001	NS
6	Receiving a death threat when on duty	5.5	5.4	5.7	4.2	4.0	3.8	NS	<0.001	<0.002
7	Becoming infected with a disease during an intervention	6.7	6.6	6.4	5.3	4.9	4.7	<0.003	<0.001	NS
8	Internal fear of being attacked	3.1	3.0	3.0	2.9	2.7	2.6	NS	NS	NS
9	Informing next of kin regarding the death of a person	4.0	3.8	3.9	3.2	3.1	3.1	NS	<0.001	NS
10	Being exposed to odor from a dead body	2.6	2.6	2.7	2.2	2.1	2.1	NS	0.003	NS
11	Handling body parts in connection with suicide or accidents	3.5	3.5	3.8	3.5	3.3	3.1	NS	NS	<0.001
12	Police intervention against crowd	4.8	4.6	4.5	3.5	3.3	3.0	<0.02	<0.001	NS
13	Working night shift	2.0	2.4	2.5	2.6	2.6	2.5	<0.001	<0.01	<0.002
14	That my colleague was suddenly shot, which led to serious injury or death	8.4	8.3	8.4	6.7	6.7	6.3	NS	<0.001	NS
15	To be injured by chemical substances	7.3	7.1	7.2	4.4	4.1	4.1	NS	<0.001	NS
16	Lacking a good supervisor	5.0	4.8	5.1	4.0	3.8	3.6	NS	<0.001	<0.01
17	That reorganization takes place	4.0	4.3	4.2	3.6	3.4	2.8	NS	<0.001	<0.001
18	That the division of roles is unclear in the unit or in the organization	4.2	4.1	4.1	3.5	3.4	3.0	NS	<0.001	<0.005
19	Living with guilt related to unsuccessful assignments	5.3	5.5	5.6	3.5	3.4	3.2	NS	<0.001	<0.001
20	Lacking advanced knowledge in police work	4.0	3.8	3.9	3.2	3.0	2.7	NS	<0.001	<0.005
21	That internal investigation is carried out when mistakes are made	4.9	4.9	4.9	3.5	3.4	3.1	NS	<0.001	<0.03
22	The cumbersome paperwork	3.6	3.5	3.3	3.8	3.5	2.8	NS	NS	<0.001
23	That supervisors do not do their job	4.3	4.4	4.4	3.5	3.4	3.1	NS	<0.001	<0.001
24	That the law is ineffective in dealing with interventions against offenders	2.9	2.7	2.8	4.6	4.3	3.6	NS	<0.001	<0.001
25	Having access to poor and outdated equipment	4.2	3.9	3.9	4.1	3.7	3.3	<0.01	NS	<0.007
26	To be away from family because of business travel within the country	2.3	2.4	2.4	2.3	2.3	2.3	NS	NS	NS
27	To be away from family because of business travel to another country	2.6	2.9	2.8	2.2	2.3	2.3	NS	<0.001	NS

(*continued*)

TABLE 1 Continued

		Norway			Sweden			*P*-value	*P*-value	*P*-value
								Comparison over time	Comparison between countries	Interaction between time and country
28	To have a low degree of communication with one's life partner	4.8	4.9	5.0	3.9	3.8	3.5	NS	<0.001	<0.002
29	Not to receive support from one's life partner when it comes to conflicts at work	4.2	4.4	4.4	3.4	3.3	3.1	NS	<0.001	NS
30	Not sharing anything from my work in order to not disturb my family	2.6	2.6	2.8	2.4	2.5	2.2	<0.02	NS	NS
31	That family members have received death threats	6.7	6.7	6.9	6.4	6.3	6.2	NS	NS	NS
32	That the image of the police is distorted on the internet and in the media, such as TV and newspapers	3.2	2.9	3.5	3.2	3.3	2.7	<0.03	NS	<0.001
33	It is hopeless to be a police officer	1.4	1.5	1.6	2.1	2.1	1.6	<0.01	<0.001	<0.001
34	That I feel that police work has become much more difficult than before	2.2	2.3	2.4	2.7	2.6	2.1	NS	<0.001	<0.001
35	That the work culture within the organization disturbs me	2.6	2.5	2.5	2.6	2.4	2.0	NS	NS	<0.001
36	Performing new routines in connection with reorganization	2.6	2.7	2.7	2.6	2.4	2.1	NS	NS	<0.001
37	My colleagues' view of me	2.3	2.4	2.5	2.1	2.2	2.1	NS	<0.001	NS
38	Regretting becoming a police officer	0.9	0.9	1.0	1.2	1.0	0.7	<0.03	<0.02	<0.001
39	To perform tasks that are against my own values	2.9	3.2	3.2	2.4	2.2	2.2	<0.03	<0.001	<0.01
40	Being harassed or receiving a death threat when off duty	4.2	4.5	5.1	3.8	4.8	4.8	<0.001	NS	NS
41	Not being able to do the job due to scarce personnel resources	4.6	4.8	4.7	4.9	4.6	4.1	NS	<0.02	<0.001
42	Meeting vulnerable people without being able to help them	4.7	4.7	4.8	4.2	3.8	3.5	NS	<0.001	<0.001

Pattern 1: No difference over time in Norway and a decreasing trend in Sweden

There were 15 items that showed no difference over time in Norway but decreased in Sweden. (**Figure 2**).

6. Receiving a death threat when on duty
16. Lacking a good supervisor
18. That the division of roles is unclear in the unit or in the organization
20. Lacking advanced knowledge in police work
21. That internal investigation is carried out when mistakes are made
22. The cumbersome paperwork
23. That supervisors do not do their job
24. That the law is ineffective in dealing with interventions against offenders
28. To have a low degree of communication with one's life partner
34. That I feel that police work has become much more difficult than before
35. That the work culture within the organization disturbs me
36. Performing new routines in connection with reorganization
38. Regretting becoming a police officer
41. Not being able to do the job due to scarce personnel resources
42. Meeting vulnerable people without being able to help them

Pattern 2: an increasing trend in Norway and a decreasing trend in Sweden

We found 6 items that in average increased over time in Norway but showed a decreasing trend over time in Sweden (**Figure 3**).

11. Handling body parts in connection with suicide or accidents
17. That reorganization takes place
19. Living with guilt related to unsuccessful assignments
32. That the image of the police is distorted on the internet and in the media, such as TV and newspapers
33. It is hopeless to be a police officer
39. To perform tasks that are against my own values

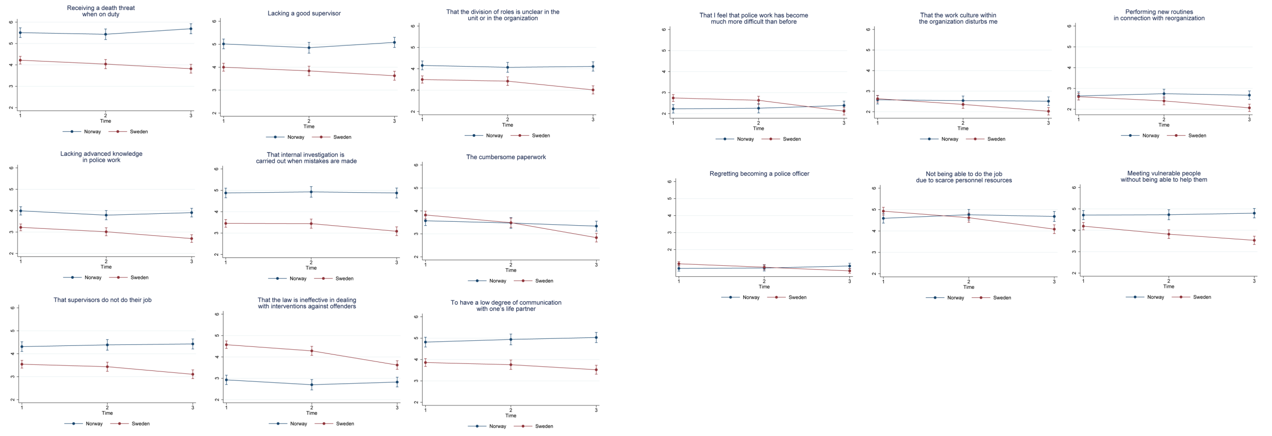

FIGURE 2
Estimated average marginal effects of stress items in pattern 1.

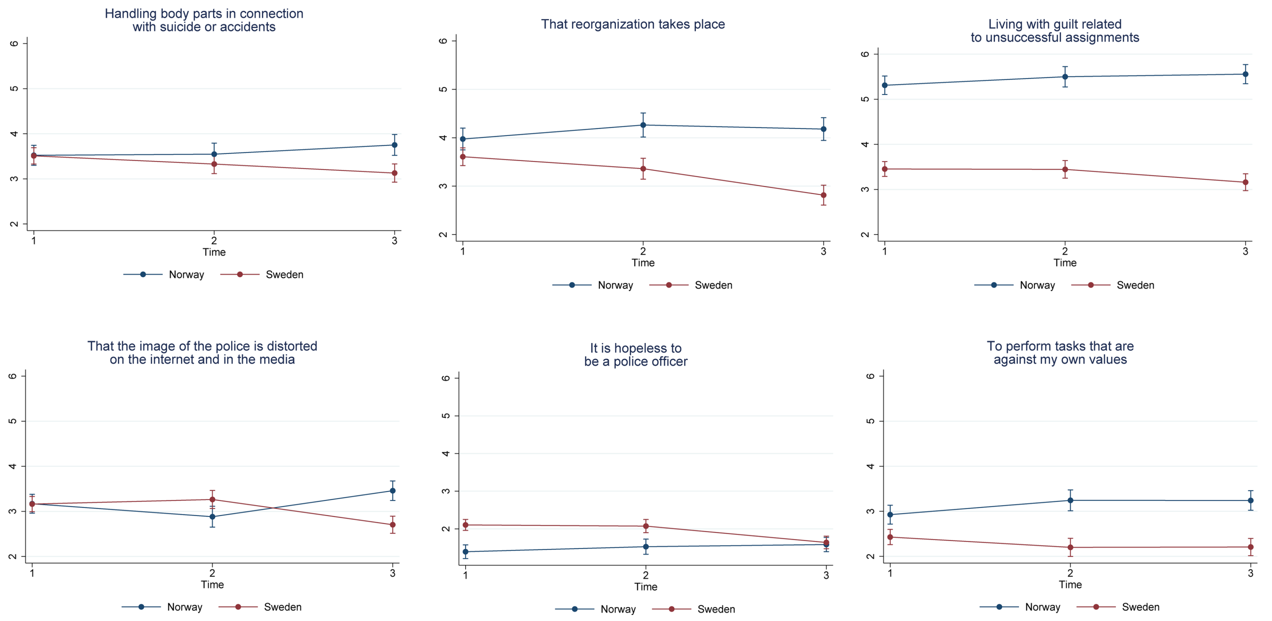

FIGURE 3
Estimated average marginal effects of stress items in pattern 2.

Pattern 3: decreasing trend for both Sweden and Norway

There was one item for which the mean value decreased over time in both countries (**Figure 4**).

25. Having access to poor and outdated equipment

Pattern 4: increasing trend in Norway and no change over time in Sweden

There was one item with an increasing trend over time in Norway but no change in Sweden (**Figure 5**).

13. Working night shift

5. Discussion

The aim of this study is to compare different types of stress among police officers in Norway and Sweden and investigate how the pattern of experiencing stress has changed over time in these countries. Both countries are highly developed and are economically comparable, but they hold significant disparities in terms of societal problems and population dynamics. Prior research tends to consider police work in northern countries in a similar manner. Researchers have also emphasized the extent to which the police in Nordic countries are renowned for emphasizing "soft policing" based on notions of prevention, social inclusion and an equal relationship between members of the civil society and the

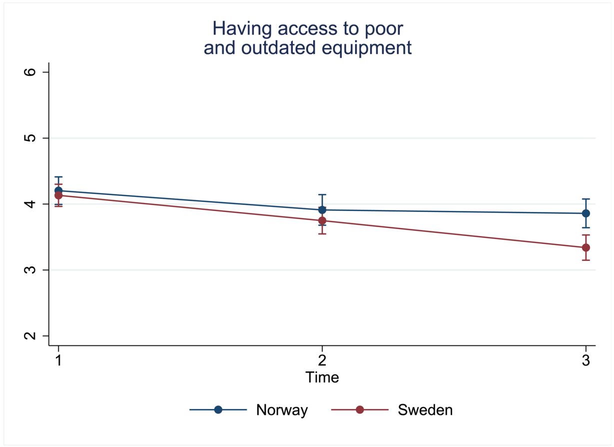

FIGURE 4
Estimated average marginal effects of stress items in pattern 3.

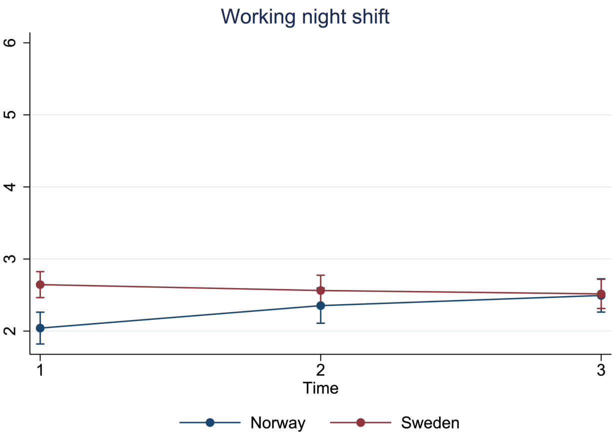

FIGURE 5
Estimated average marginal effects of stress items in pattern 4.

police (39). In general, Nordic police are endowed with a high level of public trust, and the general public perception is that discrimination and differential treatment rarely exist (13, 40, 41). We provided empirical evidence of potential differences in police work between the two countries that demand specific attention from their respective authorities. We found that Norwegian police officers experienced low stress (score of 1–3.9) for 21 items, such as "Regretting becoming a police officer" and "Working night shift"; medium stress (score of 4–6.9) for 19 items, such as "Having access to poor and outdated equipment " and "Threats of physical violence"; and high stress (score of 7–9) for 2 items, namely, "To be injured by chemical substances" and "That my colleague was suddenly shot, which led to serious injury or death." Contrary to Norway police, Swedish police had 32 items under the low stress category (e.g., "Regretting becoming a police officer"), 10 items in the medium level category (e.g., "Receiving a death threat when on duty"), and no item in the high level stress category. On average, Norwegian police officers reported higher levels of stress than their Swedish counterparts. Burke and Mikkelsen (42) reported that Norwegian police officers experience high levels of cynicism because of job stress and burnout. Findings from a nationwide survey of 3,272 Norwegian police personnel exploring the association between job stress and physical and mental health showed that frequent exposure to work stress is associated with health problems (43). The results showed that Norwegian police have high levels of musculoskeletal health problems, which are mainly associated with the frequency of job pressure and lack of support. The report concluded that daily routine work, as well as police operational duties, must be considered when assessing job stress and police health. There is a lack of national surveys among Swedish police regarding job stress, but a number of investigations have reported experienced job demand and police stress as a source of poor mental health (11, 23). Further investigation is needed to determine whether differences in aspects such as police organizational settings in the two countries are associated with higher levels of stress among Norwegian police officers.

Another explanation could be the fact that Norwegian police officers do not carry service weapons in their belts; they store their service weapons in the patrol car and equip them when necessary. This might explain why Norwegian police officers reported significantly higher stress on items 4–6, 12, and 14 (threat and violence on duty) compared with Swedish police officers when there are no significant differences for item 40 (threat of violence off duty). In other words, there is a difference in stress when the officers are on duty, with only Swedish police being armed, but there are no differences when they are off duty and unarmed. Meanwhile, there is no difference between the countries in terms of item 25, which is related to poor or outdated equipment. This needs to be investigated further as the issue of armed or unarmed police involves more perspectives than officers' perceptions of stress. Finally, the long-term effects of being armed on police officers need to be considered at individual and societal levels.

The findings of this study show a decreasing trend over time for most of the items among Swedish police officers. By contrast, the findings reveal no change or even increase over time for some items among the Norwegian participants. A possible explanation for this could be related to the Swedish police reorganization into one national authority in 2015. The first data collection was conducted three years after the reorganization, and the last data collection was conducted five years after the reorganization. During the first few years after the transformation into the national police authority, many supervisors had to apply for new positions, and during this time, many supervisor positions were temporary, resulting in accountability being at risk or unclear. In addition, many previously well-functioning units were reorganized, possibly causing distress among the personnel. The organization might have stabilized five years after the reorganization. Some studies have reviewed police reforms. For example, Mendel and colleagues (44) found relatively strong evidence for a range of risks involved in police mergers, such as the risk of loss of skills and competence, risk of disruption to employer–employee relationships, and risk of problems being exacerbated by inadequate planning and management. In addition, the Swedish Agency for Public Management (Statskontoret), which is responsible for evaluating police reorganization, found that the new organization lacks management and communication (45).

Another explanation could be that during the study period, Swedish police authorities initiated several interventions with the goal of improving safety and security in society. In 2017, the Swedish government announced a broad political consensus that Sweden's internal and external security must be strengthened through public security and institutional protection (46). Given this mission, there is a need to enhance crime prevention efforts by practical and political actors and capacity building for police units as one of the main stakeholders in fighting crime.

Our investigation has several limitations. The sample comprised only patrolling police officers which limits the generalizability of the findings. Items were selected from a range of possibilities that are relevant to patrolling police officers whose tasks are unique and somehow different from other police employees. Including desk police officers would require a different set of items that specifically concerns the target group. Being a police officer is a complex and diverse profession, and it is impossible to capture all possible stressors in police work in one questionnaire. As the first step, we decided to focus on patrolling police officers, who deal with certain types of stressors and move forward to a broader range of police stressors in future research.

In future studies, it would be relevant to use multiple methods to develop quantitative and qualitative data (such as participant observations) to explain the differences in various types of stress between the two countries. There are several other important future research directions that this study did not cover. For example, it would be interesting to investigate how subjective experiences of stress are connected to societal forces and the kinds of interactions that take place between the public and the police.

Data availability statement

The datasets presented in this article are not readily available because The data includes sensitive information and according the ethical approval we cannot share it with third party.

Ethics statement

The studies involving human participants were reviewed and approved by the Regional Ethical Review Board of Umeå University (Dnr 2017/516-31) and Swedish Ethical Review Authority (Dnr 2019-02464). The participants provided their written informed consent to participate in this study.

Author contributions

MP, MG, JH and MI: conceptualized and designed the study. JH, JS, MG and MI: collected data for the study. MP: managed and analyzed the data. MG, JH and MI: acquired funding for this study. MP: prepared the figures and tables. JH, JS and MP: prepared the first draft of the manuscript. All authors reviewed, edited, and commented on the final draft. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

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References

1. Anderson GS, Litzenberger R, Plecas D. Physical evidence of police officer stress. *Int J Police Strateg manag.* (2002) 25(2):399–420. doi: 10.1108/13639510210429437

2. Karlsson I, Christianson SÅ. The phenomenology of traumatic experiences in police work. *Int J Police Strateg manag.* (2003) 26(3):419–38. doi: 10.1108/13639510310489476

3. Maguen S, Metzler TJ, McCaslin SE, Inslicht SS, Henn-Haase C, Neylan TC, et al. Routine work environment stress and PTSD symptoms in police officers. *J Nerv Ment Dis.* (2009) 197(10):754. doi: 10.1097/NMD.0b013e3181b975f8

4. Punch M, James S. Researching law enforcement and public health. *Policing and Society.* (2017) 27:251–60. doi: 10.1080/10439463.2016.1205066

5. Ménard KS, Arter ML. Police officer alcohol use and trauma symptoms: associations with critical incidents, coping, and social stressors. *Int J Stress Manag*. (2013) 20(1):37. doi: 10.1037/a0031434

6. McLean K. Justice-restoring responses: a theoretical framework for understanding citizen complaints against the police. *Polic Soc*. (2021) 31(2):209–28. doi: 10.1080/10439463.2019.1704755

7. Ma CC, Andrew ME, Fekedulegn D, Gu JK, Hartley TA, Charles LE, et al. Shift work and occupational stress in police officers. *Saf Health Work*. (2015) 6(1):25–9. doi: 10.1016/j.shaw.2014.10.001

8. Russell LM. An empirical investigation of high-risk occupations: leader influence on employee stress and burnout among police. *Manag Res Rev*. (2014) 37(4):367–84. doi: 10.1108/MRR-10-2012-0227

9. Padyab M, Backteman-Erlanson S, Brulin C. Burnout, coping, stress of conscience and psychosocial work environment among patrolling police officers. *J Police Crim Psychol*. (2016) 31(4):229–37. doi: 10.1007/s11896-015-9189-y

10. Gutschmidt D, Vera A. Organizational culture, stress, and coping strategies in the police: an empirical investigation. *Police Pract Res*. (2022) 23(5):507–22. doi: 10.1080/15614263.2021.1958683

11. Ghazinour M, Padyab M, Hansson J. Police stress in the Swedish context: development and psychometric properties of the police stress identification questionnaire. *Nordic J Stud Policing*. 8(1):1–19. doi: 10.18261/issn.2703-7045-2021-01-05

12. Kohan A, O'Connor BP. Police officer job satisfaction in relation to mood, well-being, and alcohol consumption. *J Psychol*. (2002) 136(3):307–18. doi: 10.1080/00223980209604158

13. Høigård C. Policing the north. *Crime Justice*. (2011) 40:265–348. doi: 10.1086/659840

14. Henriksen SV, Kruke BI. The force Continuum: prevalence and characteristics of police use of coercive force. *Nordic J Stud Policing*. (2020) 7(1):5–22. doi: 10.18261/issn.2703-7045-2020-01-02

15. Jones A, Pruessner JC, McMillan MR, Jones RW, Kowalik GT, Steeden JA, et al. Physiological adaptations to chronic stress in healthy humans–why might the sexes have evolved different energy utilisation strategies? *J Physiol*. (2016) 594 (15):4297–307. doi: 10.1113/JP272021

16. Folkman S, Moskowitz JT. Coping: pitfalls and promise. *Annu Rev Psychol*. (2004) 55(1):745–74. doi: 10.1146/annurev.psych.55.090902.141456

17. Violanti JM. The police: perspectives on trauma and resiliency. *Traumatology*. (2006) 12:167–9. doi: 10.1177/1534765606296998

18. Violanti JM, Fekedulegn D, Hartley TA, Charles LE, Andrew ME, Ma CC, et al. Highly rated and most frequent stressors among police officers: gender differences. *Am J Crim Justice*. (2016) 41(4):645–62. doi: 10.1007/s12103-016-9342-x

19. Violanti JM, Aron F. Ranking police stressors. *Psychol Rep*. (1994) 75(2):824–6. doi: 10.2466/pr0.1994.75.2.824

20. Violanti JM. Shifts, extended work hours, and fatigue: An assessment of health and personal risks for police officers (2012). NIJ FINAL REPORT..

21. Violanti JM, Charles LE, McCanlies E, Hartley TA, Baughman P, Andrew ME, et al. Police stressors and health: a state-of-the-art review. *Int J Police Strateg manag*. (2017) 40(4): 642–56. doi: 10.1108/PIJPSM-06-2016-0097

22. Violanti JM, Fekedulegn D, Andrew ME, Hartley TA, Charles LE, Miller DB, et al. The impact of perceived intensity and frequency of police work occupational stressors on the cortisol awakening response (CAR): findings from the BCOPS study. *Psychoneuroendocrinology*. (2017) 75:124–31. doi: 10.1016/j.psyneuen.2016.10.017

23. Backteman-Erlanson S, Padyab M, Brulin C. Prevalence of burnout and associations with psychosocial work environment, physical strain, and stress of conscience among Swedish female and male police personnel. *Police Pract Res*. (2013) 14(6):491–505. doi: 10.1080/15614263.2012.736719

24. Duxbury L, Halinski M. It's not all about guns and gangs: role overload as a source of stress for male and female police officers. *Polic Soc*. (2018) 28(8):930–46. doi: 10.1080/10439463.2017.1342644

25. Griffin JD, Sun IY. Do work-family conflict and resiliency mediate police stress and burnout: a study of state police officers. *Am J Crim Justice*. (2018) 43(2):354–70. doi: 10.1007/s12103-017-9401-y

26. Sherwood L, Hegarty S, Vallières F, Hyland P, Murphy J, Fitzgerald G, et al. Identifying the key risk factors for adverse psychological outcomes among police officers: a systematic literature review. *J Trauma Stress*. (2019) 32(5):688–700. doi: 10.1002/jts.22431

27. Johnson S, Cooper C, Cartwright S, Donald I, Taylor P, Millet C. The experience of work-related stress across occupations. *J Manag Psychol*. (2005) 20(2):178–87. doi: 10.1108/02683940510579803

28. Roach J, Sharratt K, Cartwright A, Skou Roer T. Cognitive and emotional stressors of child homicide investigations on UK and Danish police investigators. *Homicide Stud*. (2018) 22(3):296–320. doi: 10.1177/1088767918759695

29. Cartwright A, Roach J. A price paid? A review of the research on the impact of investigating serious crime on the wellbeing of police staff. *Police J*. (2022) 95 (1):109–26. doi: 10.1177/0032258X211049335

30. Foley J, Massey KLD. The "cost"of caring in policing: from burnout to PTSD in police officers in England and Wales. *Police J*. (2021) 94(3):298–315. doi: 10.1177/0032258X20917442

31. Lucas T, Weidner N, Janisse J. Where does work stress come from? A generalizability analysis of stress in police officers. *Psychol Health*. (2012) 27 (12):1426–47. doi: 10.1080/08870446.2012.687738

32. Gershon RR, Barocas B, Canton AN, Li X, Vlahov D. Mental, physical, and behavioral outcomes associated with perceived work stress in police officers. *Crim Justice Behav*. (2009) 36(3):275–89. doi: 10.1177/0093854808330015

33. He N, Zhao J, Archbold CA. Gender and police stress: the convergent and divergent impact of work environment, work-family conflict, and stress coping mechanisms of female and male police officers. In: Natarajan M, Editor. *Women police*. London: Routledge (2005). p. 687–708.

34. Kurtz DL. Controlled burn: the gendering of stress and burnout in modern policing. *Fem Criminol*. (2008) 3(3):216–38. doi: 10.1177/1557085108321672

35. Acquadro Maran D, Varetto A, Zedda M, Ieraci V. Occupational stress, anxiety and coping strategies in police officers. *Occup Med (Chic Ill)*. (2015) 65(6):466–73. doi: 10.1093/occmed/kqv060

36. Sundqvist J, Eriksson M, Ghazinour M, Hansson J, Hjertstedt M, Padyab M. Initiativ Mareld: en studie om polisanställdas hälsa, arbetsmiljö och trygghetsskapande arbete i särskilt utsatta områden i polisregion Stockholm (2021).

37. Rabe-Hesketh S, Skrondal A. *Multilevel and longitudinal modeling using stata: Categorical responses, counts, and survival*. 3rd ed. Umeå: Stata Press (2012). Available at: http://books.google.se/books?id=KyKnpwAACAAJ.

38. Williams R. Using the margins command to estimate and interpret adjusted predictions and marginal effects. *Stata J*. (2012) 12(2):308–31. doi: 10.1177/1536867X1201200209

39. Balvig F, Holmberg L, Sørensen AS. Ringstedforsøget: livsstil og forebyggelse i lokalsamfundet. 1. udgave, 1. oplag. København: Jurist- og Økonomforbundets Forl (2005). 454 p.

40. Ipsos M. Public trust and confidence in charities (2016).

41. Kääriäinen J. Why do the Finns trust the police? *J Scand Stud Criminol Crime Prev*. (2008) 9(2):141–59. doi: 10.1080/14043850802450294

42. Burke RJ, Mikkelsen A. Burnout, job stress and attitudes towards the use of force by Norwegian police officers. *Int J Police Strateg manag*. (2005) 28(2):269–78. doi: 10.1108/13639510510597906

43. Berg AM, Hem E, Lau B, Ekeberg Ø. An exploration of job stress and health in the Norwegian police service: a cross sectional study. *J Occup Med Toxicol*. (2006) 1 (1):26. doi: 10.1186/1745-6673-1-26

44. Mendel J, Fyfe NR, den Heyer G. Does police size matter? A review of the evidence regarding restructuring police organisations. *Police Pract Res*. (2017) 18 (1):3–14. doi: 10.1080/15614263.2015.1135399

45. Uppföljning av karriärstegsreformen. Delrapport 3. Statskontoret. . Available at: https://www.statskontoret.se/publicerat/publikationer/publikationer-2017/uppfoljning-av-karriarstegsreformen.-delrapport-3/ (cited 2022 Oct 14).

46. Regeringskansliet R och. Tillsammans mot brott - ett nationellt brottsförebyggande program [Internet]. Regeringskansliet. Regeringen och Regeringskansliet (2017). Available at: https://regeringen.se/rattsliga-dokument/skrivelse/2017/03/skr.-201617126/ (cited 2022 Mar 8).

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Supporting the future of medicine: Student mental health services in medical school

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Background: Mental health issues are common among United States medical students, and the AAMC has established recommendations for student mental health services provided by medical schools. Few studies directly compare mental health services at medical schools across the United States and, to our knowledge, none analyze how well schools adhere to the established AAMC recommendations.
Objective: To determine whether mental health services at United States medical schools adhere to established guidelines.
Methods: From October 2021 to March 2022, we obtained student handbooks and policy manuals from 77% of the accredited LCME United States medical schools. The AAMC guidelines were operationalized and placed into a rubric format. Each set of handbooks was independently scored against this rubric. A total of 120 handbooks were scored and the results were compiled.
Results: Rates of comprehensive adherence were very low, with only 13.3% of schools displaying adherence to the full set of AAMC guidelines. Partial adherence was higher, with 46.7% of schools meeting at least one of three guidelines. Portions of guidelines whose requirements reflected a standard for LCME accreditation displayed a higher rate of adherence.
Conclusion: The low rates of adherence across medical schools, as measured by handbooks and Policies & Procedures manuals, represents an opportunity to improve the mental health services within United States allopathic schools. An increase in adherence could be a step towards improving the mental health of United States medical students.

KEYWORDS
student mental health and wellness, policy, handbook evaluation, student services, mental health support

Introduction

In recent years, medical schools have sought to foster wellness with encouragement of activities such as mindfulness, exercise, peer connections, healthy diet, and self-care (1). However, mental health is an often overlooked aspect of wellness, despite the higher rates of depression, burnout, and suicidal ideation present in medical students compared to the general population (2, 3). Therefore, it is necessary to ensure students are receiving adequate support and mental health services to best support their patients and themselves. However, there is little research available on the information provided to medical students regarding the availability of mental health services.

Both the Association of American Medical Colleges (AAMC) and the Liaison Committee on Medical Education recognize medical student mental health as a vital aspect of education and suggest the availability of counseling, and the AAMC has a publicly available set of

TABLE 1 Operationalized rubric of AAMC mental health guidelines for medical schools.

AAMC Guideline (2) by clause	Indeterminate	Adherent
1a. Schools should provide access to confidential counseling by mental health professionals for all students. Institutional policies regarding the confidentiality of mental health service records for medical students should be established.	Instructions on how to access information on available mental health services.	Mention and existence of the availability of explicitly confidential counseling services for medical students.
1b. These policies should make the necessary distinction between voluntary and administratively mandated evaluation and/or treatment.	Instructions on how to access policies regarding mandatory evaluation/treatment.	Mention of situations and/or criteria leading to mandatory evaluations and/or treatment.
1c. For administratively mandated evaluation, disclosure of evaluation and/or treatment results should be limited to those who required the evaluation and should be in accordance with federal or state laws governing the disclosure of confidential information.	Instructions on how to access further policies regarding confidentiality of evaluations.	Declaration of confidentiality expectations regarding mandated evaluations.
2a. Schools should have guidelines regarding the utilization of mental health professionals and/or records of assessment and treatment by mental health professionals in proceedings regarding student advancement and dismissal.	Instructions on how to access further policies regarding record use in advancement and dismissal.	Mention of use of mental health treatment records and/or assessment records with regards to advancement and dismissal, in line with relevant privacy legislation.
2b. The committee recommends that evaluation and/or treatment of students be undertaken by non-teaching faculty or at a minimum, by different individuals than those rendering advancement or promotion decisions.	Instructions on how to access information on policies on non-involvement by faculty in evaluation and/or treatment.	Explicit statement that evaluation and/or treatment will be performed by non-teaching faculty who are not rendering advancement or promotion decisions.
3. Schools should publish and regularly update a list of available mental health assessment and counseling services, the institutional assurance of confidentiality, the means of access, and the associated costs for their students.	Instructions on how to access a list of resources containing information on the following: available mental healthcare services, confidentiality policies, accessibility, and cost.	Existence of a list of resources containing information on the following: available mental healthcare services, confidentiality policies, accessibility, and cost.

guidelines regarding mental health services for students at United States allopathic schools (**Table 1**) (4, 5). Despite widespread recognition of the existing barriers to mental health care, the AAMC guidelines remain the only publicly available document guiding the structure of mental health services offered to medical students in the United States. Additionally, the authors are not aware of any research directly comparing the availability of mental health services across United States medical schools. However, the availability of substance use treatment for medical students has been assessed by examination of school handbooks and policy manuals (6). Using similar methodology to evaluate the accessibility of mental health services in medical schools, we reviewed medical school student handbooks and Policies & Procedures (*P* & *P*) manuals to assess adherence to the established AAMC guidelines.

Methods

From October 2021 to March 2022, we sought to obtain medical student handbooks and Policies & Procedures (*P* & *P*) manuals from the 155 LCME accredited US allopathic medical schools. Most documents were easily accessible *via* the schools' main websites. When a document was not readily available online, we contacted the medical school's office of student affairs or equivalent office *via* email and phone a maximum of three times. Schools replying to contact after the month of March 2022 were not included in the analysis. Documents were examined when they were identified as either a "student handbook" or "policy & procedure manual" through title or by confirmation *via* school representatives.

The AAMC guidelines for mental health services were separated into clauses, and then operationalized into a rubric (**Table 1**). Each set of documents was scored according to the ternary categorical rubric, with the three categories being "adherent," "indeterminate," and "nonadherent." Guidelines were considered "adherent" when all the rubric criteria were met. The term "indeterminate" was applied to criteria when documents contained instructions on where to obtain the corresponding information, but did not provide the information within the text. This term was chosen as the completeness of the information provided was unclear, and the multiple steps required to access the information presented a potential boundary to care. For example, a document with the statement "Inquire at the Office of Student Affairs for information on mental health services" would be labelled "indeterminate" for criteria 1a, as it does not provide any information on the availability of confidential counseling but does provide an avenue for further inquiry. Documents were considered "nonadherent" to a criteria when the information was not present in the text, and no further information on where to locate the information was presented.

The scoring of documents was performed by EWH, and frequency of criteria adherence was added into a spreadsheet. In order to ensure consistency, results were intermittently spot checked. When all documents had been scored, we generated descriptive statistics based on the frequency count of adherence for each criterion. This structure and publication of this study followed the most recent Standards for Quality Improvement Reporting Excellence (SQUIRE) guidelines (7). The Colorado

TABLE 2 Adherence, nonadherence, and indeterminate adherence by AAMC guideline.

AAMC Guideline	Adherent	Nonadherent	Indeterminate
#1 – All criteria met	20 (16.7%)		
#1 – At least one criterion met	73 (60.8%)		
#1 – Zero criteria met		27 (22.5%)	
1a. Confidential counseling with confidential records	88 (73.3%)	22 (18.3%)	10 (8.3%)
1b. Explicit distinction of mandated evaluation/treatment	50 (41.7%)	70 (58.3%)	0 (0%)
1c. Confidentiality of mandated evaluation	24 (20%)	86 (71.7%)	10 (8.3%)
#2 – All criteria met	39 (32.5%)		
#2 – At least one criterion met	60 (50%)		
#2 – Zero criteria met		21 (17.5%)	
2a. Use of mental health professionals/records	40 (33.3%)	75 (62.5%)	5 (4.2%)
2b. Non-involvement of providers	95 (79.2%)	25 (20.8%)	0 (0%)
#3. List of services, confidentiality, access, costs	36 (30%)	19 (15.8%)	65 (54.2%)
Total # of guidelines met:		The total # of guidelines met only demonstrates comprehensive, rather than partial, adherence.	
No Guidelines	64 (53.3%)		
One Guideline	33 (27.5%)		
Two Guidelines	7 (5.8%)		
All Guidelines	16 (13.3%)		

Multiple Institutional Review Board (COMIRB) designated this study as non-human research and not in need of review.

Results

Out of 155 schools, we were successful in obtaining documents from 120 (77.4%). Of the outstanding 35, six schools denied access to the documents, and the remaining 29 did not respond to repeated requests. A final 120 (77.4%) sets of school documents were inspected. Document length ranged from 14 to 454 pages.

Of the 120 sets of documents analyzed, sixteen (13.3%) adhered to all AAMC guidelines for mental health services. Thirty-three schools (27.5%) fulfilled the criteria for only one AAMC guideline, and sixty-four schools (53.3%) did not fulfill the criteria for any AAMC guideline. Guideline 2 had the highest frequency of adherence, with 39 schools (32.5%) fulfilling criteria. Individual criteria had higher rates of adherence. Criterion 2b, which details non-involvement of psychiatric providers in evaluation of patient-students, was adhered to by 95 schools (79.2%). The second highest criterion, with 88 sets of documents (73.3%) adhering, was 1a, detailing the availability of confidential counseling for students (**Table 2**). These results are graphically represented in **Figure 1**.

Discussion

Our findings demonstrate the need for increased focus on provision of mental health treatment. Fewer than 14% of schools fully adhere to all of the established AAMC guidelines. Even one of the most commonly fulfilled criteria, availability of confidential counseling services, was present in fewer than 75% of the published documents. In fact, our data show that most medical school documents did not adhere to any of the AAMC guidelines. The highest degree of adherence was to criterion 2b, which is directly related to the LCME standard of accreditation which requires that health professionals involved in psychiatric or psychological care of a medical student not be involved in that student's assessment or promotion (5). This LCME standard also recommends availability of student counseling, but the recommendation is not compulsory (5). This LCME standard relating to criterion 2b and 1a may contribute to their high rate of adherence. The other criteria are not reflected in LCME standards, and there is a drop in adherence of 29% between criterion 2b and the third most fulfilled criterion, 1b, which details the importance of separating mandatory evaluation and elective treatment. One possibility for the difference could be that medical schools' abidance to the AAMC guidelines is driven by accreditation standards. This presents the possibility that adherence to these guidelines could be improved by adapting the LCME standards to include specific requirements regarding student mental health services. If accreditation standards mandated the availability of student mental health services, it is likely that more schools would offer these services and provide information in their handbooks and official *P* & *P* manuals.

Medical students have unique mental health needs. They face intense and increasing competition in nearly all aspects of their training, from the rising standards of admission to the increasingly competitive residency match (8, 9). As a result, medical students are under immense academic and emotional stress and regularly report perceiving limited support from their medical schools, which may be one of many factors that contribute to their high rates of depression and anxiety (10). In spite of medical training in psychiatric illness, students largely report not seeking treatment for their own mental health needs, even when they recognize those needs as unmet (11). Untreated mental illness puts medical students at risk across a variety of domains. In their personal health, medical students may experience increased substance use or severe infectious illness COVID-19, both of which have demonstrated increased prevalence in individuals with untreated mental illness (12, 13). Within school, medical students with underlying mental illness may experience higher rates of sleep issues and poorer academic

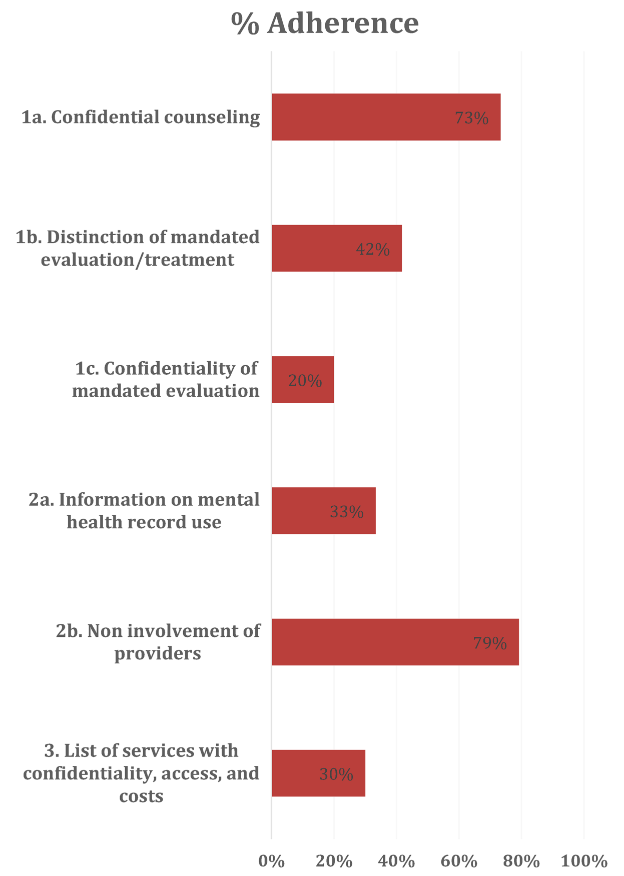

FIGURE 1
School document adherence to criteria, in percentage of total schools analyzed.

performance (14). Even after graduating, they may experience higher rates of burnout and even suicidality (15). It is incumbent upon medical schools to teach students how to mitigate this stress by instilling curriculum supporting the development help-seeking and self-care skills into their professionalism curriculum, as well as offering ample mental health resources for students.

While overall wellness includes mental health, many medical schools provide resources that primarily focus on other aspects such as meditation, exercise, and an increase in coaching relationships (1). While these aspects are important, a focus on wellness in the absence of a similar focus on and normalization of mental health treatment may lead to feelings of inadequacy, shame, or imposter syndrome when students are unable to independently "be well." (16) Furthermore, it can also increase stigma around trainees who may be considered "unwell," including those with disabilities (17). In an AAMC report, learners with disabilities described many barriers within their medical education, including lack of clear policies/procedures and lack of access to health care and wellness supports (18). Centralizing information in readily available school documents could help remove lack of resource awareness as a potential barrier to mental health treatment. Additionally, the handbooks offer an opportunity to reduce feelings of imposter syndrome for struggling learners by providing an institutional acknowledgment that the use of resources is encouraged (19).

There are both strengths and limitations inherent to the use of school documents as proxies for availability of mental health services. While it is possible that handbooks and official *P* & *P* manuals may not represent all information presented to students, and therefore underestimate rates of adherence, the handbook is often a central resource for students seeking information. More than 80% of document sets had statements indicating medical students were required to read and understand the information within, which indicates they should be a reliable reflection of school resources. Nonetheless, schools may provide information regarding mental health services through other avenues, such as email, websites, lectures, or campus announcements. Conversely, it is also possible that student handbooks provide a more robust description of services than what is realistically available to students, due to factors such as psychiatric provider shortages. For example, a school may report availability of confidential counseling, but the waitlist for an appointment may exceed several months, greatly hindering student access.

Our investigation provides an examination into the availability of mental health services at United States allopathic medical schools. Our data suggests a lack of adherence to AAMC guidelines, despite the prevalence of mental health issues among medical students and the established importance of mental health treatment. Improving the information contained within student handbooks and *P* & *P* manuals, as well as offering services recommended by the AAMC, could help reduce barriers to mental health treatment. As the awareness of barriers to psychiatric care increases, it becomes even more important that medical students are aware of resources available to support their mental health. Regardless of their chosen specialty, medical students and future physicians will ultimately be relied upon to support patients' mental and emotional health at different points in their training. Adequate mental health services must be provided to ensure students' behavioral health is maintained and supported throughout their medical education.

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 Colorado Multiple Institutional Review Board (COMIRB) designated this study as non-human research and not in need of review.

Author contributions

EWH had full access to all the data in the study and takes full responsibility for the integrity of the data and the accuracy of the data analysis. Concept, design and drafting: RAD and EWH. Critical revision, administrative support, supervision: RAD. All authors contributed to the article and approved the submitted version.

Conflict of interest

RAD served as Medical Director of Student and Resident Mental Health at the University of Colorado Anschutz Medical Campus until June 2022.

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

Publisher's note

References

1. Young C, Caceres J, Jackson A, Lee WW, Philips A, Rea M, et al. UME Wellness Programming and Strategies for Evaluating Wellness Programs: A National Review. https://www.aamc.org/media/56246/download?attachment (Accessed August 1, 2022).

2. Rotenstein LS, Ramos MA, Torre M, Segal JB, Peluso MJ, Guille C, et al. Prevalence of depression, depressive symptoms, and suicidal ideation among medical students: a systematic review and meta-analysis. *JAMA*. (2016) 316 (21):2214–36. doi: 10.1001/JAMA.2016.17324

3. Dyrbye LN, West CP, Satele D, Boone S, Tan L, Sloan J, et al. Burnout among U.S. Medical students, residents, and early career physicians relative to the general U.S. Population. *Acad Med*. (2014) 89(3):443–51. doi: 10.1097/ACM.0000000000000134

4. Association of American Medical Colleges. Recommendations Regarding Health Services for Medical Students (1992). https://www.aamc.org/professional-development/affinity-groups/gsa/health-services-recommendations (Accessed November 1, 2021).

5. Liaison Committee on Medical Education. Functions and Structure of a Medical School: Standards for Accreditation of Medical Education Programs Leading to the MD Degree 2021-22. (2017). https://lcme.org/publications/#Standards (Accessed November 10, 2021).

6. Mannes PZ, Wang TL, Ma W, Selzer J, Blanco C. Student substance use policies in US allopathic medical schools: a national study. *JAMA Psychiatry*. (2021) 78 (12):1393–5. doi: 10.1001/jamapsychiatry.2021.2666

7. Ogrinc G, Davies L, Goodman D, Batalden P, Davidoff F, Stevens D. SQUIRE 2.0 (standards for QUality improvement reporting excellence): revised publication guidelines from a detailed consensus process. *BMJ Qual Saf*. (2016) 25(12):986–92. doi: 10.1136/bmjqs-2015-004411

8. Advance Data Tables 2022 Main Residency Match®. www.nrmp.org (Accessed August 12, 2022).

9. Heller CA, Rúa SH, Mazumdar M, Moon JE, Bardes C, Gotto AM Jr. Diversity efforts, admissions, and national rankings: can We align priorities? *Teach Learn Med*. (2014) 26(3):304–11. doi: 10.1080/10401334.2014.910465

10. Lefebvre C, Hartman N, Tooze J, Manthey D. Determinants of medical specialty competitiveness. *Postgrad Med J*. (2020) 96(1139):511–4. doi: 10.1136/postgradmedj-2019-137160

11. Matheson KM, Barrett T, Landine J, McLuckie A, Soh NLW, Walter G. Experiences of psychological distress and sources of stress and support during medical training: a survey of medical students. *Acad Psychiatry*. (2016) 40(1):63–8. doi: 10.1007/s40596-015-0395-9

12. Gold JA, Johnson B, Leydon G, Rohrbaugh RM, Wilkins KM. Mental health self-care in medical students: a comprehensive look at help-seeking. *Acad Psychiatry*. (2015) 39(1):37–46. doi: 10.1007/s40596-014-0202-z

13. CDC. People with Certain Medical Conditions. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-medical-conditions.html (Accessed January 10, 2022)

14. Ahrberg K, Dresler M, Niedermaier S, Steiger A, Genzel L. The interaction between sleep quality and academic performance. *J Psychiatr Res*. (2012) 46 (12):1618–22. doi: 10.1016/J.JPSYCHIRES.2012.09.008

15. Harvey SB, Epstein RM, Glozier N, Petrie K, Strudwick J, Gayed A, et al. Mental illness and suicide among physicians. *Lancet*. (2021) 398(10303):920–30. doi: 10.1016/S0140-6736(21)01596-8

16. Rivera N, Feldman EA, Augustin DA, Caceres W, Gans HA, Blankenburg R. Do I belong here? Confronting imposter syndrome at an individual, peer, and institutional level in health professionals. *MedEdPORTAL*. (2021) 17:11166. doi: 10.15766/MEP_2374-8265.11166

17. Stergiopoulos E, Hodges B, Martimianakis MA. Should Wellness Be a core competency for physicians? *Acad Med*. (2020) 95(9):1350–3. doi: 10.1097/ACM.0000000000003280

18. Meeks LM, Jain NR. Accessibility, Inclusion, and Action in Medical Education: Lived Experiences of Learners and Physicians With Disabilities. (2018). AAMC. https://sds.ucsf.edu/sites/g/files/tkssra2986/f/aamc-ucsf-disability-special-report-accessible.pdf (Accessed August 1, 2022).

19. McGinty E, Pescosolido B, Kennedy-Hendricks A, Barry CL. Communication strategies to counter stigma and improve mental illness and substance use disorder policy. *Psychiatr Serv*. (2018) 69(2):136–46. doi: 10.1176/appi.ps.201700076

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The effect of group support psychotherapy on adherence to anti-retroviral therapy and viral suppression among HIV positive young people: Study protocol for a pilot randomized controlled trial

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Background: Several studies have demonstrated an association between psychological risk factors and HIV disease progression. However, there is limited information on the use of psychological interventions to improve HIV treatment outcomes in young people living with HIV.

Objective: This pilot trial aims to evaluate the feasibility, acceptability and preliminary effectiveness of group support psychotherapy in improving adherence to anti-retroviral therapy and viral suppression in young people living with HIV in Uganda.

Methods: We recruited 120 young people with HIV, aged 10–18 years, who had non-viral suppression 6 months after initiating first-line anti-retroviral therapy (ART) from community based HIV clinics in Kitgum district, northern Uganda. Participants were randomly assigned to receive GSP plus IAC ($N = 60$) or IAC alone ($N = 60$). Primary outcomes will be indicators of feasibility and acceptability as well as preliminary effectiveness of GSP in improving ART adherence and viral suppression analysed by intention to treat using cluster-adjusted t tests and permutation tests. Secondary outcomes will be measures of depression, anxiety and cost-effectiveness.

Results: The trial has been approved by the Makerere College of Health Sciences School of Health Sciences Research Ethics Committee, and the Uganda National Council of Science and Technology. Recruitment began in June 2021 and 120 young people living with HIV with their adult caregivers have been recruited to the trial. An analysis of baseline and 6-month data is in progress. The results of this trial will not only be presented at national and international conferences but also submitted for publication in peer-reviewed journals and as a report to the funding agencies.

Conclusions: This pilot trial will provide critical evidence to support the ongoing mental health integration into routine HIV care in Uganda.
Trial Registration: Pan African Clinical Trials Registry (PACTR): 202006601935462

KEYWORDS

Randomized controlled trial, group support psychotherapy, ART adherence, viral suppression, young people living with HIV/AIDS, Uganda

Introduction

The availability of anti-retroviral therapy (ART) has improved the life expectancy of persons living with HIV worldwide (1). However, a major concern is that, HIV morbidity and mortality have improved drastically among adults, which is not the case among young people (2). Research has shown that young people tend to experience worse immunological and viral suppression outcomes compared to adults (3–6), which in turn contributes to their higher morbidity and mortality (7).

Barriers to successful care of youth with HIV include mental health disorders, poor medication adherence, socioeconomic instability, and HIV-related stigma (8). Also transition of care from pediatric to adult clinics has been described as a challenging period in which the young people have to deal with anxieties, excessive anger, and lack of social support, self-esteem and self-efficacy (9). Consequently, they are prone to poor linkage to care, attrition from care and treatment (10).

In Uganda, the national HIV treatment guidelines include psychosocial support services in the HIV care package (11). However, the nature of psychosocial support is not structured and may not target common psychosocial challenges such as stigma, depression or post-traumatic stress. Enhanced or Intensive adherence counseling has long been used to mitigate non-viral suppression; however, recent findings from Ugandan studies indicate that this strategy may not be sufficient (12, 13).

A retrospective cohort study on all children aged 9 months to 19 years that had been enrolled into 15 HIV care programs in 15 districts supported by the Infectious Diseases Institute (IDI) assessed the outcome of Intensive adherence counseling among 449 children with viral non-suppression (13). A repeat viral load test performed on 274 children who had completed three IAC sessions indicated that 212/274 (77%) were unsuppressed and 62 (23%) were suppressed. There was no report of any other specific psycho-social intervention provided to children with viral non-suppression in the above mentioned 15 HIV care programs.

Researchers call for an urgent need for innovative strategies to respond effectively to the social, emotional and economic challenges faced by young people living with HIV (14). In particular, they recommend for intensified targeted adherence support in order to improve HIV treatment outcomes (15). To this end, a few studies on interventions to promote ART adherence among young people have started to emerge (16–19).

To mitigate mental health challenges and improve HIV treatment outcomes, we developed group support psychotherapy—a culturally sensitive evidence based intervention that has been shown to effectively treat mild to moderate depression, improve posttraumatic stress symptoms, and hazardous alcohol use among adults living with HIV in Uganda (20). Further, exposure to GSP was observed to improve viral load suppression through sequential reduction in depression and improvement in ART adherence among adults living with HIV in Uganda (21).

The cognitive behavioral theory is one of the potential existing theoretical models that could guide the development of mental health interventions for young people living with HIV. Cognitive-behavioral therapy (CBT) is recommended for treatment of children and adolescents (22). We chose to adapt group support psychotherapy for young people because it is based on the principles of cognitive behavior theory, social learning theory, and the sustainable livelihoods framework. The cognitive behavior theory holds that the way we think about our reality is central to how we react to that reality (23). The social learning theory stems from the idea that behavior is learned from the environment by observation, in which the person being observed is referred to as the model (24) The sustainable livelihoods framework shows that the absence of livelihood strategies such as the ability to adapt to adverse situations, network and increase social connections, or work and obtain savings, housing, or land, constrains livelihood opportunities (25).

Given the evidence we have gathered for group support psychotherapy, it can address the complex and dynamic interactions between young people, their families, and their environmental context (26).

The goal of this paper is to describe the protocol for the evaluation of the feasibility, acceptability and preliminary effectiveness of group support psychotherapy in improving ART adherence and viral suppression among HIV positive young people in Uganda. In the preparatory phase of this trial, we aim to conduct community-based participatory qualitative research to obtain information on the potential usefulness of group support psychotherapy in addressing the psychosocial challenges that impact adherence to anti-retroviral therapy and viral suppression among young people with HIV in northern Uganda.

In the trial phase of this study, the primary objective will be to assess the feasibility, acceptability and preliminary effectiveness of GSP in promoting ART adherence and viral suppression among HIV positive young people with non-viral suppression 6 months after initiating first-line ART at community-based HIV clinics in Kitgum district. Secondary objectives will include exploration of indicators of causal mediating processes and contextual influences, exploration of whether or not improvement in psychosocial challenges including depression, posttraumatic stress symptoms, suicide risk, social support, and stigma mediate or modify the effect of GSP on ART adherence and viral suppression, exploration of whether or not promotion of adherence through group support psychotherapy translates into better viral load suppression compared to standard care with intensive adherence counseling (IAC) and exploration of the cost-effectiveness of GSP to improve viral load suppression among HIV positive young people taking anti-retroviral therapy.

We hypothesize that in comparison to the control intervention, GSP will demonstrate better feasibility, acceptability and better preliminary HIV treatment outcomes and better cost-effectiveness. The primary end point will be 6 months after the end of the intervention. Data will be used to design a definitive cluster randomized trial which will test the hypothesis that group support psychotherapy promotes better ART adherence and viral suppression than standard care with intensive adherence counseling among HIV positive young people with non-viral suppression 6 months after initiation of first-line ART in Uganda.

Methods

Study setting

Study participants will be recruited from community based HIV clinics in Kitgum district. The clinics take care of approximately 500 young people aged 18 years and below living with HIV. At the time we conceptualized this study, HIV clinic registers in Kitgum district showed that 60% of young people living with HIV (PLWH) initiated on ART were not suppressing the HIV virus. Therefore, we drew our study sample from a pool of approximately 300 young PLWH who had viral non-suppression. Kitgum district has a population of 232,000 individuals with over 90% engaged in small scale agriculture and animal husbandry as their major income generating activity. Kitgum district endured a brutal civil war for two decades (1987–2007) which led to a breakdown of health care delivery systems, loss of property and infrastructure.

Study design

In the preparatory phase, we shall conduct a qualitative study. Thirty dyads of young people with non-viral suppression and their caregivers will be exposed to 8 sessions of the current group support psychotherapy intervention (GSP). At the end of the intervention, 6 focus group discussions will be conducted with the young people ($N = 2$); their caregivers ($N = 2$) and their HIV care providers ($N = 2$). Key informant interviews will be held with various stakeholders including psychologists, pediatricians, child and adolescent psychiatrists, district health officials, community leaders and religious leaders to determine their perceptions towards using GSP as an intervention to promote adherence to ART alongside Intensive Adherence Counseling (IAC) among young people with HIV and their caregivers. The main objective of the workshops will be to discuss the potential of the current GSP intervention content, in addressing possible challenges/barriers associated with adherence to ART among young people with HIV. A community advisory board will be created to maintain the community's trust in the research process and members will also participate in key informant interviews.

Data from these KIs/FGDs will be used to modify intervention content/delivery. Purposive sampling will be used for the qualitative interviews, which will be conducted in the local language, audio-taped and transcribed and translated (where required) verbatim. Informed consent will be obtained from participants before conducting KIs/FGDs. Thereafter, consultative meetings will be held with child and adolescent HIV and mental health experts to review our theoretical framework and assemble treatment strategies to be used in the GSP model for young people with HIV.

In the trial phase, we shall conduct a pilot single-blinded randomized controlled trial to test the feasibility and acceptability of using GSP in combination with standard care IAC vs. standard care IAC only to promote ART adherence and improve viral suppression among HIV positive young people with non-virological suppression 6 months after initiation of first-line ART (see Consolidated Standards of Reporting Trials diagram in **Figure 1**). We aim to randomize 120 youth/caregiver dyads (1:1) to either both GSP and IAC or IAC only. Participants will be evaluated at baseline, at the end of treatment, 6 and 12 months after treatment. A longitudinal process evaluation of the delivery of GSP-IAC by trained LHWs using mixed methods will run alongside the trial to assess fidelity, and how intervention recipients respond to the different intervention components.

The study protocol was registered in the Pan African Clinical Trials Registry. The study was submitted to both the Makerere University School of Health Sciences Research Ethics Committee and the Uganda National Council of Science and Technology. All study participants will be required to provide written informed consent. All study participants will receive a financial incentive to defray transport costs. The reporting of the trial will be in accordance with the Standard Protocol Items: Recommendations for Interventional Trials (SPIRIT) guidelines (27) for intervention trials (see **Supplementary Multimedia Appendix S1**) and the CONSORT statements for pilot randomized trials (28).

Participant eligibility criteria, recruitment, and masking

To be eligible for the study, participant dyads must consist of an HIV sero-positive young person (10–18 years) with ≥1,000 viral copies/ml 6 months after initiating first-line ART and a caregiver aged 19 years and older. Participant dyads will be excluded if they have visual or hearing impairments, active untreated major mental illness (untreated psychosis or mania or high suicide risk) or severe medical conditions (active tuberculosis or pneumonia) that would interfere with participation in interventions.

All participants will be recruited from community-based HIV clinics in Kitgum district. Potential participants will be identified by their HIV care providers as not responding to their current antiretroviral (ARV) treatment regimen (defined per local clinic

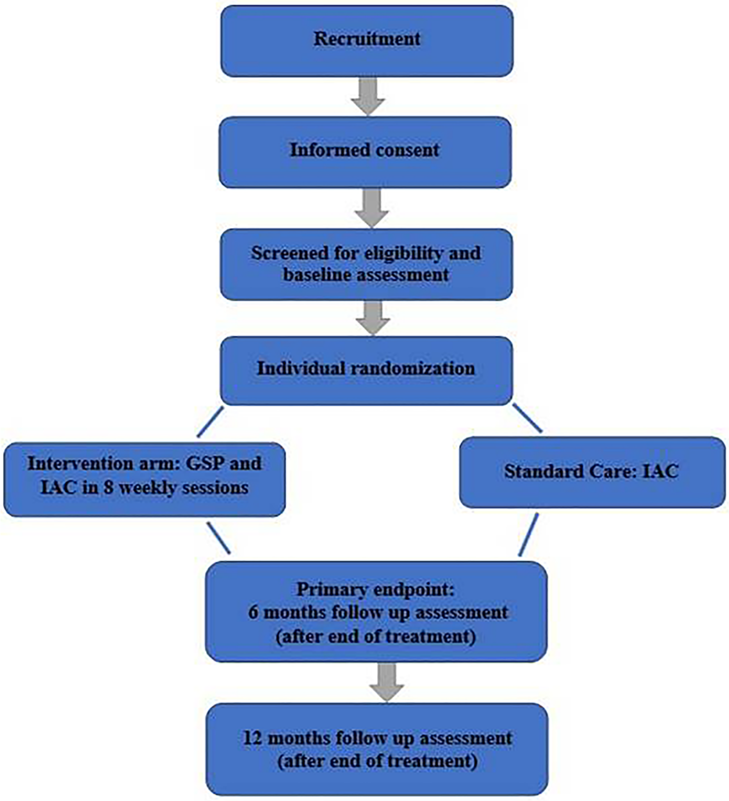

FIGURE 1
Trial flowchart.

standards as viral load >1,000 copies/ml). Research assistants (RAs) and other study staff situated at the HIV clinic will work with staff in the HIV clinics to identify potential participants as they wait for their medication refills. RAs will be Luo-speaking staff with GSP research and HIV clinical experience. They will be extensively trained in the study protocol and supervised weekly by the project coordinator who is a social worker. They will be screened for psychosis and mania using quick screening questions for psychotic and manic symptoms. They will also be screened for high suicide risk using the SAD PERSONS scale. Individuals with psychotic and/or manic symptoms and /or high suicide risk will be excluded from the study.

All young people (10–18 years)/caregiver dyads eligible to participate in the study will be approached by research assistants who will explain study procedures, determine eligibility, and then obtain informed assent/consent. Each dyad which assents/consents will be assigned to receive baseline interviewer administered demographic and psychosocial assessment battery and thereafter randomly assigned to receive either both GSP and IAC or IAC only.

Randomisation and masking

Randomisation will be done by urn randomisation picked by each participant. The young males and females will be separated into two groups. Each group will be presented with pieces of paper in opaque envelopes whereby half the number of papers will be marked X and the other half Y. Each member of the group will be asked to each pick one envelope. Individuals who pick papers with X will be assigned to both GSP and IAC while those who picked papers with Y will be assigned to IAC only. The same process was repeated for the caregivers.

By design, both experimental and control interventions will be identifiable to participants but will be masked to independent outcome assessors, and data analysts.

Interventions

Group support psychotherapy (GSP)

The content of the GSP has been described in previous publications (29, 30). GSP sessions for caregivers will proceed as previously described in the SEEK-GSP trial (20). GSP sessions for the young people will follow the same format but with a focus on challenges faced by young people living with HIV and will be delivered using play materials. Besides being gender specific, they will also be age specific with participants being grouped into the following age categories: 10–13; 14–16 and 17–18) GSP will be delivered in eight weekly sessions, each lasting 2–3 h. Participants will be divided into sex-specific groups of 10–12 participants. The groups will be closed-meaning that once the group is formed and therapy initiated no other participant can join the group. Trained health workers of the same sex as the group participants will deliver the intervention material following a scripted manual.

The first session addresses issues related to introductions, the group process, expectations, and ground rules and making a pledge to commit to all sessions. Simple games will be used to explain concepts and help the young people get to know each other's name.

The second session will use pictures and practical demonstrations with balloons, to explain the presentation and consequences of abnormal emotions such as persistent sadness, fear, anxiety and anger and how they relate to living with HIV. Thereafter, participants will be asked to communicate with peers and share newly learned knowledge.

In sessions three and four, group participants share their most painful experiences. Here, various techniques will be used to help the young people open up. For example, expressive art exercises of body pain and heart wound. Here the young people are asked to draw a figure of the human body and place a mark where they feel pain. The counselor then encourages them to talk about the feelings associated with the pain they feel in the body part that is hurting. Another technique is to present a timeline from childhood to present and ask the young people to place both positive and negative events on their time-line. Thereafter, participants are encouraged to share other problems with a trusted elder in their household or community. In sessions five and six, practical demonstrations of culturally positive coping skills such as the stress bucket, gardening, seed pounding and crocheting are used to teach participants positive coping skills. The last two sessions are dedicated to income-generating skills that young people can use to support their caregivers income generating projects. Our previous research revealed a need for an intervention that focused on treatment of depression symptoms and livelihood skills development to improve household basic income (29). Poverty is a potent risk factor for depression and researchers recommend mental health interventions that can alleviate poverty (31).

Standard of Care—Intensive Adherence Counseling

Both the World Health Organization (WHO) and the Ugandan ART guidelines recommend that asymptomatic persons living with HIV who have been identified with viral load (VL) ≥1,000 copies per ml should be offered Intensive Adherence Counseling (IAC) for 3–6 months (see **Table 1**) and repeat VL testing before

TABLE 1 Intensive Adherence Counseling Guide

Guide	Components
IAC Session 1	
Assess	• Explain purpose of session ◦ Disclose VL test results to client and explain the meaning of suppressed and non-suppressed VL ◦ Explain reasons for non-suppressed VL results (non-adherence to drugs or drugs may not be working well) ◦ Discuss implications of non-suppressed results to the client • Determine adherence levels ◦ Calculate the adherence score using the adherence percentage formula • Assess client's barriers to adherence ◦ Use the adherence assessment checklist to ascertain client's adherence practices. ◦ Identify barriers to client's adherence (arising from the assessment)
Advise	• Identify information gaps from assessment ◦ Educate client in relation to specific barriers identified • Review benefits of good adherence ◦ Assess client's knowledge of benefits ◦ Provide correct and complete information on • Discuss consequences of non-adherence ◦ Assess client's knowledge on the dangers of non-adherence ◦ Educate client on the consequences of non-adherence
Assist	• Evaluate the underlying causes of the identified barriers ◦ Prioritize the barriers ◦ Identify possible root causes of each barrier (where applicable) • Identify client specific strategies to overcome identified barriers ◦ Discuss possible options to address key barriers ◦ Provide information about available support systems e.g., CBOs, peer support groups etc • Discuss the pros and cons of each strategy/option
Agree on	• Agree on client's action points to address the key barriers ◦ Identify appropriate strategies ◦ Provide relevant and necessary information • Evaluate each action point using the 5 Ws and 1H ◦ What, where, when, who, which, how? • Document agreed upon action points on the IAC session form • Develop and document a new adherence plan on the IAC session form
Arrange	• Summarize the session ◦ Review the action points ◦ Review the new adherence plan • Arrange for ART refill • Explain the schedule for IAC intervention

(*continued*)

TABLE 1 Continued

Guide	Components
	◦ Explain the number of sessions ◦ Emphasize appointment keeping • Schedule the 2nd IAC session • Document the next appointment date on the IAC session form • Remind client to bring remaining pills at next visit • Refer and link to other services as appropriate
IAC Session 2	
Assess	Assess adherence levels • Document the adherence score • Compare current score with the previous Assess progress in dealing with barriers • Identify what worked • Identify what did not work • Discuss new strategies Assess compliance to adherence plan • Identify what worked • Identify what did not work • Discuss new strategies Assess for possible new barriers to adherence • Use adherence assessment checklist
Advise	Do as in IAC Session 1
Assist	Do as in IAC Session 1
Agree on	Do as in IAC Session 1
Arrange	Do as in IAC Session 1
IAC Session 3	
Assess	Do as in IAC Session 2
Advise	Do as in IAC Session 1
Assist	Do as in IAC Session 1
Agree on	Do as in IAC Session 1
Arrange	Review Adherence Scores For 1st, 2nd And Current IAC Visits • If Adherence Score Is Consistently Good (>95%) For Three Consecutive IAC Visits, Give 1 month Appointment For 2nd VL Bleeding • If Adherence Score Is Not Consistently Good For Three Consecutive IAC Sessions, Give Appointment For 4th IAC Session Give Appointment For 2nd Bleeding For VL Test (After 1 Month) • Remind And Emphasize To Client To Keep The Next Appointment. • Flag The Client's File As Due For Repeat VL Testing (Indicate Due Date On The Red Sticker) Discuss Reminder Plans With Clients Who Are Due For Bleeding • Provide ARV Drugs For 1 Month (Strictly) • Call Client 1 Week To The Due Date To Remind Them Of Appointment

switching to second-line therapy (32). Individuals with detectable viral load 6 months after initiating ART are invited to participate in IAC in the clinic, which consists of at least four sessions with an HIV care provider. Key messages in each counseling session are summarized below.

Participant safety

During baseline assessments, participants will be carefully screened and individuals for whom the interventions are deemed medically inappropriate or unsafe will be excluded as described in the exclusion criteria. Independent outcome assessors will screen all participants for adverse events at the end of treatment and at 6 months after the end of the intervention using a standard interview and reporting form.

Any unfavorable and unintended sign or symptom associated with the participation in group support psychotherapy, regardless of whether it is considered related to the therapy will be regarded as an adverse event (AE).Any AE that results in any of the following outcomes: Death, Life-threatening, Event requiring inpatient hospitalization, Persistent or significant disability/incapacity will be regarded as a serious adverse event (SAE). Expected AEs associated with this study would be suicide attempts due to lack of treatment response to the group support psychotherapy.

AE management

During participant recruitment, individuals will receive a suicide risk assessment (33). Individuals with high suicide risk will be excluded from the study. Those with a low to moderate risk will be included, their thoughts will be assessed at every group meeting and care givers will be asked to keep close watch on the affected individual. If suicidal thoughts are still present after 4 sessions of GSP-IAC or IAC only these individuals will be referred to a mental health worker in the Kitgum Mental Health Clinic. Details of the trial risk management plan are provided as **Supplementary material**.

Retention

In order to maximize adherence to intervention sessions and retention, lay health workers (LHWs) who facilitate the group sessions and the HIV care providers who provide the adherence counselling will be provided with a financial incentive as an appreciation of their commitment to the project. For participants who miss group sessions, the LHWs will be facilitated to make home visits to re-engage them.

Study measures and data collection schedule

Assessments of study measures will be conducted at baseline, at the end of the interventions (2 months), 6 and 12 months after the interventions. Table 2 (34–42) summarizes the study measures.

Sample size justification

The goal of this pilot trial is to test trial procedures and processes and to get estimates of parameters for the main trial sample size calculation (43). Therefore, the sample size formulae which are used for main treatment assessments are not usually applicable to pilot trials. Therefore, we applied the sample size flat rules of thumb proposed by Sim and Lewis (44) and chose a sample size of 60 per treatment arm.

Determining cost-effectiveness

We will determine the cost-effectiveness of the GSP intervention compared to the standard of care IAC. To facilitate this, our proposed costing perspective is the "societal perspective", which will include intervention costs, costs related to the use of other healthcare resources, as well as lost time to attend the intervention." We will develop a questionnaire to collect information on the use of other healthcare resources that can be impacted by the intervention such as got insurance medical visits, ambulatory care, mental health-related medication, etc.

Data on costs involved in delivering the two models will be determined and these will then be compared to the targeted outcomes of the two delivery models. The main primary outcomes of the study—ART adherence and Viral Load, will be utilized. Important to note, however, is that costs of research and research related activities shall not be included in determining cost-effectiveness. Additional data on economic costs—costs of lost time, for categories of participants, including voluntary unpaid participants, costs of additional workload, etc., in the study shall be explored, using shadow pricing methods. Costs will be identified from project documents and accountabilities. Additional costs will be generated from literature in case they may not be available in the available project documents. Major costs for services and other procurements shall be based on reimbursement contracts, and in some circumstances market rates when they were procured. Other databases including Uganda Bureau of Statistics (UBOS) shall be used to generate relevant data for use in cost-effectiveness analysis.

TABLE 2 List of study measures and data collection schedule.

Study Measures	Instrument	Data collection schedule (months)			
		0	2	6	12
Socio-demographic variables	Standardized Demographic Questionnaire	✓			
Primary outcomes					
Indicators of feasibility	The proportion of eligible participants who take up either intervention (**Reach**) The proportion who attended all 8 sessions of either intervention (**Dose delivered**) The proportion who are lost to follow-up (**Attrition**) will be determined from the attendance registers		✓		
Indicators of acceptability	A 9-item questionnaire (34) will assess participant's satisfaction, the group facilitators' knowledge and attitudes, and the participant evaluation of the intervention's ability to reduce stress		✓		
Adherence to ART	One question "During the past three weeks, on how many days have you missed taking all your medication doses?"	✓		✓	✓
Viral Load	Medical charts of study participants	✓		✓	✓
Secondary outcomes					
Fidelity	A semi-structured self-administered questionnaire completed by group facilitators will assess whether or not the interventions were delivered as planned.		✓		
Contextual influences	A semi-structured self-administered questionnaire completed by group facilitators will assess any facilitators or barriers to intervention delivery that they observed during group sessions.		✓		
Depression symptoms	The 25-item revised child and adolescent anxiety and depression scale (RCADS-25) will be used to assess anxiety and depression symptoms. Although it has not been validated in Ugandan populations, its items have face validity. It has been widely used in Europe North and South America with internal reliability ranging from 0.87 to 0.90 (35, 36), a high sensitivity of 90% and specificity of 75% (37). RCADS scores will be modeled as a continuous variable.	✓	✓	✓	✓
Suicide risk	Suicide risk will be assessed using the 10-item Patterson suicide risk assessment tool. Its validity and reliability have not been evaluated in Uganda. Due to its brevity and face validity it has been used in both adults and young people in Uganda (33)	✓	✓	✓	✓
Post-traumatic stress symptoms	The 17-item Clinician-administered post-traumatic stress disorder scale for children and adolescents (CAPS-CA) will be used to assess PTSD symptoms. Although it has not been validated in Ugandan populations, its items have face validity The tool has been widely used in Europe North and South America with internal reliability ranging from 0.83 to 0.87 (38–41), a high sensitivity of 90% and specificity of 75%. CAPS-CA scores will be modeled as a continuous variable.	✓	✓	✓	✓
Social support	The child and adolescent social support scale (CASS) will be used to assess social support. Although it has not been validated in Ugandan populations, its items have face validity. It's internal consistency reliability coefficient ranges from 0.87 to 0.94) in studies conducted in Europe (41).	✓	✓	✓	✓
Stigma	The 8-item HIV stigma scale for children (HSSC-8) will be used to assess stigma. It has internal consistency reliability coefficient of 0.81 (42).	✓	✓	✓	✓

Statistical analyses

Qualitative data

Interview transcripts from the FGDs will be reviewed for accuracy, translated into English and transcribed. Atlas.ti qualitative data analysis software will be used for coding and thematic analysis (45). The interview data will be initially coded according to a number of themes that correspond to the focus questions. The codes will be used to construct matrix displays based on the co-occurrence of codes and the two treatment groups. The resulting matrix display will provide both the frequency of responses and the detailed content of responses, allowing us to assess how often responses will vary between the two treatment groups. Inter coder reliability will be determined.

Quantitative data

For the quantitative data, we will do bivariate analyses with χ^2 tests and independent two-sample *ttests* to compare categorical and continuous baseline demographic and psychosocial variables between study groups respectively. Similarly, we will also do bivariate analyses to compare these variables between those who had completed all sessions (completers) and those who had not (non-completers). Although randomisation to GSP and GHE will be done at the individual level, study participants will receive their respective interventions in groups (clusters). Since individuals within a cluster are likely to be correlated, we will use cluster-level analyses to make allowance for intra-cluster correlation.

We will apply ttests to cluster-level summaries, which is a robust method of analysis for cluster data (46). Specifically, we will use the STATA collapse command to obtain cluster-level summaries of the study outcomes from data on individual participants. This procedure will reduce the data from 120 individual participants to 12 groups. We will then use the *clttest* command to compare cluster means across treatment groups.

To do an intention-to-treat analysis, we will impute missing values with several imputations. We will construct five imputed datasets with the multivariate normal model assuming that data were missing at random. The participants complete baseline data will be used to create the multiple imputation datasets.

Cost-effectiveness analysis

To determine the outcome measure for use in cost-effectiveness analysis, the main assumption will be that there is a link between ART adherence and viral load. If this assumption be true, then cost-effectiveness analysis will utilize viral load (VL) as the primary outcome.

This primary outcome will be mapped on to long-term outcome measures—QALY/DALY as the data may permit, using models such as WHO-CHOICE and or WHO DALY/QALY estimators, to generate cost-effectiveness (47). Appropriate adjustments, including inflation, exchange rate, and discounting for costs and outcomes shall be conducted.

The WHO-CHOICE (Choosing Interventions that are Cost-Effective) and DALY/QALY (Disability-Adjusted Life Years/Quality-Adjusted Life Years) estimators are two tools developed by the World Health Organization (WHO) to help evaluate the cost-effectiveness of healthcare interventions. The WHO-CHOICE estimator is a tool that calculates the cost-effectiveness of healthcare interventions based on their impact on disease burden and their cost. It uses a standardized approach to estimate the costs and health outcomes of different healthcare interventions, taking into account the local context of each country. The estimator is designed to be flexible and can be adapted to different healthcare settings and disease profiles.

The WHO DALY/QALY estimator is a tool that measures the burden of disease and the impact of healthcare interventions on health outcomes. It uses a measure called Disability-Adjusted Life Years (DALYs) or Quality-Adjusted Life Years (QALYs) to quantify the impact of disease on individuals and populations. DALYs and QALYs take into account both the years of life lost due to premature death and the years lived with disability or illness. The WHO DALY/QALY estimator can be used to evaluate the cost-effectiveness of healthcare interventions by comparing the cost per DALY or QALY gained. Both WHO-CHOICE and DALY/QALY estimators are widely used by policymakers, healthcare providers, and researchers to help make informed decisions about allocating healthcare resources and designing cost-effective healthcare interventions.

To determine cost-effectiveness of the service delivery models, we will compare the measures determined with conventional benchmarks such as Gross Domestic Product (GDP) per capita, or will compare with literature from other but similar contexts. Throughout the study we will apply the guidelines for economic evaluation from the second panel on cost-effectiveness (48) and the recommended CHEERS guidelines for reporting the results (49).

Ethical considerations

The study protocol will be presented to the relevant institutional review boards. Every participant will be reimbursed transport costs based on the rate for the furthest participant and refreshments will be served after focus group discussions and group support sessions. LHWs facilitating the group sessions will receive a financial incentive equivalent to 2.72USD per session.

Group support psychotherapy is offered as a continuous service at the Kitgum general hospital. All study participants will have access to GSP if found to be highly beneficial in improving ART adherence and viral suppression. This trial is registered with The Pan African Clinical Trials Registry Number PACTR202006601935462.

Results

Trial status

The trial has been approved by the Makerere School of Health Sciences Research Ethics Committee, and the Uganda National Council of Science and Technology. Recruitment began in June 2021 and closed October 2021. A total of 120 young people (10–18 years) living with HIV with their adult caregivers were recruited into the trial. They were randomized to receive the adolescent group support psychotherapy (A-GSP) and intensive adherence counseling (IAC) ($N = 61$) and IAC alone ($N = 60$). An analysis of baseline, 6 and 12-month data is in progress. The results of this trial will be presented at national and international conferences. Manuscripts will be prepared for publication in peer-reviewed journals and reports will be prepared for submission to the funding agency.

Discussion

The mental health needs of young people living with HIV have been documented in high income countries, but remain underexplored within low and middle income countries (50). The negative consequences of poor mental health, in particular, depression include poor adherence to ART, poor service engagement, and risk behaviors (51). Unfortunately, recent systematic reviews indicate a dearth of psychological interventions for these mental health issues, therefore, affected individuals continue to experience high morbidity and mortality rates especially within low and middle income countries (52).

To our knowledge, this is the first trial to examine the feasibility, acceptability and preliminary effectiveness of a psychological intervention-GSP on ART adherence and viral suppression among young people living with HIV in sub-Saharan Africa. Through qualitative research prior to the trial, the GSP model will be adapted to suit the needs of young people (10–18) years and will be delivered using play materials. Play therapy allows children to utilize toys and other play materials to express their own story and emotions without necessarily using words to participate in the counseling process (53). Play therapy has been shown to produce outcomes that are as effective as traditional talk-therapy methodologies commonly used with adult populations (54).

Given our prior research findings which indicated that GSP improved viral suppression through sequential reduction in depression symptoms and improvement in ART adherence (21), in this trial we selected those young people who had failed to suppress the HIV virus after 6 months of ART use. We assume this category of young people is more likely to have mental health challenges like depression which are amenable to GSP. We hypothesize that remission of depression would then lead to motivation to take ART and improve viral suppression. However, reduction of depression in of itself has been shown to improve viral suppression in our adult HIV study samples (21). Prior studies have shown that reduction in ANS activity brought about by reduction in stress inhibits HIV viral replication (55, 56). This pilot trial provides an opportunity to replicate these associations among young people living with HIV.

Potential impact and significance of the study

Mental health problems such as depression largely affect ART adherence which is critical to the success of viral suppression among young people living with HIV (57, 58). There is a dearth of mental health interventions to improve HIV treatment outcomes in young people living with HIV (59). This trial evaluates the feasibility and preliminary effectiveness of a psychological intervention in improving ART adherence and viral suppression. Further, the trial will provide an opportunity to explore mechanisms that affect HIV treatment adherence and viral suppression, which could be exploited to improve HIV treatment outcomes in other low resource settings. Further, the trial will provide evidence for scale up of GSP in both young and adult populations with HIV in low resource settings.

Limitations

This study has several limitations. First, the study will include only 120 participants from five community based HV clinics in one northern Uganda district. Our results may not be generalizable to other areas in Uganda. Second, study participants will reside in similar villages attending similar HIV clinics, thus the chances of contamination are high which may result in non-detection of significant differences when they truly existed. However the major goal of this trial is to determine feasibility and acceptability of study procedures in preparation of a definitive trial in the near future. Further, in view of the small number of mental health workers trained in delivering GSP using play materials, supervision of treatment sessions was not possible. Also, the limited numbers of diploma and degree-level health workers restrict the long term accessibility and sustainability of GSP among young people. Future research will assess whether or not the intervention can be administered by lay health workers.

Conclusions

Successful completion of this trial will pave way for a definitive cluster randomized trial that can critically inform the national dissemination and implementation of GSP to improve HIV treatment outcomes in young people living with HIV in low resource settings.

Ethics statement

The studies involving human participants were reviewed and approved by both the Makerere University School of Health Sciences Research Ethics Committee and the Uganda National Council of Science and Technology. Written informed consent to participate in this study was provided by the participants' legal guardian/next of kin.

Author contributions

EN-M, KW, IJ, and CN conceptualized the study, and EN-M sought and obtained funding. EN-M conducted statistical analyses. JDN and BA managed the literature searches. EN-M, IJ, and CN wrote the initial manuscript.SM, SB, EJM, and JBN revised the manuscript critically for important intellectual content. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frhs.2023.1011898/full#supplementary-material.

References

1. Joint United Nations Programme on HIV/AIDS (UNAIDS). Ending AIDS: Progress towards the 90–90–90 targets. Available at: http://www.unaids.org/sites/default/files/media_asset/Global_AIDS_update_2017_en.pdf

2. World Health Organization. *A global research for adolescents living with HIV*. Geneva: WHO (2017).

3. Jobanputra K, Parker LA, Azih C, Okello V, Maphalala G, Kershberger B, et al. Factors associated with virological failure and suppression after enhanced adherence counselling, in children, adolescents and adults on antiretroviral therapy for HIV in Swaziland. *PLoS ONE*. (2015) 10(2):e0116144. doi: 10.1371/journal.pone.0116144

4. Cruz ML, Cardoso CA, Darmont MQ, Souza E, Andrade SD, D'AlFabbro MM, et al. Viral suppression and adherence among HIV-infected children and adolescents on antiretroviral therapy: results of a multicenter study. *J Pediatr (Rio J)*. (2014) 90(6):563–71. doi: 10.1016/j.jped.2014.04.007

5. Zanoni BC, Mayer KH. The adolescent and young adult HIV cascade of care in the United States: exaggerated health disparities. *AIDS Patient Care STDS*. (2014) 28 (3):128–35. doi: 10.1089/apc.2013.0345

6. Nachega JB, Hislop M, Nguyen H, Dowdy DW, Chaisson RE, Regensberg L, et al. Antiretroviral therapy adherence, virologic and immunologic outcomes in adolescents compared with adults in Southern Africa. *J Acquir Immune DeficSyndr*. (2009) 51 (1):65–71. doi: 10.1097/QAI.0b013e318199072e

7. Idele P, Gillespie A, Porth T, Suzuki C, Mahy M, Kasedde S, et al. Epidemiology of HIV and AIDS among adolescents: current status, inequities, and data gaps. *J Acquir Immune DeficSyndr*. (2014) 66(Suppl 2):S144–53. doi: 10.1097/QAI.0000000000000176

8. Pettitt ED, Greifinger RC, Phelps BR, Bowsky SJ. Improving health services for adolescents living with HIV in sub-saharan Africa: a multi-country assessment. *Afr J Reprod Health*. (2013) 17(4):17–31. PMID: 24689314

9. Dahourou DL, Gautier-Lafaye C, Teasdale CA, Renner L, Yotebieng M, Desmonde S, et al. Transition from paediatric to adult care of adolescents living with HIV in sub-Saharan Africa: challenges, youth-friendly models, and outcomes. *J Int AIDS Soc*. (2017) 20(Suppl 3):21528. doi: 10.7448/IAS.20.4.21528

10. Ryscavage P, Macharia T, Patel D, Palmeiro R, Tepper V. Linkage to and retention in care following healthcare transition from pediatric to adult HIV care. *AIDS Care*. (2016) 28(5):561–5. doi: https://doi.org/10.1080/09540121.2015.1131967

11. Ministry of Health. *Consolidated guidelines for the prevention and treatment of HIV in Uganda*. Kampala: Ministry of Health (2016). 88–98.

12. Birungi J, Cui Z, Okoboi S, Kapaata A, Munderi P, Mukajjanga C, et al. Lack of effectiveness of adherence counselling in reversing virological failure among patients on long-term antiretroviral therapy in rural Uganda. *HIV Med*. (2020) 21(1):21–9. doi: 10.1111/hiv.12790

13. Nasuuna E, Kigozi J, Babirye L, Muganzi A, Sewankambo NK, Nakanjako D. Low HIV viral suppression rates following the intensive adherence counseling (IAC) program for children and adolescents with viral failure in public health facilities in Uganda. *BMC Public Health*. (2018) 18(1):1048. doi: 10.1186/s12889-018-5964-x

14. Armstrong A, Nagata JM, Vicari M, Irvine C, Cluver L, Sohn AH, et al. A global research agenda for adolescents living with HIV. *J Acquir Immune Defic Syndr*. (2018) 78(1):S16. doi: 10.1097/QAI.0000000000001744

15. Fawzi MC, Ng L, Kanyanganzi F, Kirk C, Bizimana J, Cyamatare F, et al. Mental health and antiretroviral adherence among youth living with HIV in Rwanda. *Pediatrics*. (2016) 138(4):e20153235. doi: 10.1542/peds.2015-3235

16. Nestadt DF, Saisaengjan C, McKay MM, Bunupuradah T, Pardo G, Lakhonpon S, et al. CHAMP+ Thailand: pilot randomized control trial of a family-based psychosocial intervention for perinatally HIV-infected early adolescents. *AIDS Patient Care STDS*. (2019) 33(5):227–36. doi: 10.1089/apc.2019.0021

17. Evans-Gilbert T, Kasimbie K, Reid G, Williams SA. Psychosocial outcomes in a cohort of perinatally HIV-infected adolescents in Western Jamaica. *Paediatr Int Child Health*. (2018) 38(3):175–80. doi: 10.1080/20469047.2018.1428074

18. Bermudez LG, Ssewamala FM, Neilands TB, Lu L, Jennings L, Nakigozi G, et al. Does economic strengthening improve viral suppression among adolescents living with HIV? Results from a cluster randomized trial in Uganda. *AIDS Behav*. (2018) 22(11):3763–72. doi: 10.1007/s10461-018-2173-7

19. MacCarthy S, Wagner Z, Mendoza-Graf A, Gutierrez CI, Samba C, Birungi J, et al. A randomized controlled trial study of the acceptability, feasibility, and preliminary impact of SITA (SMS as an incentive to adhere): a mobile technology-based intervention informed by behavioral economics to improve ART adherence among youth in Uganda. *BMC Infect Dis*. (2020) 20(1):1–10. doi: 10.1186/s12879-020-4896-0

20. Nakimuli-Mpungu E, Musisi S, Wamala K, Okello J, Ndyanabangi S, Birungi J, et al. Effectiveness and cost-effectiveness of group support psychotherapy delivered by trained lay health workers for depression treatment among people with HIV in Uganda: a cluster-randomised trial. *Lancet Glob Health*. (2020) 8(3):e387–98. doi: 10.1016/S2214-109X(19)30548-0

21. Nakimuli-Mpungu E, Smith C, Wamala K, Okello J, Birungi J, Etukoit M, et al. Long-term effect of group support psychotherapy on depression and HIV treatment outcomes: secondary analysis of a cluster randomized trial in Uganda. *Psychosom Med*. (2022) 84(8):914–23. doi: 10.1097/PSY.0000000000001128

22. Das JK, Salam RA, Lassi ZS, Khan MN, Mahmood W, Patel V, et al. Interventions for adolescent mental health: an overview of systematic reviews. *J Adolesc Health*. (2016) 59(4):S49–S60. doi: 10.1016/j.jadohealth.2016.06.020

23. Beck JS. *Cognitive behavior therapy: Basics and beyond*. 2nd ed. Guilford Press (2011).

24. Bandura A. Human agency in social cognitive theory. *Am Psychol*. (1989) 44:1175–84. doi: 10.1037/0003-066X.44.9.1175

25. Carney D. *Sustainable livelihoods approach: progress and possibilities for change*. London: Department for International Development (2003).

26. Hoagwood K, Burns BJ, Kiser L, Ringeisen H, Schoenwald SK. Evidence-based practice in child and adolescent mental health services. *Psychiatr Serv*. (2001) 52 (9):1179–89. doi: 10.1176/appi.ps.52.9.1179

27. Chan A, Tetzlaff J, Altman D, Laupacis A, Gøtzsche PC, Krleža-Jerić K, et al. SPIRIT 2013 Statement: defining standard protocol items for clinical trials. *Ann Intern Med*. (2013) 158(3):200–7. doi: 10.7326/0003-4819-158-3-201302050-00583

28. Eldridge SM, Lancaster GA, Campbell MJ, Thabane L, Hopewell S, Coleman CL, et al. Defining feasibility and pilot studies in preparation for randomised controlled trials: development of a conceptual framework. *PLoS One*. (2016) 11:e0150205. doi: 10.1371/journal.pone.0150205

29. Nakimuli-Mpungu E, Wamala K, Okello J, Alderman S, Odokonyero R, Musisi S, et al. Developing a culturally sensitive group support intervention for depression among HIV infected and non-infected Ugandan adults: a qualitative study. *J Affect Disord*. (2014) 163:10–7. doi: 10.1016/j.jad.2014.03.042

30. Nakimuli-Mpungu E, Wamala K, Okello J, Alderman S, Odokonyero R, Mojtabai R, et al. Group support psychotherapy for depression treatment in people with HIV/AIDS in northern Uganda: a single-centre randomised controlled trial. *Lancet HIV*. (2015) 2(5):e190–9. doi: 10.1016/S2352-3018(15)00041-7

31. Lund C. Poverty, inequality and mental health in low- and middle-income countries: time to expand the research and policy agendas. *Epidemiol Psychiatr Sci*. (2015) 24(02):97–9. doi: 10.1017/S2045796015000050

32. Consolidated Guidelines for Prevention and Treatment of HIV in Uganda. (2018). Available at: http://library.health.go.ug/publications/hivaids/consolidated-guidelines-prevention-and-treatment-hiv-uganda

33. Patterson WM, Dohn HH, Bird J, Patterson GA. Evaluation of suicidal patients: the SAD PERSONS scale. *Psychosomatics*. (1983) 24(4):343–45, 348. doi: 10.1016/S0033-3182(83)73213-5

34. Purcell DW, Garfein RS, Latka MH, Thiede H, Hudson S, Bonner S, et al. Development, description, and acceptability of a small-group, behavioral intervention to prevent HIV and hepatitis C virus infections among young adult injection drug users. *Drug Alcohol Depend*. (2007) 91(Suppl 1):S73–S80. doi: 10.1016/j.drugalcdep.2007.03.004

35. Ebesutani C, Reise SP, Chorpita BF, Ale C, Regan J, Young J, et al. The revised child anxiety and depression scale—short version: scale reduction via exploratory bifactor modeling of the broad anxiety factor. *Psychol Assess*. (2012) 24:833–45. doi: 10.1037/a0027283

36. Piqueras JA, Martín-Vivar M, Sandin B, San Luis C, Pineda D. The revised child anxiety and depression scale: a systematic review and reliability generalization meta-analysis. *J Affect Disord*. (2017) 218:153–69. doi: 10.1016/j.jad.2017.04.022

37. Park AL, Ebesutani CK, Bose D, Chorpita BF. Psychometric properties of a Spanish translation of the revised child anxiety and depression scale–parent version. *J Psychopathol Behav Assess*. (2016) 38:307–19. doi: 10.1007/s10862-015-9517-7

38. Nader KO, Kriegler JA, Blake DD, Pynoos RS, Newman E, Weather FW. *Clinician administered PTSD scale, cchild and adolescent version*. White river junction, VT: National Center for PTSD (1996).

39. Lee CS, Seo JY, Kim DH, Bhang SY. Assessment tools for psychological trauma in children and adolescent after a disaster. *J Korean Neuropsychiatr Assoc*. (2015) 54 (3):269–75. doi: 10.4306/jknpa.2015.54.3.269

40. Barroca I, Velosa A, Cotovio G, Santos CM, Riggi G, Costa RP, et al. Translation and validation of the clinician administered PTSD scale (CAPS-CA-5) for Portuguese children and adolescents. *Acta Med Port*. (2022) 35(9):652–62. doi: 10.20344/amp.16718

41. Kerres Malecki C, Kilpatrick Demaray M. Measuring perceived social support: development of the child and adolescent social support scale. *Psychol Sch*. (2002) 39 (1):1–18. doi: https://doi.org/10.1002/pits.10004

42. Wiklander M, Rydstrom LL, Ygge BM, Naver L, Wettergren L, Eriksson LE. Psychometric properties of a short version of the HIV stigma scale, adapted for children with HIV infection. *Health Qual Life Outcomes*. (2013) 11:195. doi: 10.1186/1477-7525-11-195

43. Whitehead AL, Julious SA, Cooper CL, Campbell MJ. Estimating the sample size for a pilot randomized trial to minimize the overall trial sample size for the external pilot and main trial for a continuous outcome variable. *Stat Methods Med Res*. (2016) 25(3):1057–73. doi: 10.1177/0962280215588241

44. Sim J, Lewis M. The size of a pilot study for a clinical trial should be calculated in relation to considerations of precision and efficiency. *J Clin Epidemiol*. (2012) 65:301–8. doi: 10.1016/j.jclinepi.2011.07.011

45. Braun V, Clarke V. Using thematic analysis in psychology. *Qual Res Psychol*. (2006) 3(2):77–101. doi: 10.1191/1478088706qp063oa

46. Hayes R, Moulton L. *Cluster randomized trials*. Boca Raton: Chapman & Hall/CRC (2009).

47. WHO. Global Health Estimates: Life expectancy and leading causes of death and disability. Geneva, Switzerland: WHO (2020). Available from: http://www.who.int/healthinfo/global_burden_disease/metrics_daly/en/

48. Sanders GD, Neumann PJ, Basu A, Brock DW, Feeny D, Krahn M, et al. Recommendations for conduct, methodological practices, and reporting of cost-effectiveness analyses: second panel on cost-effectiveness in health and medicine. *JAMA*. (2016) 316(10):1093–103. doi: 10.1001/jama.2016.12195

49. Husereau D, Drummond M, Augustovski F, de Bekker-Grob E, Briggs AH, Carswell C, et al. Consolidated health economic evaluation reporting standards (CHEERS) 2022 explanation and elaboration: a report of the ISPOR CHEERS II good practices task force. *Value Health*. (2022) 25(1):10–31. doi: 10.1016/j.jval.2021.10.008

50. Laurenzi CA, Skeen S, Gordon S, Akin-Olugbade O, Abrahams N, Bradshaw M, et al. Preventing mental health conditions in adolescents living with HIV: an urgent need for evidence. *J Int AIDS Soc*. (2020) 23:e25556. doi: 10.1002/jia2.25556

51. Cluver L, Pantelic M, Toska E, Orkin M, Casale M, Bungane N, et al. STACK Ing the odds for adolescent survival: health service factors associated with full retention in care and adherence amongst adolescents living with HIV in South Africa. *J Int AIDS Soc*. (2018) 21(9):e25176. doi: 10.1002/jia2.25176

52. Bhana A, Kreniske P, Pather A, Abas MA, Mellins CA. Interventions to address the mental health of adolescents and young adults living with or affected by HIV: state of the evidence. *J Int AIDS Soc*. (2021) 24:e25713. doi: 10.1002/jia2.25713

53. Carmichael KD. Legal and ethical issues in play therapy. *Int J Play Ther*. (2006) 15(2):83. doi: 10.1037/h0088916

54. LeBlanc M, Ritchie M. A meta-analysis of play therapy outcomes. *Couns Psychol Q*. (2001) 14(2):149–63. doi: 10.1080/09515070110059142

55. Cole SW, Naliboff BD, Kemeny ME, Griswold MP, Fahey JL, Zack JA. Impaired response to HAART in HIV-infected individuals with high autonomic nervous system activity. *Proc Natl Acad Sci USA*. (2001) 98(22):12695–700. doi: 10.1073/pnas.221134198

56. Cole SW, Kemeny ME, Fahey JL, Zack JA, Naliboff BD. Psychological risk factors for HIV pathogenesis: mediation by the autonomic nervous system. *Biol Psychiatry*. (2003) 54(12):1444–56. doi: 10.1016/S0006-3223(02)01888-7

57. Gonzalez JS, Batchelder AW, Psaros C, Safren SA. Depression and HIV/AIDS treatment nonadherence: a review and meta-analysis. *J Acquir Immune DeficSyndr*. (2011) 58(2) 181–7. doi: 10.1097/QAI.0b013e31822d490a

58. Ouansafi I, Chibanda D, Munetsi E, Simms V. Impact of friendship bench problem-solving therapy on adherence to ART in young people living with HIV in Zimbabwe: a qualitative study. *PLoS One*. (2021) 16(4):e0250074. doi: 10.1371/journal.pone.0250074

59. Okonji EF, Mukumbang FC, Orth Z, Vickerman-Delport SA, Van Wyk B. Psychosocial support interventions for improved adherence and retention in ART care for young people living with HIV (10–24 years): a scoping review. *BMC Public Health*. (2020) 20(1):1. doi: 10.1186/s12889-020-09717-y

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Providing crisis care in a pandemic: a virtual based crisis stabilization unit

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Background: Winnipeg, Canada operates a 16-bed subacute unit, the Crisis Stabilization Unit (CSU), for voluntary patients in crisis not requiring hospital admission. The virtual CSU (vCSU) launched in March 2020 as an adjunct to the in-person CSU during the COVID-19 pandemic, providing the same resources virtually, allowing patients to remain at home.
Methods: Program data were collected for vCSU admissions between April 1, 2020 and April 7, 2021 ($n = 266$) to examine patient characteristics and discharge outcomes. Data were retrieved from the electronic patient record (EPR) for both in-person and vCSU admissions during the same period for comparison ($n = 712$). vCSU admissions ($n = 191$) were summarized by patient demographics, clinical factors/outcomes, and compared on the same measures to in-person CSU admissions ($n = 521$) using binary logistic regression.
Results: 30.1% of patients admitted to the vCSU received initial mental health assessment virtually (phone/videoconference), therefore receiving all care at home. Clinical symptoms at assessment included depression/anxiety (39.0%), psychosis/mania (2.7%), suicidal behaviour/self-harm (27.4%), psychosocial event/stressor (19.8%). Average stay was 4.9 days. Compared to the in-person CSU, vCSU referrals were associated with the absence of psychosis [odds ratio (OR).40, 95% confidence interval (CI).18–0.89] and no prior 1-year contact with referral site (OR.43, 95% CI.28–0.64). Those living farther away from the referral site were more likely to receive a vCSU referral.
Conclusion: The vCSU model is feasible for a diverse group of patients experiencing mental health crises. Future work is needed to better determine who the model is right for and examine longer term outcomes.

KEYWORDS

virtual ward, virtual care, mental health, crisis care, COVID-19

1. Introduction

The COVID-19 pandemic created many challenges in the provision and accessibility of mental health crisis care. Due to the implementation of public health restrictions, changes in care delivery resulted in a reduction of in-person services and treatment (1). The reduction of these services may have disproportionately impacted the health of individuals living with mental illness (2). For example, individuals with mental illness were shown to be at increased risk of infection with COVID-19, and faced greater accessibility issues when seeking treatment (2). Additionally, pre-existing mental illness was associated with increased difficulty coping with the pandemic's effect on psychosocial factors leading to increased levels of stress, insomnia, depression, and anxiety compared to the general population (2–4).

The combination of required changes to the administration of services due to public safety measures and the need for increased services for individuals with mental illness created a unique opportunity for the rapid expansion of virtual mental health services (5).

The concept of "virtual wards" was first introduced in the United Kingdom to provide short-term transitional home and community-based care for high risk and complex patients during their transition from hospital to their home and return to community (6). In Canada, virtual wards have been introduced in an attempt to reduce hospital re-admissions and their associated costs (7). The COVID-19 pandemic saw a proliferation of virtual wards that specifically leveraged technology to provide care in response to reductions in service capacity and the need to provide alternatives to in person visits (8, 9). For example, several virtual wards targeting the management of COVID-19 infection through the use of telephone and videoconferencing visits in combination with remote monitoring have been described (9).

In response to the decreased accessibility of in-person mental health services during the COVID-19 pandemic, Crisis Response Services in Winnipeg, Manitoba rapidly virtualized the delivery of a full spectrum of crisis care to individuals requiring urgent mental health services (10). Crisis Response Services is comprised of a 24/7 walk-in stepped care mental health crisis centre [the Crisis Response Centre (CRC); akin to a mental health-specific emergency department], a follow-up post-crisis care program, and the Crisis Stabilization Unit (CSU). The CSU is a community-based unit that provides short-term admissions and supportive care for voluntary individuals in crisis who do not require hospitalization (11). At the outset of COVID-19, the CSU reduced capacity by half to accommodate public health guidelines and staff were redeployed to open a 6-bed virtual CSU or "vCSU".

The first part of this study aimed to describe the vCSU admissions, in terms of demographics, clinical characteristics, service delivery, and outcomes. The second part of the study involved a comparison of all referrals to both the virtual and in-person CSU from the largest referral source (the CRC) to identify factors that predicted the type of referral initiated. Given the novelty of virtual-based wards such as the vCSU, this study can inform the future planning and implementation of similar virtual models to increase the accessibility of mental health services.

2. Materials and methods

2.1. Study design

The first part of this study was a retrospective analysis of all admissions to the vCSU between the opening of the unit on April 1, 2020 and April 7, 2021 to examine patient characteristics and discharge outcomes. The second part was a secondary analysis of an administrative database consisting of all referrals to both the vCSU and in-person CSU from the largest referral source (CRC) from April 1, 2020 to April 7, 2021. Data were extracted from the electronic patient record (EPR) to compare the characteristics of the individuals referred to the different units.

2.2. Setting

The Winnipeg-based CSU is a 16-bed subacute unit for voluntary patients in crisis who may be at risk for hospitalization (11). Patients can be referred to the CSU from a variety of sources within the city including the CRC, emergency departments, urgent care centers, and specific community mental health services. The CSU is staffed by a multidisciplinary mental health team including crisis clinicians and nurses with access to psychiatry as needed. The CSU provides short-term supportive care and treatment with therapeutic group programing including skills-based classes as well as connection to community resources (11). Winnipeg is the largest urban centre in the province, home to just over 50% of Manitoba's total population (12). The majority of healthcare delivery is under provincial jurisdiction; CSU services are fully funded for all users.

The Virtual CSU (vCSU) was created as a full virtualization of the same services offered at the in-person CSU while permitting patients to remain in their own homes in the community. Services are delivered virtually by a combination of phone, text, email, and videoconferencing platforms (Zoom or Microsoft Teams) and patients have access to the same multidisciplinary staff as the in-person CSU including crisis workers, mental health clinicians, nurses, and psychiatry as needed. Patients are monitored daily and have access to clinical staff 24 hours per day for crisis support. They also have access to the skills-based classes available on the physical unit, delivered virtually, and are offered the same referrals and connections to community resources (**Figure 1**).

The same referral criteria applied for both units: the patient is voluntary, medically stable, not actively intoxicated or in acute withdrawal requiring medical intervention, and the patient is agreeable to commit to refraining from engaging in self-harm/behaviours and/or violence. A full mental health assessment and/or psychiatric consultation was required before referral describing the crisis episode which is interfering with functioning. There are no specific diagnostic exclusions or restrictions for patients except as it pertains to medical stability. Applicable to referrals to the vCSU only, the patient was required to have access to a technological device capable of accessing the service (either by phone or videoconferencing service) such as a mobile phone, tablet, or computer. The decision to refer to one or the other was based on clinical assessment and patient choice.

2.3. Participants/data sources

For all admissions to the vCSU, a vCSU clinician completed a form at the time of discharge that recorded patient demographics and clinical data as well as information about participation in vCSU services and outcomes. These forms were submitted to the study team approximately quarterly and inputted into a database by a research assistant.

For the second part of the study, an existing administrative database generated for another study (13) containing visit details extracted from the EPR at the CRC was used. The CRC represents the largest and most frequent source of referrals to

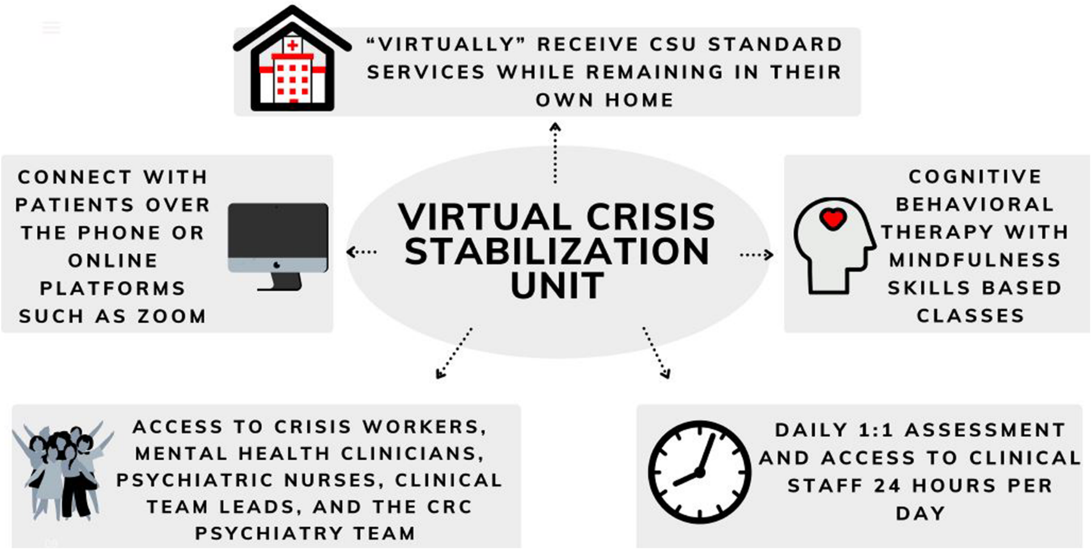

FIGURE 1
Summary of services offered by the virtual CSU.

both the CSU and vCSU accounting for over 70% of admissions. All individuals are identified by a unique CRC file number and all visits are assigned a unique visit number. The clinician or psychiatry team member conducting the mental health assessment enters sociodemographic and clinical data into the EPR which includes both fixed and free text fields.

2.4. Ethics

Research ethics approval for the study was obtained from the University of Manitoba Research Ethics Board [HS23878 (H2020:196)].

2.5. Variables

2.5.1. Discharge forms

2.5.1.1. Sociodemographics

Demographic data collected included age, gender (female, male, other) and living situation prior to admission (alone, with family, with roommates, other).

2.5.1.2. Clinical information

Non-mutually exclusive categories were available to code reason for referral (medication management, risk/symptom monitoring, problem-solving/recovery planning, other) as well as main clinical problem at presentation (depression, anxiety, psychosis, mania, suicidal/self-harm, psychosocial event/stressor, personality disorder, other). The presence of suicidal ideation/self-harm was further characterized by the highest level identified at presentation (ideation, planning, or attempt). Origin of referral (CRC, Emergency Department, Urgent Care, Other) and active substance use (present or absent) were also captured.

2.5.1.3. Service delivery

Variables assessing the delivery of vCSU service included length of stay, attendance for skills-based classes, method of contact with treatment team (phone or video), virtual family involvement for support and care planning while in the vCSU, and if psychiatry was consulted for an assessment during the stay.

2.5.1.4. Outcomes

A variety of disposition options were available to patients after admission and were coded in non-mutually exclusive categories including discharge to pre-existing follow-up (primary care, psychiatry, other mental health supports), referral to the urgent post-crisis follow-up clinic, admission to hospital, detox/addiction services, or transfer to physical CSU. Some individuals were lost to follow-up prior to discharge.

2.5.2. Electronic patient record (EPR)

2.5.2.1. Visit type

The initial mental health assessment prior to referral could be conducted either in-person (individual seen onsite at the CRC) or virtual (assessment done by telephone or videoconference).

2.5.2.2. Sociodemographics

Age at time of visit was calculated as the difference in years between visit date and date of birth. Gender was coded as male, female or other. Distance in kilometers (km) between the individual's residence and CRC was calculated using the CRC's address and geographic centre of the forward sortation area (FSA) corresponding to the first 3 digits of the individual's postal code. FSA data was obtained from Statistics Canada boundary files (14). As described elsewhere in previous work (13), we limited the sample to those living within 30 km of the CRC to reflect the typical geography of referral (Winnipeg and surrounding area) and to exclude individuals who had a recorded residence very far from the CRC and who may have been visiting Winnipeg or attending other services in the city prior to their CSU referral (n = 28 excluded). Median household income was retrieved from Statistics Canada's 2016 census profile for every FSA in the original dataset (15). A subset of the sample containing only unique individuals was created to generate income quintiles with Q1 representing the lowest household income and Q5 representing the highest. As a result, if individuals assessed at the CRC from specific income quintiles were more likely to be referred to the CSU, these will be overrepresented in the dataset.

2.5.2.3. Clinical characteristics

For each CRC visit, a 1-year lookback was conducted to determine if the individual had a prior visit to the CRC within the last year. Diagnostic impression was based on the clinician assessment and available collateral information. Non-mutually exclusive categories included depression or anxiety (included adjustment problems, sleep problems, obsessive compulsive and trauma-related problems), psychosis, bipolar spectrum disorders, cognitive impairment (dementia, delirium, intellectual disability, acquired brain injury, autism), and other (ADHD, eating disorders and other impulse control problems). Presence of substance use was coded as present or absent.

2.6. Data analysis

For the first part of the study, descriptive statistics were generated for variables collected. All responses were calculated as counts and percentages or means as appropriate. For the second part of the study, descriptive statistics for the sample were generated, stratified by whether the referral was to the CSU or vCSU. To assess for relationships between the visit characteristics and the outcome (referral to the CSU or vCSU) we first conducted unadjusted binary logistic regressions for each variable using the visit as the unit of analysis, and then a fully adjusted model including all of the variables (age, gender, income quintile, distance, prior year visit, suicidal behaviour, substance use, and diagnostic impression). Model fit was evaluated using Hosmer and Lemeshow's goodness-of-fit test.

3. Results

3.1. Part 1: vCSU admission characteristics and outcomes

3.1.1. Patient characteristics

Discharge forms were completed for a total of 266 patients who were admitted to the vCSU during the study period. Full data are summarized in Table 1. The average age of patients was 35 years old (range 18–77), the majority identified as female (*n* = 179, 67.3%) and most lived with family (*n* = 158, 59.4%). A wide variety of clinical symptoms were present at initial assessment

TABLE 1 Patient Variables from the vCSU Discharge Forms.

Baseline variable	Overall sample *N* = 266
Average Age [y], (range) [missing = 20]	34.8 (18–77)
Gender, *n* (%) [missing = 3]	
Female	179 (67.3)
Male	80 (30.1)
Other	4 (1.1)
Living situation, *n* (%) [missing = 9]	
Alone	60 (22.6)
With family	158 (59.4)
With friends/roommates	30 (11.3)
Other	9 (3.4)
Clinical symptoms present at initial assessment, *n* (%)^a [missing = 16]	
Depression & anxiety	244 (39.0)
Psychosis & mania	17 (2.7)
Suicidal behaviour and/or self-harm	171 (27.4)
Psychosocial event or stressor	124 (19.8)
Personality disorder	25 (4.0)
Other	44 (7.0)
Suicidal behaviour, *n* (%) [missing = 29]	
None	43 (16.2)
Ideation	141 (53.0)
Planning	33 (12.4)
Attempt	20 (7.5)
Active substance use, *n* (%) [missing = 4]	96 (36.1)
Reason for referral, *n* (%)^a [missing = 2]	
Medication management	31 (6.9)
Risk and/or symptom management	164 (36.3)
Problem solving and/or recovery planning	216 (47.8)
Referral to other sources	31 (6.9)
Other	10 (2.2)
Source of referral, *n* (%) [missing = 0]	
Crisis Response Centre	191 (71.8)
Emergency department or urgent care centre	70 (26.3)
Other	5 (1.9)
Referral assessment conducted virtually, *n* (%) [missing = 5]	80 (30.1)
Mean length of stay [days], (range) [missing = 10]	4.9 (1–10)
Assessed by psychiatry during vCSU stay, *n* (%) [missing = 27]	17 (6.4)
Attended minimum one skills class, *n* (%) [missing = 17]	102 (38.3)
Virtual family involvement during vCSU, *n* (%) [missing = 10]	15 (5.6)
Primary contact by phone, *n* (%) [missing = 19]	241 (90.6)
Discharge outcomes, *n* (%)^a [missing = 45]	
Pre-existing services (primary care, psychiatry, mental health)	191 (61.2)
Referral to outpatient mental health services	64 (20.5)
Detox or addictions services	5 (1.6)
Transfer to physical CSU	14 (6.0)
Admission to hospital	5 (1.9)
Lost to follow-up	7 (2.2)
Other	23 (7.4)

[a] Non-mutually exclusive categories.

including depression and anxiety (39.0%), psychosis or mania (2.7%), suicidal behaviour and/or self-harm (27.4%), and the presence of a psychosocial event or stressor (19.8%). Suicidal behaviour was further characterized by the highest level of severity present at assessment: ideation (53.0%), planning (12.4%), or attempt (7.5%). The reasons for referral to vCSU included medication monitoring (6.9%), risk and symptom monitoring (36.3%), problem solving and recovery planning (47.8%), and to initiate outpatient referrals (6.9%).

3.1.2. Patient engagement

Nearly one third (30.1%) of initial assessments (mental health or psychiatry) that instigated the referral to the vCSU were conducted virtually with patients, meaning the patient never entered a facility. Analysis of service delivery variables revealed the primary means of communication with staff was over the phone ($n = 241$, 90.6%). Just over one third ($n = 102$, 38.3%) of all patients attended at least one virtual skills-based class during their stay. Psychiatry consultation occurred in 17 cases (6.4%). Similarly, 15 (5.6%) cases involved families or other supports in some way during the vCSU stay.

3.1.3. Outcomes

There were a wide variety of discharge outcomes from the vCSU, most commonly to a pre-existing care team including primary care, mental health, or psychiatric services (61.2%). Twenty percent of patients were referred to outpatient mental health services. A small proportion of individuals were transferred to the in-person CSU ($n = 14$, 6.0%) and 5 individuals (1.9%) were admitted to hospital. Some reasons for transfer to the in-person CSU included: patient request, technological limitations, and clinician impression that the individual needed a higher level of observation and support. Reasons for hospital admissions included increasing self-harm and/or suicidal behaviour.

3.2. Part 2: CSU and vCSU comparison

3.2.1. Patient demographics

A total of 712 visits to the CRC for 609 unique individuals during the study period resulted in referral to either the in-person CSU ($n = 521$) or vCSU ($n = 191$). Repeat admissions occurred for 9 of the vCSU admissions (4.7%) and 72 of the CSU admissions (13.8%). A small number of individuals had admissions to both units. The crude rates of sociodemographic factors did not appear to differ substantially between referrals resulting in admission to one or the other units, other than a higher proportion of vCSU referrals being present in the higher income quintiles. Level of suicidal behaviour was distributed almost equally between the groups. vCSU referrals had notably lower crude rates of prior year contact with the CRC than in-person CSU referrals (24.6% vs. 45.1%). Compared to CSU referrals, vCSU referrals had lower rates of substance use problems and psychosis, and higher rates of depressive and anxiety problems. Full results are summarized in Table 2.

TABLE 2 Rates of patient variables in CSU and vCSU cohorts.

Baseline variable	Overall sample $N = 712$	
	CSU ($N = 521$)	vCSU ($N = 191$)
Average Age [y] [missing = 0]	34.8	34.0
Gender, *n* (%) [missing = 5]		
Male	165 (31.8)	50 (26.6)
Female	343 (66.1)	136 (72.3)
Other	11 (2.1)	2 (1.1)
Income quintile, *n* (%) [missing = 1]		
Q1 – lowest	133 (25.6)	28 (14.7)
Q2	121 (23.3)	49 (25.7)
Q3	118 (22.7)	46 (24.1)
Q4	69 (13.3)	35 (18.3)
Q5 – highest	79 (15.2)	33 (17.3)
Suicidal behaviour, *n* (%) [missing = 9]		
None	136 (26.4)	50 (26.6)
Ideation	197 (38.3)	75 (39.9)
Planning	71 (13.8)	20 (10.6)
Self-harm/attempt	111 (21.6)	43 (22.9)
Had CRC assessment in prior year, *n* (%) [missing = 0]	235 (45.1)	47 (24.6)
Assessed by psychiatry at presentation, *n* (%) [missing = 0]	65 (12.5)	22 (11.5)
Substance use problem, *n* (%) [missing = 9]	232 (45.0)	70 (37.2)
Cognitive disorder, *n* (%) [missing = 9]	30 (5.8)	10 (5.3)
Depressive or anxiety problem, *n* (%) [missing = 9]	388 (75.3)	164 (87.2)
Personality disorder, *n* (%) [missing = 9]	183 (35.5)	62 (33.0)
Bipolar spectrum disorder, *n* (%) [missing = 9]	35 (6.8)	13 (6.9)
Psychosis, *n* (%) [missing = 9]	83 (16.1)	9 (4.8)
Other disorders (ADHD, eating disorder), *n* (%) [missing = 9]	35 (6.8)	12 (6.4)

9 cases missing data for suicidal ideation, substance use, diagnoses as seen by psychiatry only and these variables are not captured in that documentation.

3.2.2. Referral analysis

The unadjusted and adjusted logistic regressions examining factors associated with referral to the vCSU relative to the in-person CSU are reported in Table 3. The fully adjusted model was a good fit for the data [$\chi^2(8) = 5.31$, $p = .72$]. In both the unadjusted and adjusted analyses, referrals to the vCSU were associated with living further away from the CRC [adjusted OR (aOR) 1.09 95% CI 1.03–1.15] and having no previous contact with the CRC in the past year (aOR.43 95% CI .28-0.64). In the unadjusted model, income quintile Q2, Q4 and Q5 were significantly more likely to be referred to the vCSU relative to Q1, the lowest. In the adjusted model, only Q2 remained significant. The absence of psychosis in the clinical assessment was significantly associated with a referral to the vCSU as opposed to the CSU, even after adjustment. While depressive and anxiety problems were significantly associated with referral to the

TABLE 3 Binary logistic regression for referral to the vCSU relative to the in-person CSU (*n* = 697).

Variable	Unadjusted		Adjusted	
	OR	95% CI	OR	95% CI
Age	.99	.98, 1.01	1.00	.98, 1.01
Gender (reference: female)				
Male	.76	.52, 1.12	.94	.62, 1.43
Other	.46	.10, 2.10	.38	.079, 1.80
Income quintile (reference: Q1, lowest)				
Q2	**1.87**	**1.10, 3.18**	**2.24**	**1.26, 3.97**
Q3	1.67	.97, 2.86	1.21	.69, 2.14
Q4	**2.29**	**1.28, 4.08**	1.28	.67, 2.45
Q5, highest	**1.99**	**1.12, 3.54**	1.29	.67, 2.49
Level of suicidal behaviour (reference: none)				
Ideation	1.05	.69, 1.61	1.14	.72, 1.80
Planning	.78	.43, 1.42	.90	.48, 1.69
Self-harm/attempt	1.05	.65, 1.70	1.14	.67, 1.94
Distance from residence to CRC	**1.07**	**1.03, 1.12**	**1.09**	**1.03, 1.15**
Prior 1-year visit (reference: no)	**.40**	**.27,.58**	**.43**	**.28,.64**
Substance use problem (reference: no)	.74	.52, 1.04	.79	.54, 1.17
Cognitive disorder (reference: absent)	.92	.44, 1.92	1.44	.63, 3.26
Depressive or anxiety problem (reference: absent)	**2.19**	**1.36, 3.52**	1.44	.80, 2.59
Personality disorder (reference: absent)	.90	.63, 1.28	1.03	.69, 1.54
Bipolar spectrum disorder (reference: absent)	1.06	.55, 2.06	1.19	.55, 2.59
Psychosis (reference: absent)	**.26**	**.13,.54**	**.40**	**.18,.89**
Other (reference: absent)	.94	.48, 1.86	.88	.43, 1.82

Bolded values represent statistically significant results ($P < .05$).

vCSU in the unadjusted analysis, the correlation disappeared after adjusting for the other factors. The level of suicidal behaviour was not associated with referral outcome.

4. Discussion

The COVID-19 pandemic provided a unique opportunity for the rapid development of virtual mental health care services (5). The complete spectrum of mental health services offered through Winnipeg Crisis Response Services, including the vCSU, offered virtual options for services within weeks of the first documented COVID-19 case in Manitoba (15). Over 200 individuals with a wide range of mental health concerns at presentation, such as depression and anxiety, suicidal ideation, and psychosocial stressors, were able to access supports through the vCSU because of this transformation during a time of heightened restrictions, reductions in facility capacity, and high public anxiety. Patients admitted to the vCSU received the same clinical services as those admitted to the physical CSU and were connected to a variety of follow-up services as required. Our data demonstrate that a wide variety of patients presenting to a crisis centre can be referred to a virtual short stay crisis unit and managed in community.

Nearly one third (30.1%) of patients admitted to the vCSU were assessed entirely through virtual means from the outset of their presentation to crisis services and throughout their stay in the vCSU. This means that one third of all patients receiving these services did not have to enter a facility of any kind. The ability for patients to be assessed and receive services in their homes directly reduces the need for in-person assessments and in-person stays. This can not only relieve some of the burden on the healthcare system by limiting the use of inpatient beds, but it also has the potential to reduce problem of overcrowding and wait times in emergency departments and urgent care centres as patients can wait to receive assessments and services in their own homes (16).

Further, providing care to patients while allowing them to remain in the community has the potential to improve access to services for a multitude of patient-centered reasons. Patients often have competing demands such as work, school, and childcare that could hinder their ability to visit an in-person facility and wait an undetermined amount of time for an assessment (17). Even after receiving an in-person assessment, an extended in-person stay may not be a feasible option for someone with personal or family obligations. In comparison, a virtual ward admission would provide a similar level of support, however, allow for flexibility to continue attending to responsibilities in the home and community. For patients who live in rural areas or with limited access to public transportation, virtual care has the potential to improve accessibility and reduce costs associated with transportation and time (18). Although our analysis focused on referrals within Winnipeg and surrounding area, we still found that living further away from the CRC was associated with a referral to the virtual unit rather than the in-person CSU. There are a variety of patient-centered factors that influence care seeking which could be addressed with accessible virtual services. Virtual wards provide a convenient means of accessing intensive mental health supports in a stepped care fashion while continuing to remain in community and attend to personal commitments. A small proportion of individuals referred to the vCSU did ultimately require transfer to the physical CSU or admission to hospital and this could be co-ordinated directly from community.

Other factors that were associated with referral to the vCSU over the physical CSU were income and the absence of psychosis at presentation. Although all upper income quintiles were more often associated with a vCSU referral compared to the lowest income quintile in the unadjusted analysis, after adjusting for other factors, only Q2 remained significant in the model. This may point to the importance of some socioeconomic stability (eg. stable housing, availability of supports, employment, affordability of medications, and so on) in the lowest income groups to support a virtual stay, as opposed to the higher income groups where this may not be a differentiating concern. Given the clinical features of psychosis, it would be expected that in-person assessments and services would often be recommended for the treatment of this population (19). In addition, it is possible that this reflected patient preference and/or staff comfort with virtual services for individuals with these symptoms. No association, however, was found for a wide variety of other clinical symptoms, including the presence of suicidal behaviour. This suggests that there may be a subset of patients who present with suicidal behaviour who could be safely managed in community with access to virtual services and supportive interventions. The utilization of thorough suicide risk assessments to evaluate patients and their individual presentations would be an important component of this assessment and further research is warranted to identify additional factors that fit well with virtual care in the context of suicidal behaviour. In other work done by our team, some preliminary patient profiles that fit well with the model from the perspective of the providers were established to guide future service planning (20).

The predominant population admitted to the vCSU were adults who identified as female and who lived with family. The most common presenting issues at admission were depression and anxiety, suicidal behaviour/self harm, and/or the presence of a psychosocial event or stressor. The majority of referrals were initiated for risk and symptom monitoring or to assist with problem solving and recovery planning. In Manitoba, from 2014 to 2019, twenty-six percent of residents aged 10 or older were treated for at least one mental illness (21). The most common mental health presentations during this period were mood and anxiety disorders and the cumulative rate of mental illness for females was higher than males for all age groups (21). As such, the vCSU effectively captures a representation of the general Manitoba population who struggle with mental illness and are representative of the broader population receiving crisis support services.

4.1. Limitations

There are several limitations of our study. The vCSU was implemented rapidly during a unique situation created by the COVID-19 pandemic. The model remained stable throughout the study period, but as public health restrictions varied, patient preference and suitability for vCSU care may have shifted. For example, patients at high risk for or infected with COVID-19 were not eligible for in-person services. In the comparison analysis, data were only available for referrals from the CRC, and EPR data were not inclusive of other factors that could be influencing virtual admissions. Although there were repeat admissions for a portion of individuals, each visit was treated as an independent observation in the analysis since individuals can present for very different reasons from one visit to the next. There are, however, unmeasured variables that may affect referral to one or the other for a small number of frequent users of services (eg. care plans that limit number of admissions to the CSU in a given time period). Our study did not evaluate the perspective of the patients receiving these services and did not include a detailed examination of factors leading to transfer to in-person services. Future research would include input from patients especially regarding their preferences for care and the comparison of the perceived efficacy of virtually administered care compared to in person. While the data support that the vCSU increased access to mental health services during the COVID-19 pandemic, it is important to note that a lack of access to a phone or video conferencing technology device serves as a potential barrier to individuals for geographical and/or socioeconomic reasons that do not have, or cannot use, these communication platforms (22). This, along with other social determinants of health that are disproportionately experienced by those with lower socioeconomic status, speak to the complexities in understanding how to deliver virtual mental health services at a population level (23). This is an area requiring further exploration as systems move forward with expanded virtual care plans.

4.2. Conclusions

The unique situation created by the COVID-19 pandemic presented an unprecedented opportunity for the rapid establishment of novel virtual care models including the vCSU. This study has demonstrated this type of model as a safe, effective, and feasible mechanism for providing mental health crisis care. An admission to the vCSU can accommodate a wide variety of clinical presentations, provide services at an intensity that would otherwise be reserved for in-person facilities, and decrease wait times in emergency departments. Additional work is needed to further evaluate the effectiveness of virtual care compared to traditional in-person care and establish the sustainability and cost-effectiveness of virtual models of care. Virtual models can simultaneously provide person-centred care options and optimize health system resources and wait times.

Data availability statement

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

Ethics statement

This study involving human participation was reviewed and approved by the University of Manitoba Research Ethics Board [HS23878 (H2020:196)]. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

KP contributed to the study conception, data collection, analysis and interpretation, and drafted the manuscript. AC to data collection, analysis and interpretation, and drafted the manuscript. JB contributed to study conception, data interpretation and revised the manuscript. EH contributed to study conception, data interpretation, and revised the manuscript. SS contributed to data collection and analysis, and revised the manuscript. JH contributed to the study conception, data analysis and interpretation, and drafted the manuscript. All authors contributed to the article and approved the submitted version.

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Publisher's note

References

1. Hoffman DA. Increasing access to care: telehealth during COVID-19. *J Law Biosci*. (2020) 7(1). doi: 10.1093/jlb/lsaa043

2. Brooks SK, Webster RK, Smith LE, Woodland L, Wessely S, Greenberg N, et al. The psychological impact of quarantine and how to reduce it: rapid review of the evidence. *Lancet*. (2020) 395(10227):912–20, doi: 10.1016/S0140-6736(20)30460-8

3. Cullen W, Gulati G, Kelly BD. Mental health in the COVID-19 pandemic. *QJM*. (2020) 113(5):311–2. doi: 10.1093/QJMED/HCAA110.

4. Marroquín B, Vine V, Morgan R. Mental health during the COVID-19 pandemic: effects of stay-at-home policies, social distancing behavior, and social resources. *Psychiatry Res*. (2020) 293. doi: 10.1016/j.psychres.2020.113419

5. Shore JH, Schneck CD, Mishkind MC. Telepsychiatry and the coronavirus disease 2019 pandemic-current and future outcomes of the rapid virtualization of psychiatric care. *JAMA Psychiatry*. (2020) 77(12):1211–2. doi: 10.1001/jamapsychiatry.2020.1643

6. Lewis G. Predictive modeling in action: how "virtual Wards" help high-risk patients receive hospital care at home. *The Commonwealth Fund: Issues in Int Health Policy*. (2010) 90(1430). Available from: https://www.commonwealthfund.org/sites/default/files/documents/___media_files_publications_issue_brief_2010_aug_1430_lewis_predictive_modeling_in_action_virtual_wards_intl_brief.pdf.

7. Ndegwa S. The use of virtual wards to reduce hospital readmissions in Canada. *Environmental Scan: Canadian Agency for Drugs and Technologies in Health*. (2011) 27. Available from: https://www.cadth.ca/sites/default/files/pdf/ES-27_virtual_wards_e.pdf.

8. Canady VA. Virtual clinic to assist patients with urgent psychiatric care. *Mental Health Weekly*. (2020) 30(17):7. doi: 10.1002/mhw.32338

9. Vindrola-Padros C, Singh KE, Sidhu MS, Georghiou T, Sherlaw-Johnson C, Tomini SM, et al. Remote home monitoring (virtual wards) for confirmed or suspected COVID-19 patients: a rapid systematic review. *EClinMed*. (2021) 37. doi: 10.1016/j.eclinm.2021.100965

10. Hensel JM, Bolton JM, Svenne DC, Ulrich L. Innovation through virtualization: crisis mental health care during COVID-19. *Canad J Commun Ment Health*. (2020) 39 (2):71–5. doi: 10.7870/cjcmh-2020-014

11. Shared Health Manitoba. Crisis Stabilization Unit. Available at: https://sharedhealthmb.ca/services/mental-health/crisis-stabilization-unit 2020 (Accessed July 6, 2022).

12. Statistics Canada. 2021 Census of Population. Catalogue no. 98-316-X2021001. Statistics Canada. (2023).

13. Vakil T, Carignan Svenne D, Bolton J, Jiang D, Svenne S, Hensel J. Analysis of the uptake and associated factors for virtual crisis care during the pandemic at a 24-hour mental health crisis centre in Manitoba, Canada. *BMC Psychiatry*. (2022) 22:527.

14. Statistics Canada. Census Forward Sortation Area Boundary File. 2016 Census. (2017).

15. Statistics Canada. 2016 Census. Catalogue no. 98-316-X2016001. Statistics Canada. (2017).

16. Kelen G, Wolfe R, D'Onofrio G, Mills A, Diercks D, Stern S, et al. Emergency department crowding: the canary in the health care system. *NEJM Catal*. (2021) 5 (2). doi: 10.1056/CAT.21.0217

17. Morland LA, Poizner JM, Williams KE, Masino TT, Thorp SR. Home-based clinical video teleconferencing care: clinical considerations and future directions. *Int Rev Psychiatry*. (2015) 27(6):504-12. doi: 10.3109/09540261.2015.1082986

18. Jong M, Mendez I, Jong R. Enhancing access to care in northern rural communities via telehealth. *Int J Circumpolar Health*. (2019) 78(2. doi: 10.1080/22423982.2018.1554174

19. Byrne P. Managing the acute psychotic episode. *Br Med J*. (2007) 334(7595). doi: 10.1136/bmj.39148.668160.80

20. Lee K, Bolton SL, Shterenberg R, Bolton JM, Hensel JM. Early learning from a low-resource COVID-response virtual mental health crisis ward: mixed methods study. *JMIR Form Res*. (2022) 6(11). doi: 10.2196/39861

21. Manitoba Health S and AL. Annual Statistics (2018–2019. 2020).

22. Reiss F. Socioeconomic inequalities and mental health problems in children and adolescents: a systematic review. *Soc Sci Med*. (2013) 90:24–31. doi: 10.1016/j.socscimed.2013.04.026

23. Crawford A, Serhal E. Digital health equity and COVID-19: the innovation curve cannot reinforce the social gradient of health. *J Med Internet Res*. (2020) 22. doi: 10.2196/19361

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The impact of psychological distress on quality of care and access to mental health services in cancer survivors

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Introduction: Psychological distress is highly prevalent among cancer survivors and significantly impacts their health outcomes. Our study aim is to examine the impact of psychological distress on the quality of care in cancer survivors.
Methods: We utilized longitudinal panels from the Medical Expenditure Panel Survey data spanning from 2016 to 2019 to estimate the impact of psychological distress on quality of care. We compared a sample of cancer survivors with psychological distress ($N = 176$) to a matched sample of cancer survivors without psychological distress ($N = 2{,}814$). We employed multivariable logistic regression models and Poisson regression models. In all models, we adjusted for age at the survey, sex, race/ethnicity, education, income, insurance, exercise, chronic conditions, body mass index, and smoking status. Descriptive statistics and regression models were performed using STATA software.
Results: Our findings revealed a higher prevalence of psychological distress among younger survivors, females, individuals with lower incomes, and those with public insurance. Cancer survivors with psychological distress reported more adverse patient experiences compared to those without distress. Specifically, survivors with distress had lower odds of receiving clear explanations of their care (OR: 0.40; 95% CI: 0.17–0.99) and lower odds of feeling respected in expressing their concerns (OR: 0.42; 95% CI: 0.18–0.99) by their healthcare providers. Furthermore, psychological distress was associated with increased healthcare utilization, as evidenced by a higher number of visits ($p = 0.02$). It also correlated with a decrease in healthcare service ratings ($p = 0.01$) and the affordability of mental health services ($p < 0.01$) for cancer survivors.
Discussion: These findings indicate that psychological distress can significantly impact the delivery of healthcare and the patient experience among cancer survivors. Our study underscores the importance of recognizing and addressing the mental health needs of cancer survivors. It provides insights for healthcare professionals and policymakers to better understand and cater to the mental health needs of this population.

KEYWORDS

psychological distress, quality of care, cancer survivors, mental health services, access to care

Introduction

Psychological distress is highly prevalent among cancer survivors and significantly affects their health outcomes and healthcare utilization, resulting in increased expenses (1). Psychological distress refers to the emotional suffering experience as a result of various psychological disorders (2). Approximately 25% of cancer survivors experience psychological distress, which can manifest as depression, anxiety, panic attacks, posttraumatic stress disorder, cancer worry, or anger (3–5). Furthermore, psychological distress can persist for up to 20 years following a cancer diagnosis, negatively impacting survivors' health status and quality of life (6, 7). Despite the high prevalence of psychological distress among cancer survivors, little is known about how psychological distress impacts patients' quality of care. A better understanding of how psychological distress impacts the quality of care can inform cancer care guidelines and policies to effectively manage psychological distress in clinical settings.

Psychological distress has been linked to a range of negative outcomes, including reduced quality of life, unhealthy behaviors, increased healthcare utilization, decreased treatment adherence, and higher mortality rates (8, 9). The effect of psychological distress on health outcomes is often linked to the perceived quality of care received by patients. Psychological distress can negatively affect the patient experience and satisfaction, which can further lead to overuse of healthcare services (10). Given the significant impact of psychological distress on cancer survivors' health outcomes and healthcare service utilization, it is essential to understand how psychological distress impacts patient experiences, particularly with respect to access to mental health services. Access to mental health services is critical for effective treatment plans, but clinicians may overlook signs of psychological distress during follow-up visits, particularly when there are other pressing physical health issues and limited time for clinic visits. This oversight can exacerbate the impact of psychological distress on patients' perception of their physical and mental health. Recognizing the importance of addressing psychological distress for high-quality cancer care, the American College Surgeons Commission on Cancer Care mandated psychological distress screening for accreditation of cancer centers in 2015 (11). This mandate underscores the need to prioritize the mental health needs of cancer survivors and ensure that they receive the necessary support to cope with the emotional toll of cancer. However, more research is needed to understand and improve the quality of mental health care services to cancer survivors, with a particular emphasis on patient experience measures (12).

Patient experience measures are widely used to evaluate the quality of care and physician performance (13). In the National Quality Strategy, patient experience is recognized as one of three primary goals, alongside improving population health and reducing healthcare costs. The Consumer Assessment of Healthcare Providers and Systems (CAHPS) is a validated tool used to measure patient experience in cancer care (14). However, cancer survivors have reported lower quality scores for patient experience compared to non-cancer adults (15). Multiple factors can affect cancer patients' reported experiences, including social and psychological factors, as well as patient characteristics. Patient experience is not solely determined by the quality of care provided. Other factors such as psychological and social factors, as well as patients' characteristics, can also influence their reported experiences (16). Previous studies have found that patient experience can be associated with a patient's race, socioeconomic status, and gender (16). Additionally, sociodemographic characteristics, as well as the type and stage of cancer diagnosis, can also influence the extent of psychological distress experienced by survivors (17). For instance, survivors from ethnic minority groups may face additional cultural and social barriers to accessing mental health services. Moreover, physical health and functional impairments resulting from cancer treatment may further exacerbate psychological distress (2). Thus, it is essential to consider the unique needs of each patient when addressing psychological distress among cancer survivors.

Existing research has demonstrated a clear link between psychological factors and patients' perceptions of care quality and treatment outcomes. In spine surgery patients, those experiencing psychological distress reported lower levels of satisfaction than their non-distressed counterparts (18). Similarly, in the context of fertility clinics, patients with lower levels of anxiety reported more positive experiences and perceived higher levels of patient-centered care than those with higher anxiety levels (19). For cancer patients, the levels of psychological distress and predictors for such distress can vary by the survivorship period (20). Health-related quality of life, particularly regarding the empathy displayed by healthcare providers, has been shown to be associated with satisfaction reported by childhood cancer survivors (21). Furthermore, perceived lower care quality has been linked to experiences of stress or depression among hematological cancer survivors (22).

There is a scarcity of research that specifically examines the quality of care provided in mental health services as its primary focus. Previous studies in the mental health field have primarily concentrated on treatment effectiveness or mortality rates (23–25), with limited information available about patient experience. Moreover, there is a deficiency of specific and validated measures to assess the quality of care in mental healthcare compared to physical healthcare. Consequently, further research is needed to develop a more comprehensive understanding of patient experience within mental health services.

This study aims to examine the relationship between psychological distress and patient experiences among cancer survivors. Our hypothesis is that higher levels of psychological distress will be associated with lower reported measures of patient experience and limited access to care among cancer survivors. Understanding the impact of psychological distress on patient experiences can aid in developing patient-centered approaches to improve the quality of care received by cancer survivors.

Materials and methods

Data and sample

We utilized data from the Medical Expenditure Panel Survey (MEPS) for panels 21, 22, and 23 spanning the years 2016–2019 (26). The data we used was collected through the household component of the survey, which obtained information from a representative sample of non-institutionalized individuals in the United States. This sample was selected from individuals who participated in the National Health Interview Survey. For each panel, participants were interviewed in person and also provided self-administered questionnaires over a period of two years, amounting to five rounds of data collection. The MEPS dataset includes comprehensive information on sociodemographic characteristics, health status, medical conditions, and the quality of care received (27).

We initially identified participants who self-reported a diagnosis of cancer, excluding nonmelanoma skin cancers, which aligns with previous studies that did not classify nonmelanoma skin cancer as cancer survivors (28). From our dataset, we identified a total of 3,413 individuals who were cancer survivors. Among them, 423 participants had missing information about psychological distress, and they were excluded from the analysis. This left us with a final sample of 2,990 eligible cancer survivors, with 176 reporting psychological distress and 2,814 not reporting psychological distress.

To address any potential bias from missing information about the quality of care, we conducted a sensitivity analysis. The analysis compared the percentage of psychological distress between those with missing information and those without missing information. The results of our analysis indicated that there were no significant differences in the percentage of psychological distress between the group of participants with missing information about the quality of care and the group without missing information ($p = 0.76$).

For our matched analysis, we employed propensity score matching methods to create a matched sample of cancer survivors without psychological distress. The matching was based on age, sex (male or female), and race/ethnicity (Hispanic or non-Hispanic White, Black, Asian, or other). Propensity score matching involved predicting the conditional probability of having psychological distress based on the matched covariates. Using the propensity score, we matched each cancer survivor with psychological distress to a cancer survivor without psychological distress using the nearest neighbor matching process in STATA.

Variables

Outcome variables

We assessed the quality of care outcomes using a self-administered questionnaire adapted from the Consumer Assessment of Healthcare Providers and Systems Clinician and Groups (CAHPS-CG) survey. This survey is widely used to measure patient experience among both cancer survivors and non-cancer patients. All the measures we used pertained to experiences within the last 12 months.

In our analysis, we focused on eight specific measures. One measure examined access to mental health services and asked whether participants "Ever delay, forgo or make changes to mental health services because of cost?". The remaining five measures assessed various aspects of patient experience, including: (1) how often healthcare providers explained things in a way that was easy to understand, (2) how often healthcare providers showed respect for what participants had to say, (3) how often healthcare providers spent enough time with participants, (4) how often healthcare providers listened carefully to participants, and (5) how often participants received care as soon as they needed it. Participants provided responses on a 4-point Likert scale, with 1 representing "never," 2 representing "sometimes," 3 representing "usually," and 4 representing "always." To facilitate analysis, we transformed these responses into binary variables, with "never/sometimes" grouped together and "usually/always" grouped together.

Two additional measures focused on the participant's rating of healthcare services on a scale from 0 to 10, where 0 represented the worst possible healthcare and 10 represented the best possible healthcare. Lastly, we considered utilization, which referred to the number of times a person sought care from a doctor's office or clinic.

Psychological distress

Psychological distress was assessed using the Kessler (K6) questionnaire, which has been widely used and validated as a screening tool for clinically significant psychological distress (29). This questionnaire has demonstrated consistency in measuring distress across various socio demographic populations.

The K6 questionnaire consisted of several questions that inquired about the frequency of certain experiences within the past 30 days. These experiences included questions about how often patients felt so sad that nothing could cheer them up; felt nervous; restless, or fidgety; felt hopeless; felt that everything was an effort, or felt worthless in the past 30 days. The response options were as follows: "none of the time" = 0, "a little of the time" = 1, "some of the time" = 2, "most of the time" = 3, and "all of the time" = 4. A total symptom score ranging from 0 to 24 was calculated based on the participant's responses. Previous studies have established a cutoff point of 13 or higher to indicate clinically significant distress, using methods validated by prior research. Therefore, individuals with a score of 13 or above were classified as experiencing clinically significant psychological distress.

Psychological distress was assessed using the Kessler (K6) questionnaire, which has demonstrated consistency in measuring distress across various sociodemographic populations and has been validated as a screening tool for clinically significant psychological distress. The questionnaire consisted of items asking about the frequency of experiencing feelings such as sadness, nervousness, restlessness, hopelessness, lack of motivation, and worthlessness over the past 30 days. Response options ranged from "none of the time" to "all of the time" and were assigned values from 0 to 4, respectively. A total symptom score was calculated, with a score of 13 or higher indicating clinically significant distress based on established criteria used in previous studies.

Covariates

The sociodemographic characteristics considered in this study included age, sex, education level, race/ethnicity, and family income. Family income was categorized using poverty statistics from the Current Population Survey (CPS). The income categories were defined as follows: poor (<100% of the poverty level), near poor (100% to <125% of the poverty level), low income (125% to <200% of the poverty level), middle income (200% to <400% of the poverty level), and high income (>400% of the poverty level).

Participants' health insurance status was categorized based on their self-reported type of insurance coverage, which included private insurance, public insurance, or being uninsured. An elevated body mass index (BMI) was defined as a BMI value exceeding 25 kg/m^2. Adverse health behaviors were assessed by participants' current smoking status and regular exercise habits (not meeting the guideline of 150 min per week).

Chronic conditions were identified based on participants' self-reported diagnoses of certain medical conditions. These conditions included high blood pressure, heart disease, stroke, high cholesterol, diabetes, asthma, chronic bronchitis, and arthritis.

Analysis

Descriptive statistics, including chi-square tests and t-tests, were employed to compare the characteristics of cancer survivors with psychological distress and those without psychological distress. To estimate the impact of psychological distress and quality of care, multivariable logistic regression models were utilized. For outcomes related to the number of visits and doctors' ratings, Poisson regression models were employed. In all models, adjustments were made for various factors, including age at the survey, sex, race/ethnicity, education, income, insurance, exercise, chronic conditions, body mass index, and smoking status. Both matched and unmatched analyses were conducted, and odds ratios were reported as the measure of effect. The descriptive statistics and regression models were performed using STATA software.

Results

Characteristics of cancer survivors with and without psychological distress

We conducted a comparison between two groups of cancer survivors: those with psychological distress ($N = 176$) and those without psychological distress ($N = 2{,}814$). Among the cancer survivors, we observed that higher levels of psychological distress were more prevalent among younger survivors, females, individuals with lower incomes, and those with public insurance as opposed to private insurance. Additionally, smoking and physical inactivity were more commonly reported among survivors with psychological distress when compared to those without psychological distress (Table 1). Moreover, there was a significant positive association between the presence of chronic conditions and psychological distress. The included cancer types in our study were listed in Table 2.

TABLE 1 Characteristics of cancer survivors with psychological distress and control group: medical expenditure panel survey 2016–2019.

Characteristics	Cancer survivors with psychological distress	Cancer survivors without psychological distress	*P*-value
	N = 176 (5.89%)	*N* = 2,814 (94.11%)	
Age Mean (SD)	57.65 (15.42)	65.15 (13.85)	<0.001
Sex *N* (%)			
Female	119 (6.91)	1,603 (93.09)	0.006
Male	57 (4.50)	1,211 (95.50)	
Race/Ethnicity *N* (%)			
Hispanic	27 (9.57)	255 (90.43)	0.07
Non-Hispanic-White	123 (5.32)	2,191 (94.68)	
Non-Hispanic- Black	18 (6.64)	253 (93.36)	
Non-Hispanic-Asian	<5 (5.88)	48 (94.12)	
Non-Hispanic-Other	5 (6.94)	67 (93.06)	
Poverty *N* (%)			
Poor	56 (15.82)	298 (84.18)	<0.01
Near poor	14 (10.14)	124 (89.86)	
Low income	10 (10.18)	353 (89.82)	
Middle Income	38 (5.07)	711 (94.93)	
High Income	28 (2.06)	1,328 (97.94)	
Insurance *N* (%)			
Private	64 (3.57)	1,729 (96.43)	<0.01
Public	108 (9.42)	1,039 (90.58)	
Uninsured	<5 (8.00)	46 (92.00)	
Smoking			
No	75 (4.74)	1,508 (95.26)	<0.01
Yes	39 (15.54)	212 (84.46)	
Regular Physical activity			
No	127 (8.10)	1,441 (91.90)	<0.01
Yes	39 (2.84)	1,335 (97.16)	
Having chronic conditions			
No	6 (1.70)	347 (98.3)	<0.01
Yes	170 (6.45)	2,467 (93.55)	
Explain			
Never/Sometimes	18 (18.56)	79 (81.44)	<0.01
Usually/Always	74 (4.92)	1,431 (95.08)	
Listen			
Never/Sometimes	20 (17.86)	92 (82.14)	<0.01
Usually/Always	72 (4.82)	1,421 (95.18)	
Respect			
Never/Sometimes	17 (18.28)	76 (81.72)	<0.01
Usually/Always	52 (5.05)	978 (94.95)	
Spent time			
Never/Sometimes	19 (12.67)	131 (87.33)	<0.01
Usually/Always	73 (5.01)	1,384 (94.99)	
Access to care right			
Away	15 (17.24)	72 (82.76)	<0.01
Never/Sometimes	49 (7.81)	578 (92.19)	
Usually/Always			
Doctor rating mean (SE)	7.5 (0.23)	8.5 (0.04)	<0.01

SD, standard deviation; *N*, number; SE, standard error.
$P \leq 0.05$ = significant.

TABLE 2 Cancer type and visit number during last 12 months for cancer survivors with psychological distress and control group: medical expenditure panel survey 2016–2019.

Characteristics	Cancer survivors with psychological distress%	Cancer survivors without psychological distress%	*P*-value
Cancer types			
Melanoma	18.34	21.67	0.08
Cancer breast	16.57	20.06	
Cancer cervix	15.43	6.56	
Cancer prostate	5.14	13.78	
Cancer colon	4.73	5.80	
Cancer bladder	4.62	9.77	
Lymphoma (non-Hodgkin)	4.00	2.68	
Lung cancer	3.43	3.26	
Cancer uterus	2.96	4.61	
Other cancers	28.57	20.44	
Number of doctors' visits			
1	18.68	13.25	<0.01
2	10.99	16.64	
3	10.99	15.18	
4	13.19	14.38	
5–9	21.98	22.77	
10 or more	24.18	17.78	

SD, standard deviation; *N*, number; SE, standard error.
$P \leq 0.05$ = significant.

Health behaviors, chronic conditions, and socioeconomic status associated with psychological distress

In a multivariable logistic regression model, cancer survivors with psychological distress were more likely than cancer survivors without psychological distress to have lower incomes (OR: 1.56; 95% CI: 1.35–1.81), exercise less regularly (OR: 2.63; 95% CI: 1.61–4.17), and smoke (OR: 2.21; 95% CI: 1.40–3.51). Having at least one of the chronic conditions was associated with higher odds of having psychological distress (OR: 3.98; 95% CI: 1.75–9.07).

Quality of care associated with psychological distress

Cancer survivors with psychological distress reported significantly lower patient-reported quality of care. They indicated that healthcare providers were less likely to explain things in a way they understood (odds ratio OR: 0.25; 95% Confidence Interval CI: 0.13–0.47), show respect for what they had to say (OR: 0.35; 95% CI: 0.18–0.65), spend enough time with them (OR: 0.44; 95% CI: 0.24–0.48), and listen carefully to them (OR: 0.31; 95% CI: 0.17–0.57). However, when a matched sample was utilized, psychological distress remained significantly associated with providers explaining things in a way they understood (OR: 0.40; 95% CI: 0.17–0.99) and providers showing respect for survivors' perspectives (OR: 0.42; 95% CI: 0.18–0.99) (Table 3).

Furthermore, health care service ratings on a scale of 0–10 were lower by 0.8 ($p = 0.02$) among cancer survivors with psychological distress compared to those without distress. Additionally, survivors with psychological distress had an increase of one additional visit every two years ($p = 0.01$) compared to survivors without psychological distress (Figure 1).

Among cancer survivors, those with more severe psychological distress were more likely to report that mental health services were unaffordable compared to those with less severe distress (15.15% vs. 5.63%, OR: 0.90; 95% CI: 0.85–0.97, $p < 0.01$) (Figure 2).

Discussion

Our study utilized national population-based data to examine the impact of psychological distress on various aspects of cancer survivors' patient-reported experiences, access to mental health services, healthcare utilization, and healthcare service ratings. We found that psychological distress had a significant influence on how cancer survivors perceived their interactions with physicians, particularly in terms of understanding treatment plans and feeling respected. Furthermore, cancer survivors with psychological distress reported lower ratings for healthcare services, limited access to mental health services, and higher

TABLE 3 Regression coefficients for matched and unmatched effects of psychological distress on outcomes: medical expenditure panel survey 2016–2019.

Outcome	Unmatched sample estimate (95% CI)	*P*-value	Matched sample estimate (95% CI)	*P*-value
Afford mental health services (OR)	0.91 (0.85–0.98)	0.01	0.90 (0.83–0.97)	0.005
Doctor explained well (OR)	0.25 (0.13–0.47)	0.001	0.40 (0.17–0.99)	0.05
Doctor listened well (OR)	0.31 (0.17–0.57)	0.001	0.53 (0.23–1.24)	0.14
Doctor spent enough time (OR)	0.44 (0.24–0.48)	0.005	0.75 (0.34–1.67)	0.50
Doctor show respect (OR)	0.35 (0.18–0.65)	0.001	0.42 (0.18–0.99)	0.05
Access to care right away (OR)	0.63 (0.32–1.34)	0.17	0.51 (0.22–1.22)	0.13
Doctors rating (ln)	−0.09 (−0.15–−0.03)	0.004	−0.11 (−0.21–−0.016)	0.02
Number of visits (ln)	0.14 (0.04–0.26)	0.01	0.21 (0.05–0.37)	0.01

OR, Odds Ratio for logistic regression models.
CI, Confidence Interval.
$P \leq 0.05$ = significant.

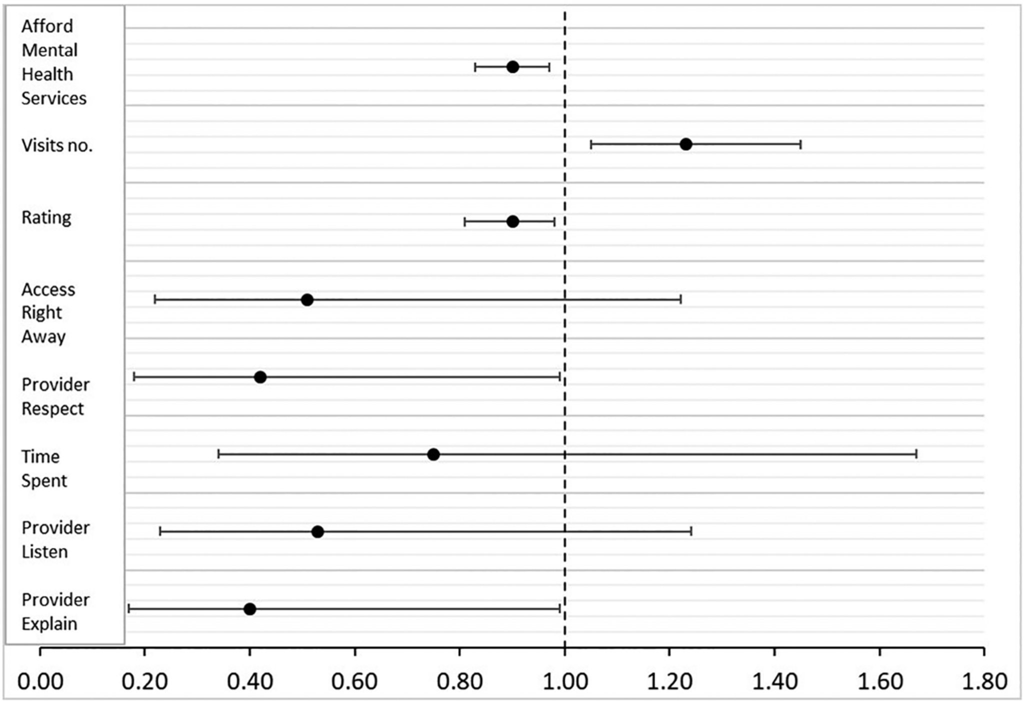

FIGURE 1
Quality and access to care associated with psychological distress: medical expenditure panel survey 2016–2019. Odds ratios and confidence intervals for quality and access to care factors associated with psychological distress. Ratios above one mean positive association and ratios below one mean negative association. The number of visits increased and health service rating, affordability of mental health services, providers respect, and explain scores decreased in patients with psychological distress compared to patients with no psychological distress.

healthcare utilization rates. These findings align with previous research conducted on non-cancer patients and support existing literature indicating that patient satisfaction and perceived quality of care measures can be affected by the level of psychological distress (8, 18, 30–32).

Patient experience plays a crucial role in assessing the quality of care and has a significant impact on patient outcomes and healthcare costs (33). Positive patient experiences and effective communication contribute to improved care and treatment adherence, particularly for cancer survivors who often face multiple mental and physical health challenges (4). Research suggests that patient experiences are influenced by both individual characteristics and structural factors within the healthcare system (34). For instance, sociodemographic disparities can affect the patient experience, with ethnic minority patients often reporting lower satisfaction than their white patients (5). Furthermore, healthcare structural factors such as resource availability, training, and policies can also impact patient experience. In our analysis, we observed that the presence of psychological distress in patients was associated with patients reporting less time spent with healthcare providers. It is essential for providers to address not only the physical but also the mental health needs of cancer survivors. However, resource limitations, such as limited visit time and the prioritization of more urgent physical health needs, often result in the neglect of survivors' mental health. A systematic review highlighted that primary care services for cancer patients often fail to address their psychological needs, leading to increased healthcare utilization (35).

The treatment of cancer is often complex, requiring sufficient visit time with physicians and clear explanations that patients can easily understand. Moreover, it is important to consider the psychological and cultural factors that may influence the treatment of cancer patients. Previous research has highlighted the significance of understanding patients' culture and perceptions when assessing, diagnosing, and treating depression in this population (36). In our study, we observed that cancer patients with psychological distress reported a lack of clear explanations from their doctors in a way that they could understand. This finding aligns with previous studies that have highlighted the unmet informational needs of cancer survivors (37). Policy guidelines and healthcare institutions that prioritize patient experience as a measure of care quality can play a crucial role in supporting researchers and healthcare providers in addressing the gaps in screening and managing psychological distress among cancer survivors (38).

Psychological distress imposes a significant economic and health burden (39), particularly among cancer survivors (1, 35). Consistent with previous research, our study using data from the National Health Interview Survey (NHIS) revealed that long-term cancer survivors had a higher prevalence of psychological distress compared to adults without a history of cancer (5.6% vs. 3%) (6). In our study, we also found that 5.9% of cancer survivors reported experiencing psychological distress. Moreover, cancer

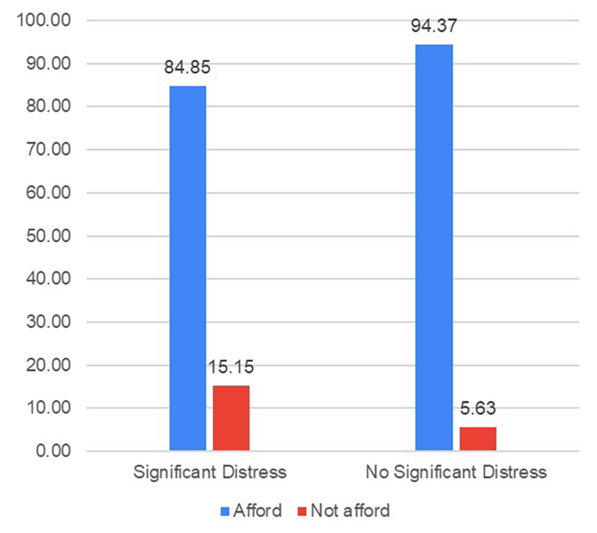

FIGURE 2
Percentage of individuals unable to afford mental health services by severity of mental distress. Rates of inability to afford mental health services among cancer survivors by psychological distress status. Survey question: "Ever delay, forgo or make changes to mental health services because of cost?" Respondents selected "yes" and "no" for the question. Kessler 6 includes a self-reported questionnaire: Participants were asked to indicate the frequency of experiencing specific feelings in the past 30 days, including feeling extremely sad to the point where nothing could cheer them up, feeling nervous, restless, or fidgety, feeling hopeless, feeling that everything was an effort, or feeling worthless. The response options ranged from "none of the time" to "all of the time" and were assigned numerical values of 0–4, respectively. A total symptom score was calculated by summing the individual item scores, resulting in a possible range of 0–24. Scores equal to or greater than 13 were indicative of clinically significant distress, based on established criteria used in prior studies.

survivors face challenges in accessing mental health services, primarily due to the high associated costs. Among various chronic conditions, the healthcare costs related to psychological distress are particularly high in cancer survivors (40). However, there is limited evidence on the effective management of psychosocial problems in cancer survivors within general practice settings (35). Therefore, there is a pressing need to incorporate consistent and validated screening measures for psychological distress, as well as cost-effective management protocols, into cancer survivorship care plans (41).

The higher prevalence of psychological distress among cancer survivors, coupled with the limited access to mental health services (42), underscores the importance of implementing policy interventions alongside treatment plans to address psychological distress and meet the comprehensive healthcare needs of patients (43).

Psychological distress among cancer survivors was found to be associated with lower quality of care indicators. Previous research has demonstrated that preoperative anxiety and depression in prostate cancer patients were linked to higher postoperative pain levels during hospitalization and after discharge (44). Similarly, distressed breast cancer survivors reported a greater number of treatment-related complaints (20). Depression among cancer survivors was associated with perceived lower quality of care in various aspects, including treatment delivery, treatment decision-making, follow-up care, respectful communication, patient preferences and values, and access to cancer information (22).

Conversely, good doctor-patient communication has been shown to be associated with lower psychological distress among cancer survivors (21, 45). These findings emphasize the importance of addressing psychological distress in the healthcare setting to improve the overall quality of care for cancer survivors. By focusing on effective communication and addressing the emotional needs of patients, healthcare providers can contribute to better patient experiences and outcomes in survivorship care.

Previous studies on health behavior interventions have demonstrated a significant positive impact on reducing psychological distress and improving quality of care outcomes in cancer survivors (46–48). These interventions have shown promising results in enhancing the well-being of survivors.

For instance, early implementation of cognitive-behavioral stress management programs has been found to reduce depression in breast cancer patients even up to 15 years after their diagnosis (49). This highlights the potential long-term benefits of psychological interventions in improving mental health outcomes for cancer survivors. Additionally, research has revealed a biological link between stress management and increased survival rates among cancer patients (50, 51), further emphasizing the importance of addressing psychological distress in cancer care.

Our study is subject to several limitations that should be considered when interpreting the findings. Firstly, the cross-sectional nature of the data prevents us from establishing causal relationships between psychological distress and quality of care. However, we took measures to ensure that patients reported on the quality of care after the diagnosis of psychological distress by using longitudinal panels. Secondly, the lack of information on cancer stage, severity, and time since diagnosis in the public data used for our analysis is a limitation. These factors are known to influence psychological distress in cancer survivors, and their absence may impact the generalizability of our findings. Nonetheless, previous studies have indicated that psychological distress is prevalent among cancer survivors across different cancer types and regardless of the time since diagnosis (6, 40). Thirdly, we did not have detailed information on specific psychological disorders diagnosed in the participants. Therefore, we were unable to account for the influence of specific disorders on the association between psychological distress and quality of care. However, the Kessler psychological distress survey used in our study has demonstrated high sensitivity and specificity in detecting psychological distress, as well as screening for symptoms of depression and anxiety. Finally, we were not able to study the impact of COVID-19 on psychological distress and quality of care in cancer survivors, as we were unable to include data from the COVID-19 years. The data collection process for 2020 was affected by the pandemic, leading to difficulties in pooling the data. Furthermore, the quality of care indicators, which are evaluated every other year, were last reported in 2019, and data for 2021 is currently unavailable. Finally, despite previous studies documenting the high psychological burden and unmet needs among cancer survivors during the COVID-19 pandemic (52, 53), we encountered challenges in studying the impact of COVID-19 on psychological distress and quality of care in cancer survivors, as we were unable to include data from the COVID-19 years. The data collection process for 2020 was affected by the pandemic, leading to difficulties in pooling the data. Furthermore, the quality of care indicators, which are evaluated every other year, were last reported in 2019, and data for 2021 is currently unavailable.

Future research should aim to examine the effectiveness of interventions targeting the reduction of psychological distress in improving patient experience and quality of care. By addressing these limitations and conducting further investigations, we can gain a better understanding of the complex relationship between psychological distress and quality of care in cancer survivors.

Conclusion

High prevalence of psychological distress among cancer survivors has significant implications for the quality of care they receive. It can negatively impact patient experience, particularly when access to mental health services is limited. Providing adequate psychological support to cancer survivors is crucial for improving the quality of care, optimizing healthcare utilization, and enhancing health outcomes. This study carries important implications for healthcare providers and policymakers involved in improving the well-being of cancer survivors. These findings identify gaps in cancer survivorship care and guide the development of interventions aimed at improving access to and quality of mental health services. Furthermore, it can inform policy initiatives that promote equitable access to mental health services for cancer survivors, resulting in improved patient experiences and health outcomes.

Data availability statement

Publicly available datasets were analyzed in this study. This data can be found here: https://meps.ahrq.gov//mepsweb/data_stats/download_data_files_results.jsp?cboDataYear=All&;buttonYearandDataType=Search.

Ethics statement

Ethical review and approval was not required for the study on human participants in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

OA contributed to the conception and design of the study. OA organized the database. OA performed the statistical analysis. OA wrote the first draft of the manuscript. OA wrote sections of the manuscript. The author confirms being the sole contributor of this work and has approved it for publication.

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Conflict of interest

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

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References

1. Abdelhadi OA, Pollock BH, Joseph JG, Keegan THM. Psychological distress and associated additional medical expenditures in adolescent and young adult cancer survivors. *Cancer*. (2022) 128(7):1523–31. doi: 10.1002/cncr.34064

2. Andrykowski MA, Lykins E, Floyd A. Psychological health in cancer survivors. *Semin Oncol Nurs*. (2008) 24(3):193–201. doi: 10.1016/j.soncn.2008.05.007

3. Medicine I of. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. (Cited 2022 Nov 6). Available at: https://nap.nationalacademies.org/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs (2007).

4. Zebrack B, Kayser K, Bybee D, Padgett L, Sundstrom L, Jobin C, et al. A practice-based evaluation of distress screening protocol adherence and medical service utilization. *J Natl Compr Cancer Network*. (2017) 15(7):903–12. doi: 10.6004/jnccn.2017.0120

5. Mitchell AJ, Lord K, Slattery J, Grainger L, Symonds P. How feasible is implementation of distress screening by cancer clinicians in routine clinical care? *Cancer*. (2012) 118(24):6260–9. doi: 10.1002/cncr.27648

6. Hoffman KE, McCarthy EP, Recklitis CJ, Ng AK. Psychological distress in long-term survivors of adult-onset cancer: results from a national survey. *Arch Intern Med*. (2009) 169(14):1274–81. doi: 10.1001/archinternmed.2009.179

7. Maass SWMC, Boerman LM, Verhaak PFM, Du J, Bock GH, de Berendsen AJ. Long-term psychological distress in breast cancer survivors and their matched controls: a cross-sectional study. *Maturitas*. (2019) 130:6–12. doi: 10.1016/j.maturitas.2019.09.003

8. Giesinger JM, Kuster MS, Behrend H, Giesinger K. Association of psychological status and patient-reported physical outcome measures in joint arthroplasty: a lack of divergent validity. *Health Qual Life Outcomes*. (2013) 11(1):64. doi: 10.1186/1477-7525-11-64

9. Hamer M, Stamatakis E, Saxton JM. The impact of physical activity on all-cause mortality in men and women after a cancer diagnosis. *Cancer Causes Control*. (2009) 20(2):225–31. doi: 10.1007/s10552-008-9237-3

10. Mosadeghrad AM. Factors influencing healthcare service quality. *Int J Health Policy Manag*. (2014) 3(2):77–89. doi: 10.15171/ijhpm.2014.65

11. American College of Surgeons Commission on Cancer. Cancer Program Standards: Ensuring Patient-Centered Care Manual. Standard 3.2—Psychosocial Distress Screening, pp. 56–57. Available at: https://www.facs.org/quality-programs/cancer/coc/standards (Accessibility verified June 1, 2018) (2016).

12. D'Lima D, Crawford MJ, Darzi A, Archer S. Patient safety and quality of care in mental health: a world of its own? *BJPsych Bull*. (2017) 41(5):241–3. doi: 10.1192/pb.bp.116.055327

13. Bastemeijer CM, Boosman H, van Ewijk H, Verweij LM, Voogt L, Hazelzet JA. Patient experiences: a systematic review of quality improvement interventions in a hospital setting. *Patient Relat Outcome Meas*. (2019) 10:157–69. doi: 10.2147/PROM.S201737

14. Consumer Assessment of Healthcare Providers and Systems (CAHPS) Home Page. (cited 2022 Nov 6). Available at: https://www.ahrq.gov/cahps/index.html.

15. Krzyzanowska MK, Barbera L, Elit L, Razzaq A, Saskin R, Yeritsyan N, et al. Identifying population-level indicators to measure the quality of cancer care for women. *Int J Qual Health Care*. (2011) 23(5):554–64. doi: 10.1093/intqhc/mzr043

16. Alessy SA, Alhajji M, Rawlinson J, Baker M, Davies EA. Factors influencing cancer patients' experiences of care in the USA, United Kingdom, and Canada: a systematic review. *EClinicalMedicine*. (2022) 47:101405. doi: 10.1016/j.eclinm.2022.101405

17. Romito F, Dellino M, Loseto G, Opinto G, Silvestris E, Cormio C, et al. Psychological distress in outpatients with lymphoma during the COVID-19 pandemic. *Front Oncol*. (2020) 10:1270. doi: 10.3389/fonc.2020.01270

18. Abtahi AM, Brodke DS, Lawrence BD, Zhang C, Spiker WR. Association between patient-reported measures of psychological distress and patient satisfaction scores in a spine surgery patient population. *J Bone Joint Surg Am*. (2015) 97 (10):824–8. doi: 10.2106/JBJS.N.00916

19. Aarts JWM, Huppelschoten AG, van Empel IWH, Boivin J, Verhaak CM, Kremer JAM, et al. How patient-centred care relates to patients' quality of life and distress: a study in 427 women experiencing infertility. *Hum Reprod*. (2012) 27 (2):488–95. doi: 10.1093/humrep/der386

20. Syrowatka A, Motulsky A, Kurteva S, Hanley JA, Dixon WG, Meguerditchian AN, et al. Predictors of distress in female breast cancer survivors: a systematic review. *Breast Cancer Res Treat*. (2017) 165(2):229–45. doi: 10.1007/s10549-017-4290-9

21. Tremolada M, Schiavo S, Varotto S, Basso G, Pillon M. Patient satisfaction in Italian childhood cancer survivors: human aspects of treatment as a key factor in patients' quality of life. *Health Soc Work*. (2015) 40(4):e148–55. doi: 10.1093/hsw/hlv067

22. Tzelepis F, Sanson-Fisher RW, Hall AE, Carey ML, Paul CL, Clinton-McHarg T. The quality of patient-centred care: haematological cancer survivors' perceptions. *Psychooncology*. (2015) 24(7):796–803. doi: 10.1002/pon.3728

23. Harris AHS, Gupta S, Bowe T, Ellerbe LS, Phelps TE, Rubinsky AD, et al. Predictive validity of two process-of-care quality measures for residential substance use disorder treatment. *Addict Sci Clin Pract*. (2015) 10(1):22. doi: 10.1186/s13722-015-0042-5

24. Schmidt EM, Gupta S, Bowe T, Ellerbe LS, Phelps TE, Finney JW, et al. Predictive validity of outpatient follow-up after detoxification as a quality measure. *J Addict Med*. (2017) 11(3):205–10. doi: 10.1097/ADM.0000000000000298

25. Watkins KE, Paddock SM, Hudson TJ, Ounpraseuth S, Schrader AM, Hepner KA, et al. Association between quality measures and mortality in individuals with co-occurring mental health and substance use disorders. *J Subst Abuse Treat*. (2016) 69:1–8. doi: 10.1016/j.jsat.2016.06.001

26. Medical Expenditure Panel Survey Download Data Files. (cited 2022 Nov 6). Available at: https://www.meps.ahrq.gov/mepsweb/data_stats/download_data_files.jsp.

27. Medical Expenditure Panel Survey Background. (cited 2022 Nov 6). Available at: https://meps.ahrq.gov/mepsweb/about_meps/survey_back.jsp.

28. Ekwueme DU, Yabroff KR, Guy GP, Banegas MP, de Moor JS, Li C, et al. Medical costs and productivity losses of cancer survivors–United States, 2008-2011. *MMWR Morb Mortal Wkly Rep*. (2014) 63(23):505–10. PMID: 24918485.

29. Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SLT, et al. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med*. (2002) 32(6):959–76. doi: 10.1017/S0033291702006074

30. Roh YH, Noh JH, Oh JH, Baek GH, Gong HS. To what degree do shoulder outcome instruments reflect patients' psychologic distress? *Clin Orthop Relat Res*®. (2012) 470(12):3470–7. doi: 10.1007/s11999-012-2503-4

31. Potter MQ, Wylie JD, Sun GS, Beckmann JT, Aoki SK. Psychologic distress reduces preoperative self-assessment scores in femoroacetabular impingement patients. *Clin Orthop Relat Res*®. (2014) 472(6):1886–92. doi: 10.1007/s11999-014-3531-z

32. Lavernia CJ, Alcerro JC, Brooks LG, Rossi MD. Mental health and outcomes in primary total joint arthroplasty. *J Arthroplasty*. (2012) 27(7):1276–82. doi: 10.1016/j.arth.2011.11.015

33. Mariotto AB, Enewold L, Zhao J, Zeruto CA, Yabroff KR. Medical care costs associated with cancer survivorship in the United States. *Cancer Epidemiol Biomarkers Prev*. (2020) 29(7):1304–12. doi: 10.1158/1055-9965.EPI-19-1534

34. Deckx L, Chow KH, Askew D, van Driel ML, Mitchell GK, van den Akker M. Psychosocial care for cancer survivors: a systematic literature review on the role of general practitioners. *Psychooncology*. (2021) 30(4):444–54. doi: 10.1002/pon.5612

35. Saunders C, Abel G, Lyratzopoulos G. Inequalities in reported cancer patient experience by socio-demographic characteristic and cancer site: evidence from respondents to the English cancer patient experience survey. *Eur J Cancer Care (Engl)*. (2015) 24(1):85–98. doi: 10.1111/ecc.12267

36. Bailey RK, Geyen DJ, Scott-Gurnell K, Hipolito MMS, Bailey TA, Beal JM. Understanding and treating depression among cancer patients. *Int J Gynecol Cancer*. (2005) 15(2):203–8. doi: 10.1111/j.1525-1438.2005.15204.x

37. Beckjord EB, Arora NK, McLaughlin W, Oakley-Girvan I, Hamilton AS, Hesse BW. Health-related information needs in a large and diverse sample of adult cancer survivors: implications for cancer care. *J Cancer Surviv*. (2008) 2(3):179–89. doi: 10.1007/s11764-008-0055-0

38. Slide Set: National Quality Strategy Overview | Agency for Healthcare Research and Quality. (cited 2022 Nov 9). Available at: https://www.ahrq.gov/workingforquality/nqs-tools/briefing-slides.html.

39. Razzouk D. Burden and indirect costs of mental disorders. In: Razzouk D, editor. *Mental health economics: The costs and benefits of psychiatric care*. Cham: Springer International Publishing (2017). p. 381–91. (cited 2022 Nov 22). Available at: doi.org/10.1007/978-3-319-55266-8_25

40. Arega MA, Dee EC, Muralidhar V, Nguyen PL, Franco I, Mahal BA, et al. Psychological distress and access to mental health services among cancer survivors: a national health interview survey analysis. *J Gen Intern Med*. (2021) 36(10):3243–5. doi: 10.1007/s11606-020-06204-3

41. Christ G, Messner C, Behar L. *Handbook of oncology social work: psychosocial care for people with cancer*. Oxford: Oxford University Press (2015). 873.

42. Kaiser NC, Hartoonian N, Owen JE. Toward a cancer-specific model of psychological distress: population data from the 2003−2005 national health interview surveys. *J Cancer Surviv*. (2010) 4(4):291–302. doi: 10.1007/s11764-010-0120-3

43. American Society of Clinical Oncology Clinical Expert Statement on Cancer Survivorship Care Planning|JCO Oncology Practice. (cited 2022 Oct 20). Available at: https://ascopubs.org/doi/10.1200/JOP.2014.001321

44. Ene KW, Nordberg G, Johansson FG, Sjöström B. Pain, psychological distress and health-related quality of life at baseline and 3 months after radical prostatectomy. *BMC Nurs*. (2006) 5(1):8. doi: 10.1186/1472-6955-5-8

45. Abdelhadi OA, Pollock BH, Joseph J, Keegan THM. Shared decision-making among adolescent and young adult cancer survivors and noncancer adults: associated medical expenditures and health care utilization. *J Adolesc Young Adult Oncol*. (2023) 12(2):168–76. doi: 10.1089/jayao.2021.0207

46. Daley AJ, Crank H, Saxton JM, Mutrie N, Coleman R, Roalfe A. Randomized trial of exercise therapy in women treated for breast cancer. *JCO*. (2007) 25 (13):1713–21. doi: 10.1200/JCO.2006.09.5083

47. Gabriel I, Creedy D, Coyne E. A systematic review of psychosocial interventions to improve quality of life of people with cancer and their family caregivers. *Nurs Open*. (2020) 7(5):1299–312. doi: 10.1002/nop2.543

48. Lutgendorf SK, Andersen BL. Biobehavioral approaches to cancer progression and survival: mechanisms and interventions. *Am Psychol*. (2015) 70:186–97. doi: 10.1037/a0035730

49. Stagl JM, Bouchard LC, Lechner SC, Blomberg BB, Gudenkauf LM, Jutagir DR, et al. Long-term psychological benefits of cognitive-behavioral stress management for women with breast cancer: 11-year follow-up of a randomized controlled trial. *Cancer*. (2015) 121(11):1873–81. doi: 10.1002/cncr.29076

50. Spiegel D. Mind matters in cancer survival. *Psychooncology*. (2012) 21 (6):588–93. doi: 10.1002/pon.3067

51. Carlson LE, Beattie TL, Giese-Davis J, Faris P, Tamagawa R, Fick LJ, et al. Mindfulness-based cancer recovery and supportive-expressive therapy maintain telomere length relative to controls in distressed breast cancer survivors. *Cancer*. (2015) 121(3):476–84. doi: 10.1002/cncr.29063

52. Zomerdijk N, Jongenelis M, Short CE, Smith A, Turner J, Huntley K. Prevalence and correlates of psychological distress, unmet supportive care needs, and fear of cancer recurrence among haematological cancer patients during the COVID-19 pandemic. *Support Care Cancer*. (2021) 29(12):7755–64. doi: 10.1007/s00520-021-06369-5

53. Bartmann C, Fischer LM, Hübner T, Müller-Reiter M, Wöckel A, McNeill RV, et al. The effects of the COVID-19 pandemic on psychological stress in breast cancer patients. *BMC Cancer*. (2021) 21(1):1356. doi: 10.1186/s12885-021-09012-y

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How is physical healthcare experienced by staff, service users, and carers in adult community mental health services in a south London mental health trust? A service evaluation

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Background: Adults with a serious mental illness (SMI) are at greater risk of physical health morbidity and premature death than the general population, largely as a result of preventable physical health issues. Staff working in mental health services have a role to play in addressing these inequalities, but little is known about how they perceive their role and how this impacts on their practice. Understanding this better would enable services to improve their approach and support better health outcomes for SMI patients. A service evaluation was undertaken to investigate how physical healthcare is approached within adult community mental health teams (CMHTs) at a South London (UK) Mental Health Trust.

Methods: This was a prospective, cross-sectional evaluation design. Interviews and focus groups were conducted with clinical staff, service users and carers (non-professional caregivers e.g., family or friends, of adults living with an SMI), to understand their experiences and to identify key barriers and facilitators to supporting physical healthcare support for adults with SMI. Thematic analysis was conducted to identify key themes which were classified into five main categories.

Results: 50 participants took part in the study, 38 were clinical staff, eight were service users and four were carers. We found staff widely recognised the importance of supporting physical healthcare. However, there was variability in how staff approached physical healthcare in routine practice, and differences in how physical healthcare is experienced by service users and carers. Staff were keen to engage in changes to the way physical healthcare is delivered in CMHTs. However, they sought clearer guidance on their roles and responsibilities, and wanted to better understand the rationale for changes in community mental health practice, such as increased screening for physical healthcare. Service users and carers felt equally that the role of CMHTs in physical healthcare was unclear, which limited their ability to access it and understand the benefit for their overall care. Staff articulated gaps in leadership and training that impacted on their ability to implement the overall vision for physical healthcare within the Trust.

Conclusion: Mental health staff recognise the role they play in supporting the physical health of adults living with SMI. This evaluation provides insight into common barriers and facilitators faced by staff, service users and carers when providing or accessing physical healthcare within adult CMHTs. These findings indicate a more comprehensive and better articulated approach to physical healthcare in mental health Trusts is needed to ensure service users and their carers understand what support is available and how to access it and to equip staff to provide and sustain that care in routine practice.

KEYWORDS

service evaluation, physical healthcare, community mental health teams, serious mental illness (SMI), adults

1. Introduction

Adults with a serious mental illness (SMI) such as schizophrenia, schizoaffective disorder, bipolar disorder, and depressive psychosis are at greater risk of physical health morbidity and premature death than the general population (1). Within the UK, primary care is the first point of contact for people to access physical healthcare services but for people with SMI they may also access support through secondary mental health services, which would usually be a Community Mental Health Team (CMHT).

Several small-scale UK studies have considered the challenges in providing physical healthcare for adults living with SMI. One study identified multiple barriers including mental health professionals seeing physical healthcare planning as secondary to mental health care planning (2) and another identified that processes set up for screening and managing physical healthcare for adults with SMI are often limited due to staff lacking appropriate skills and knowledge to do this (3). Both studies suggested that effective integrated care is facilitated when service users are involved in developing services and when general practitioners are aware of any secondary care planning involving the physical health of their patients.

Other research has explored the experience of mental healthcare staff who provide physical healthcare and the impact this has on the provision of care for service users. A survey of mental healthcare professionals undertaken by Papachristou et al. (2019) (4) suggested that clinical staff were unclear about which service users had comorbid health conditions and frequently lack training or resources to facilitate dual care (4). Butler (2020) (5) investigated the attitudes of healthcare professionals to the provision of physical healthcare in CMHTs and suggested that how staff experience the changes and how these impact on service users needs to be better understood by policymakers. They also found that clinicians with specific physical health training were more likely to advocate for physical health support for their service users.

Several papers have explored the perspectives of service users [e.g., (6, 7)], who largely feel their physical health is not prioritised when accessing mental health services and want to see greater physical health knowledge amongst mental healthcare professionals. Hughes (2009) (7) explored the experiences of service users with sexual health concerns and found they valued being able to talk openly about concerns relating to all aspects of their health with mental healthcare professionals and for those concerns to be addressed in a coordinated way.

Finally, a study by Onwumere et al. (2018) (8) explored the experiences of non-professional caregivers (e.g., family or friends) of adults living with an SMI, revealing frustrations with the lack of coordinated care for adults with SMI when moving between parts of the care system, and the systemic burden it creates for carers. They found that the identification and management of physical health problems, gaps in services for comorbid health problems and the impact on carers when supporting loved ones outside of statutory care were key concerns.

1.1. Rationale and aims for a service evaluation

This service evaluation was undertaken in the South London and Maudsley NHS Foundation Trust (referred to as ‘the Trust’ throughout). The National Institute for Health and Care Excellence (NICE, 2014) (9) issued guidance in 2014 for the provision of annual physical health checks for adults with SMI with care shared between primary and secondary services. The Trust responded to this guidance by developing a strategy that outlined the responsibilities of the organisation and its staff when providing physical healthcare for adults with SMI. The Trust were keen to understand how physical healthcare is currently approached by clinical staff working within adult CMHTs, and how it is experienced by service users and carers using those services.

The scope of this service evaluation was discussed and agreed between the researchers and the Trust. We aimed to gather a wide range of staff perspectives to obtain a general view and not to draw comparisons between professional groups, teams or services within the organisation.

We aimed to explore which barriers and facilitators contribute to five main areas of interest as identified by the Trust:

i. The approach and practice of staff towards physical healthcare
ii. The use of physical health systems and tools
iii. The physical health knowledge and skills used by staff
iv. The perceptions and attitudes of staff towards physical healthcare within the Trust

v. The experiences and outcomes of service users and carers

The service evaluation was designed to enable the Trust to use the insights gained to inform local decision-making and improve future routine practice regarding physical healthcare (10).

Note: facilitation of shared care, or the integration of care services between primary and secondary care providers sits outside of the scope of this evaluation.

2. Methodology

2.1. Design

This was a prospective, cross-sectional service evaluation designed by the research team in collaboration with the Trust, and experts with lived and clinical experience of SMI. Qualitative data collection methods were used to gain in-depth, detailed perspectives on the evaluation questions from the study participants. We conducted interviews and focus groups with staff working in or responsible for CMHTs, as well as focus groups with service users and their carers.

2.2. Ethics

Approval was obtained from Clinical and Information Governance professional leads at the Trust (on 14th March 2022). All participants involved in the study were briefed prior to taking part and given written information about how their data would be used within the evaluation process and as part of any final publications. Participants provided written informed consent to participate in the study. Participation was voluntary and withdrawal was possible at any stage.

2.3. Setting

This service evaluation was conducted in Adult Community Mental Health services at the South London and Maudsley NHS Foundation Trust, the largest mental health Trust in the UK, serving a local population of 1.3 million people in south east London. The Trust supports approximately 40,000 service users within community services across four boroughs: Southwark, Lambeth, Lewisham, and Croydon (11).

2.4. Participants

2.4.1. Inclusion criteria

Staff: were over 18 years old, currently working within adult CMHTs with experience of supporting adults with SMI with associated physical health problems.

Service users and carers: had to have used adult CMHT services (as a service user or carer) at the Trust within the past 12 months and be aged over 18 years old.

2.4.2. Sampling and recruitment

A purposive sampling technique was used to ensure participants were from a wide range of clinical roles, from different sociodemographic groups and to ensure service user and carer representation.

2.4.2.1. Clinical staff

Key clinical roles based within adult CMHTs were identified with clinical service leads. These roles included community matrons, general managers, clinical service leads, team leaders, doctors at different grades (i.e., attending level physicians and residents in the USA), nurses, social workers, and occupational therapists. Staff demographic data from the Trust were used to ensure the final sample was demographically representative of the Trust's workforce, as set out in the 2021–2022 Workforce Equality and Diversity Report (12).

2.4.2.2. Service users and carers

Service users and carers were recruited via existing patient and public involvement within the Trust. An online participation advert was also used. Service users and carers were selected using the INCLUDE framework (13) to ensure sufficient diversity and inclusion across participants. Demographic data from across all four boroughs were used to inform participant selection to ensure representativeness, using the 2021/2022 Trust-wide Equality Information Report (14). Service users and carers were paid for their involvement in accordance with national guidelines.

2.5. Procedure for interviews and focus groups

Participants interested in taking part were contacted by a researcher (GT) who explained the evaluation to them. All participants taking part provided written informed consent and were asked to complete a demographic questionnaire prior to the interview or focus group.

2.5.1. Interview and focus group design

The evaluation team developed a schedule of questions to use in interviews and focus groups (see additional material 1). Based on the five main areas of interest (see Section **1.1**) the researchers co-developed questions with an independent panel of clinical staff, service users, and carers. Questions were reviewed by the evaluation team made up of clinicians and academics (including authors: GT, RM, JW, NSt, NS, FG, ES and KA). A semi-structured interview format was used, with additional prompts used to support wider enquiry during questioning. Before data collection, two pilot interviews and two pilot focus groups were undertaken to test questions and practice facilitation. All recordings were saved with a participant ID number transcribed by an independent transcriber. Transcripts were saved securely in a password protected file on a SLaM electronic drive and the original recordings were deleted.

2.5.2. Interviews

General managers, clinical service leads, team leaders, mental health nurses, occupational therapists, social workers, advanced practitioners, and physical health leads were invited to participate in online interviews using Microsoft Teams. All interviews lasted for one hour.

2.5.3. Focus groups

Focus groups were conducted online using Microsoft Teams with doctors, care coordinators, service users, and carers. All focus groups lasted for one hour for clinical staff, and two hours for service users and carers. Sessions were led by two facilitators (one researcher, GT, and one expert by experience) and had a maximum of six participants per group.

3. Stakeholder involvement

Throughout the evaluation, progress was reviewed in the existing Trust and project forums including fortnightly meetings with Physical Health Leads from the Trust and monthly evaluation team meetings.

An independent group of clinical advisors was recruited to ensure the experiences of clinical professionals and people using services were included throughout. The group was made up of clinical advisors working within Trust CMHT services (two doctors and four care coordinators) and three experts with lived experience (two service users and one carer). Applications for expert roles were advertised and all advisors were selected following an interview. Members of the above groups were involved throughout the study to routinely share progress and gather feedback at key stages.

4. Analysis

The analysis was undertaken by a team with one main coder (GT), a main reviewer (JW) and two additional reviewers (ES and RM).

4.1. Data extraction and coding

All transcripts were uploaded to NVivo (version 12) (QSR International, 2020). Initially GT, JW and RM read three early transcripts and extracted 5 preliminary themes and related subthemes from these (see **Figure 1**). Once these preliminary codes were agreed, GT continued to extract and categorise codes from the remaining transcripts. JW systematically read through the detailed coding once completed to check coding quality and accuracy. ES and RM reviewed the coding structure at regular intervals: when 10%, 25%, 50%, 75% and finally 100% of transcripts had been coded. Each review interval provided an opportunity to review the original aims of the study, to review the code structure and to observe patterns from the data. The research team were then able to synthesise the data into five main themes and related subthemes. These themes were then translated into recommendations for practice by the Trust, and these were shared with participants (4 workshops with 30 staff, 10 service users and 5 carers) to check whether these reflected the experiences of the participants.

5. Results

5.1. Demographics

50 participants took part in the study. 38 were clinical staff, eight were service users and four were carers. We collected

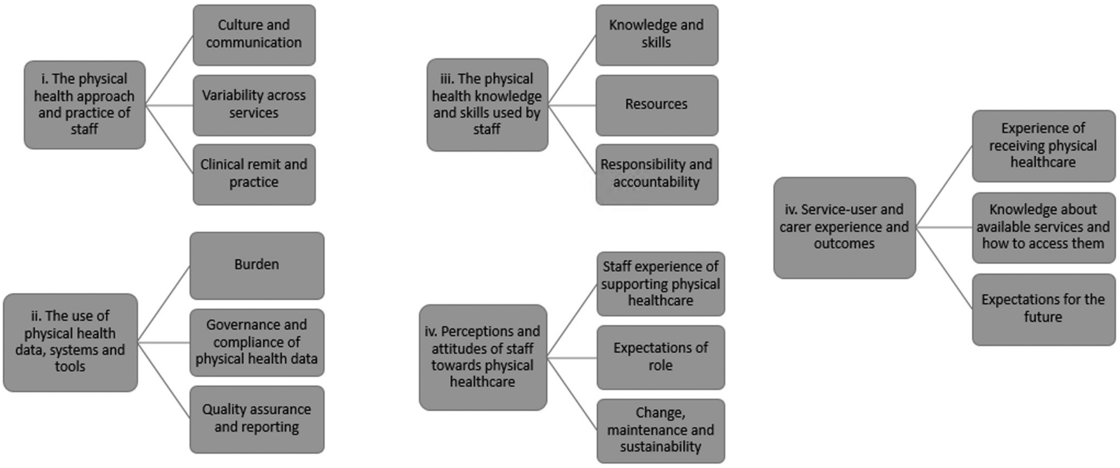

FIGURE 1
Schematic representation of the five main themes and related subthemes that were identified from the data set.

TABLE 1 Demographics of clinical staff.

Demographics of clinical staff who provided their demographic data ($N = 22$)	
Characteristics	No. participants
Age	
20–29	2
30–39	2
40–49	7
50–59	9
60–69	2
Gender	
Male	7
Female	15
Ethnic background	
White British	13
White Irish	1
White Other	2
Black British	1
Black African	3
Asian British	2
No. years working within mental health services at SLaM	
3–5 years	7
6–10 years	2
11–15 years	3
16–20 years	2
21–25 years	5
26 years or more	3
Missing data	16

TABLE 2 Demographics of service users and carers.

Demographics of service users and carers ($N = 12$)	
Characteristics	No. participants
Age	
30–39	2
40–49	2
50–59	3
60–69	2
70+	3
Gender	
Male	4
Female	8
Ethnic background	
White British	8
White Irish	1
Black British	1
Mixed British	1
Asian British	1
No. years accessing mental health services at SLaM	
2 years or less	2
3–5 years	5
11–15 years	2
16–20 years	2
Mental Health Conditions	
SMI (Psychosis, including Schizophrenia, Schizoaffective Disorder, Bipolar Disorder and Depressive Psychosis)	11
Post-Traumatic Stress Disorder (PTSD)	1
Neurological Disorders	2
Physical Health Conditions	
Obesity	2
Physical health effects of medication	8
Missing data	0

demographic data from 22 clinical staff and all service users and carers. Participant demographics are shown in Tables 1, 2.

The mean age of participants was 51, with most participants being female. For the staff we had demographic data for the largest ethnic group was White British, followed by Black African, which is proportional to the workforce. Most participants had worked in the Trust for at least three years. Amongst service users and carers the largest ethnic group was also White British, followed by Black British, Mixed British, and Asian British, with one participant per non-white ethnicity. All service users, except for two participants, reported having a diagnosed SMI and had accessed CMHT services at the Trust for 12 months or more.

23 interviews were completed with clinical staff from a range of teams and professional roles. Eight focus groups were held: four with clinical staff (15 participants), two with service users (eight participants), and two with carers (four participants).

5.2. Findings

35 hours of interview and focus group recordings were fully transcribed and submitted for analysis. Five main themes and related subthemes were identified (see Figure 1). These themes were mapped against the five main areas of interest (themes) (see 1.1). Sections 5.2.1–5.2.4 report on clinical staff experiences and section 5.2.5. reports on the experience of service users and carers.

5.2.1. Physical health approach and practice of staff

5.2.1.1. Culture and communication

All participants identified with the importance of addressing physical healthcare, however, there was variability in awareness of the Trust's vision and strategy. For example, some participants, mostly clinical managers, were aware the Trust has a vision for better whole-person healthcare, often referring to the Trust strategy Aim High, Changing Lives (2021–2026) (15) but were uncertain of how to embed this into teams and everyday practice. Participants consistently reported being unclear on policy and expectations for physical healthcare practice across the organisation. Some participants in frontline roles suggested staff involvement in developing visions and strategies to inform change initiatives would help with this lack of clarity.

> *"At this stage, I don't know if [the policy] has been put into practice yet. It feels like an idea, and it sounds positive, but what does that look like on the ground? How is it impacting the actual delivery of care? We can have ideas around what things should look like, but how has that changed the way care is being delivered?" – P1*

Participants' experiences of communication from the Trust regarding physical healthcare varied largely based on their role and the borough in which they worked. Participants who had experienced positive communication described clear guidance from managers and regular opportunity to feedback on their experiences. Participants who had encountered difficulties in communication were unclear about both the organisation's role and their individual remit, but also reported a lack of opportunities to discuss experiences of physical healthcare with colleagues or managers.

> *"We're trying to bring in a structure for communicating things, so we're actually communicating information that needs to be handed over in a clear and concise manner. I know I've sat in meetings where people talk round and round, and you don't actually get a sense of what's happening. I think it's [providing] a safe space for people to say, 'I'm not sure about this,' and feel supported so they're not carrying things… it's about team ownership…working together as a team." – P2*

5.2.1.2. Variability across services

Participants discussed variability in how individual services and teams approached physical healthcare in routine practice. Some participants in managerial roles identified that they had the confidence to use their personal agency to develop plans locally, whereas others felt they needed more support from strategic leaders to do this. Some participants reflected on variable progress in the approaches to physical healthcare in their localities. All participants recognised the need for localised plans that respond to the needs of the local population, however many noted this could also be a barrier to consistency across the organisation. Enablers included having a more structured and coordinated implementation plan for physical healthcare to ensure consistency between teams, and regular forums for frontline staff and managers to share best practice and develop common solutions.

> *"There's confusion across all the different boroughs, we are all supposed to be doing the same thing, [but] some boroughs have got their own physical health team, others don't, so my confusion is what does the central team do for us? Things like that." – P3*

Most participants reported variability of approach was a barrier in how physical health checks were approached across services which led to an uncoordinated approach to engaging service users and engagement with primary care. Some participants expressed confusion about what physical health monitoring should look like whereas others were confident about what was expected and were keen to develop and share best practice with others.

> *"At the moment we know all the different teams work differently. We're trying to look through the data, see where the good practice is, see where the maybe not so good practice is, and then target those specific areas." – P4*

5.2.1.3. Clinical remit and practice: differences between primary and secondary care services

Participants in frontline clinical roles reported a lack of clarity about which services should be accountable for providing physical healthcare and was largely perceived as the responsibility of primary care. Some participants were concerned that if mental health staff complete physical health checks, aspects may be missed, or primary care may perceive those needs are being addressed in secondary care services when they cannot be. Participants in frontline roles suggested that to mitigate confusion staff in SLaM need to be clear about their clinical remit when providing physical healthcare in routine mental health practice and this should be shared with colleagues in primary care, as well as service users and carers.

> *"I think sometimes the right hand doesn't know what the left hand's doing…the GP thinks mental health services are doing it, the mental health services think the GPs are doing it. I mean, there's an argument…for both sides to do that." - P5*

5.2.2. The use of physical health systems and tools

5.2.2.1. Burden

Most participants in frontline staff roles reported barriers to using multiple processes and systems for recording physical health including capacity, burden, and knowledge. The main concern was a lack of confidence in what data should be recorded, how, why, and where. Most participants felt greater clarity was needed on why these data are collected in mental health services, and how they can be used effectively in mental health care provision and planning.

> *"[Using multiple systems] has increased my personal workload because, every time I see the patients, I go through the physical health, I go through the records, and again it's other issues – so records are not always up to date…so, it increases the workload…I need to screen to make sure the patient has the kind of physical health investigations as they should." - P6*

5.2.2.2. Governance and compliance of physical health data

Governance and compliance of physical health data capture, use and reporting was variable across teams. Some participants in frontline roles commented that the use of multiple systems to capture service user physical health data created difficulties in practice, such as poor integration of and continuity across care records. Some participants in managerial roles reported difficulties in navigating various data systems to report physical health data accurately and to a consistent standard. Streamlined systems or greater interoperability between systems, clearer guidance, training, and refresher training, as well as clear access to support in the event of concerns with data completion or reporting were seen as enablers.

> *"A system that can be put in place to help us prioritise and continue to monitor physical health issues I think that would be helpful as well, because currently we don't really have a system to monitor that and keep track of things." - P7*

5.2.2.3. Quality assurance and reporting

Many participants in frontline roles wanted simpler reporting systems and tools within routine practice to support how they monitor and report on the physical health of their service users. Some participants in managerial roles identified concerns about how to effectively report physical health data and how to support their staff to collect accurate data that can inform good quality reporting processes. Most participants in managerial roles were concerned about quality monitoring and reporting procedures for physical health, for example, many reported issues with reporting effectively upwards and using data to inform improvements in services on the ground.

> *"I think, for me, data's helpful but, unless you've got the context, you can't place it, you can't understand it. You go to any quality and performance meetings at the board level, they want data, but the data is only telling you one side of the story. It's not giving you the barriers or enablers as to why your results are what they are. I think we don't look at the qualitative stuff. I know we're looking at bigger numbers and it's a performance thing, but I think that is a really key part." - P8*

5.2.3. The physical health knowledge and skills of staff

5.2.3.1. Knowledge and skills

All participants were aware of and had completed the mandatory Trust training on physical health but perceived it as limited (both in terms of content covered and duration) and requiring further development if physical healthcare is to be given more prominence in routine practice. Most participants felt role-specific training would ensure specific learning needs are identified and met. Participants in managerial roles identified training on how to manage team approaches to physical healthcare practice would be helpful.

> *"Staff in the community are coming from a different background. It could be nursing staff who know how to do basic things like blood pressure, etc., pulse, respiration, etc. And there are social workers who don't have a clue what we're talking about. …I think, when we target the training, the training should be targeted at different groups in the community mental health team." – P9*

5.2.3.2. Resources

Some participants felt there was a lack of resources (e.g., information, time, and equipment) to support physical healthcare within Trust services. Participants felt physical healthcare could be difficult to prioritise alongside other targets, or when staffing is limited. Some expressed often being without immediate access to key equipment or estates and having to source alternative options to be able to administer physical healthcare. Some participants also sought more accessible information on common physical health problems that could be given directly to patients, such as self-help resources. Participants felt that a central resource with information that could be shared directly with service users and carers would also be helpful to assist with relevant signposting and referrals. Many participants also mentioned the value of existing knowledge from colleagues who were able to share their experiences to support others, whether in their roles, or as champions of physical health.

> *"If we had the staff, if we had the resources…but…because we haven't got the resources…unfortunately, because of low resources and staff shortages, we haven't got enough clinical rooms or substantial volumes of equipment and staff to facilitate more in the way of physical health [alongside routine mental health care]." – P10*

5.2.3.3. Responsibility and accountability

Participants in all roles were interested and motivated to learn more about how to support physical healthcare but there was uncertainty about who was individually responsible or accountable for providing or assuring provision of physical healthcare within the Trust. Some participants in frontline roles recognised their lack of experience in providing physical healthcare but would support provision of it if given appropriate training or support. Enablers identified by participants included: opportunities to continuously review individual understanding and shared responsibilities e.g., through refresher training or skills sharing, and reminders within teams about who is available to support physical healthcare (e.g., champions). For managers there was an interest in establishing a competency framework to support staff and ensure consistent individual competency, and to foster shared accountability within teams.

> *"At the moment we don't formally assess on people's competency on physical health… I think that would help, as long as we provided the training, we provided the opportunities for people to use that, then we can then assess people to say, 'OK, how is it going?' and then that would hopefully give us the gaps that we can try and fill in. That would be good…we do for medication competencies to make sure people are practicing safely, so I suppose that would be a good thing to have." – P11*

5.2.4. Perceptions and attitudes of staff regarding physical healthcare

5.2.4.1. Staff experience of supporting physical healthcare

All participants were highly motivated to support the physical health of their service users. Most participants in managerial roles reported an increase in awareness about physical health problems service users may face and noted a general change in attitude amongst staff to talk more openly about their experiences, to share knowledge, and to support colleagues in day-to-day practice. Most participants in frontline roles were aware of at least one person within their team who was knowledgeable about physical health they would feel confident to approach if they had a question.

> *"I think it's a lot higher on the agenda. I just think that there did need to be additional support to support people with it. I think that that's quite important." – P12*

5.2.4.2. Expectations of role

All participants sought clarity over their role in supporting service user physical health. Many participants in frontline roles reported service users did not seek specific physical health support, and where it was discussed, it was usually regarding issues that arose as a result of a mental health problem e.g., side effects from taking psychotropic medications. As a result, some participants expressed confusion about how much they were expected to know about physical health within their roles. Most participants in frontline roles expressed uncertainty in how to discuss physical health problems with service users as they were not sure what their role was. Some participants in managerial roles also lacked confidence in how to talk about physical health with their staff and how to set clear expectations or give appropriate guidance.

> *"If you haven't done a physical health screen in a year, you might not feel very confident… if it goes off the radar, then the confidence level changes, and then… that can contribute to why somebody might feel a little bit less confident or enthusiastic even about doing a physical health care screen." – P13*

5.2.4.3. Change, maintenance, and sustainability

Participants expressed that change in the way physical healthcare is approached and practiced within CMHTs was needed to improve overall care outcomes. Additionally, most participants reported innovation fatigue with the number of changes to policy, procedure, and practice experienced in recent years. Most participants reported interest in developing physical healthcare interventions and pathways to support physical health but wanted a more coordinated plan from the Trust to be able to do so. Participants in managerial roles suggested a greater focus on maintenance and sustainability of initiatives would better support staff to deliver a consistent model of healthcare more confidently. This could be strengthened with a focus on improvement of existing interventions rather than constant reinvention or major organisational change which tends to be disruptive to staff learning, practice, and service user care.

> *"It would be good to see outcomes from interventions that happen and any sort of changes. I'm sure that sort of thing will be available, reports and things, rather than just numbers going up, but just what that actually means and any feedback from the Trust as a whole about what's been happening, about any changes that we've had and what the differences it makes in outcomes, would be good to see. I think that always helps people to see that it's actually meaningful in every person's life." - P14*

5.2.5. Service user and carer experience of accessing physical healthcare

5.2.5.1. Experience of receiving physical healthcare

Service users and carers reported that in their experience mental health staff are not confident in talking about physical health and this impacted on their confidence to disclose physical health problems, which limited support-seeking for physical health problems when under mental health services. Carers experienced issues with mental health staff not understanding the possible physical health problems that can affect people with long-term mental illnesses, and as a result most carers said they would not direct physical health support enquiries to a mental health practitioner.

> *"Well, if it's a lot of physical health issues, obviously they're out of scope; they don't have experience; they don't know. They don't want to give advice. They don't have enough experience and enough knowledge for certain physical health, so they can't give that advice for it. So, what they'll do is they'll discuss with myself, or the doctor, and we'll discuss with the GP to make a plan or signpost us away from secondary care services." - P15*

5.2.5.2. Knowledge about available services and how to access them

Service users did not perceive mental health Trusts as providers of physical healthcare. They would seek advice from their GP if they had a physical health problem.

> *"…it's about continuity - where primary care or the GP have a similar level of knowledge to what SLaM do, I think there is a huge disparity. GPs largely seem to be the physical health experts, SLaM largely seem to be the mental health experts, and never the twain shall meet, which is usually problematic for service users navigating through an already complex system." – P16*

Service users did not expect to receive physical health support from their mental health team and wanted to know what support was available. Service users were concerned that the physical health data captured by their CMHT was not currently being used to inform their care, or additional support they may be entitled to access. All service users said if they were better informed, and more involved in their care, they may have a better understanding of what support is available and how they can access it.

Carers conveyed frustration that physical and mental health needs are separated and accessed via different services. Carers suggested it would be helpful if secondary care services had knowledge of how to check for signs of poor physical health amongst adults with SMI and could give guidance on how to prevent symptoms worsening. Carers said if they knew what support was available within secondary care, they too could encourage service users to ask for it or to enquire on their behalf.

5.2.5.3. Expectations for the future

Overall, service users wanted more clarity about what physical healthcare was available from secondary care, how this could be accessed, and how this could support their care outcomes. Carers sought greater ownership and transparency from secondary care about what they provide, and better communication with service users about options to access, or to review it.

> *"I was told recently that I'm very anxious - that was news to me, and I couldn't relate. I'm beginning to notice that physically more within my body and was realising the struggle to get into the day…I'm feeling strange and unsettled. I introduced that to the mental health side, and it's like, 'that's trivial.' I mentioned it to the GP, and it's again trivialised, not connected with. The broader thing is, you've got mental health, so the physical health impact isn't taken into account. It's not coordinated at all, it's kind of clunky." – P17*

All service users and carers agreed integrated care was important for the future of mental health services and wanted clarity about what this means in everyday practice.

6. Discussion

In this service evaluation we found that there was high staff motivation to support the physical healthcare of adults with SMI, but staff wanted more clarity about the Trust's vision and strategy, and importantly, how this aligns to their roles and should benefit service user care. Staff had clear views of what would support them including clear operational guidance, a comprehensive training programme, clarity around roles and responsibilities, clear physical health leadership, and collaboration from colleagues. Staff also wanted to feel part of decision-making about physical health and to contribute to a best practice approach across the organisation. Our findings add to existing research. For example, we identified the impact on staff of having unclear guidance, limited knowledge, and a lack of resources when administering physical healthcare, building upon the findings of Small (2017) (2) and Gray (2017) (3). We also found staff experience burden when they perceive themselves as lacking in confidence or without appropriate skills to practice physical healthcare which echoes the work of Papachristou et al. (2019) (4). Yet our findings go further and show the need for clearer leadership in physical healthcare, supported by structures that facilitate a culture anchored in robust training and policy. Work by Belling (2011) (16) has shown consideration of culture and leadership when implementing change influences staff attitudes and practice, indicating this as a valuable finding from our study.

Service users did not expect mental health providers to offer physical healthcare but wanted a more integrated and coordinated approach across primary and secondary care and sought clarity on exactly what physical health support CMHTs could offer alongside their GP. Carers stressed the need for transparency with the service user about what physical health information is being collected, how this will support their care, and how they can be involved in using that information to support care planning and improvements in practice. A recent review suggested the views of service users towards interventions to screen for and treat physical healthcare problems in secondary care are largely overlooked in research and could be hindering effective implementation in practice (17). This review reported that authentically including service users in physical healthcare evaluation can support policy being implemented in a tailored way that truly meets the needs of service users. Moreover, there is a need to communicate better with service users about their physical health, what they can expect to receive from services and how this will support their journey of care.

For carers, we identified similar findings to the studies conducted by Onwumere (2018) (8), regarding the burden of poorly coordinated care being passed onto carers. However, our findings went further, as carers in our study wanted to be informed by healthcare providers about what care options are available. Carers felt having the opportunities to convey their needs was vital, and wanted clarity over available support, as well as better coordinated and equitable care for their loved ones. They felt that that the absence of this hindered the experience, care, and recovery of the service user they were supporting.

More coordinated and integrated care is the aim of the Community Mental Health Transformation Programme (18). However, a recent paper by Hannigan et al. (2018) (19) suggested healthcare providers need to consider what their expectations are for improved coordination and how changes in policy play out in routine practice if it is to be achieved sustainably. This review of mental health policy in practice showed effective care coordination across primary and secondary services can be achieved through strong communication, collaborative working, and training. It is, however, time consuming and resource dependent which can often lead to strain on staff, resulting in outcomes such as fatigue, withdrawal, or resistance towards original change ideas or policy. This is key as poor implementation of policy not only leads to poor adoption from staff, but ultimately hinders practice that impacts service user care. Our findings reflect this thinking, as the Trust's staff shared their frustrations with constant change, and wanted a focus on the maintenance and sustainability of interventions. Beyond this, international partners in mental health are also questioning the implications of physical health problems being unaddressed amongst the SMI population (e.g., Wright-Berryman et al., 2017) and suggest integration of physical and mental health services could foster greater opportunities for collaboration, improved policy, and practice for SMI patients.

Overall, the broader context for staff, service users, and carers concerned the general approach of the organisation towards physical healthcare, and how this was shown in the vision, strategy, policy, culture, organisational leadership, and adoption of change initiatives within individual services. For example, staff expressed the need for greater support for leaders and managerial staff to enable them to guide and support their teams and work with partner organisations to deliver good quality physical healthcare. Equally, team leaders, managers or supervisors identified a gap in their own knowledge and practice when supporting frontline staff to realise the organisations vision for physical healthcare and to make appropriate decisions in routine practice. A study by Singh (2000) (20) highlighted the significance of having clarity of purpose, a shared vision and frequent review of team operations to achieve effective team cultures, behaviour, and outcomes. This paper shows that if secondary care services plan to support the physical health of service users, greater consideration is needed by the organisation towards the implementation of that vision, and the culture, processes, and systems required to ensure good quality physical healthcare.

6.1. Strengths and limitations

6.1.1. Strengths

The research team's diverse membership of clinicians, researchers, and experts by experience enabled greater collaboration over research design and delivery. The involvement of the evaluation team ensured a range of perspectives (including that of clinicians, academics, and service users) informed decision-making throughout the evaluation process - including in setting up the scope and aims of the work jointly with the Trust at the onset of the evaluation, which enhanced the utility of the findings. High engagement from staff, service users, and carer participants enabled the researchers to select from a large pool of interested participants from a range of different professional roles. This meant that there was a healthy sized sample for this qualitative study, which was both professionally diverse amongst the staff participants, and demographically diverse amongst service user and carer participants. As a result, we were able to conduct all planned interviews and focus groups and obtain rich and varied experiences based on current practices in adult CMHTs.

6.1.2. Limitations

16 staff participants declined to complete the demographic questionnaire provided, which means that despite our efforts to pre-select a demographically diverse sample, we are unable to accurately report this. Therefore, we are unable to determine how representative our final sample is of staff working within the Trust. Further, due to the nature of the methods used, we are unable to generalise beyond the context of the services and participants who took part in this work.

6.2. Implications for policy

These findings show potential gaps in guidance on how physical healthcare is being approached within community services. In 2014, NICE set out recommendations for the completion of physical health checks in secondary care services. Yet the findings of this study suggest our understanding of what is required and how it should be delivered has evolved since this guidance was published. There is therefore a question of whether additional guidance is required to support mental health Trusts in their approach to physical healthcare, both in the interventions they provide but the follow-up care that is offered to service users as well. Moreover, in light of the recent transformation of CMHTs across England, this could be an opportunity to consider how guidance on physical healthcare applies and if basic checks are sufficient to support service users in the future.

6.3. Implications for clinical practice

To improve the experience of staff, service users and carers, the vision regarding physical health needs to be better communicated and understood. There needs to be better training for staff, more clearly defined roles and responsibilities, and greater opportunities for staff, service users and carer involvement in defining how physical health is supported. The research team aims to support the Trust with this using Implementation Science methodologies that help with change management. These methodologies could also be helpful for other Trusts.

6.4. Implications for research

The findings could be used to explore whether similar themes are true and generalisable to other Trusts that offer mental health services. The research team aims to use the findings from this evaluation to develop a framework that could support the Trust to consider physical healthcare practice in community settings. Further research could be completed to evaluate the use and impact of this framework in other Trusts to support a more consistent approach within CMHTs generally and contribute to a wider body of work developing nationally and internationally on this subject. Future research could also explore attitudes and expectations of staff in primary care to understand that perspective and inform improved integrated care. Importantly any future research must prioritise the involvement of staff, service users and carers to ensure their experiences are embedded into and inform future initiatives.

7. Conclusion

Mental health staff recognise and are motivated to provide support for the physical health of adults living with SMI. The findings presented in this paper provide insight into common barriers and facilitators faced by staff, service users, and carers when providing or accessing physical healthcare within adult CMHTs. This evaluation has led to a better understanding of the physical healthcare experiences of service users and will help to develop more effective ways to improve them. Moreover, we have explored the role of mental health staff and what may need to change for them in how they work within teams, and how they interact with other parts of the organisation to improve physical healthcare for people with SMI. The findings indicate that what is needed is a more comprehensive and sustainable approach to physical healthcare provision in CMHTs.

Data availability statement

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

Ethics statement

This study was reviewed and approved by the Clinical Governance Committee and Information Governance Committee at South London and Maudsley NHS Foundation Trust. The patients/participants provided their written informed consent to participate in this study.

Author contributions

GT, JW, RM, FG, NS: designed the service evaluation. GT: undertook all data collection with support from JW, RM, JT and LO. Analysis was undertaken by GW, JW, RM with support from ES, NS, FG, NSt, JT and LO. The manuscript was written by GT and JW with comments from RM, NS, FG, ES, SC, NSt, JT and LO. All authors contributed to the article and approved the submitted version.

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Conflict of interest

NS is the director of the London Safety and Training Solutions Ltd, which offers training in patient safety, implementation solutions and human factors to healthcare organisations and the pharmaceutical industry. The other authors have no conflicts of interest to declare.

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Publisher's note

Supplementary material

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References

1. John A, McGregor J, Jones I, Chim Lee S, Walters JTR, Owen MJ, et al. Premature mortality among people with severe mental illness — new evidence from linked primary care data. *Schizophr Res.* (2018) 199:154–62. doi: 10.1016/j.schres.2018.04.009

2. Small N, Brooks H, Grundy A, Pedley R, Gibbons C, Lovell K, et al. Understanding experiences of and preferences for service user and carer involvement in physical health care discussions in mental health care planning. *BMC Psychiatry.* (2017) 17:138. doi: 10.1186/s12888-017-1287-1

3. Gray R, Brown E. What does mental health nursing contribute to improving the physical health of service users with severe mental illness? A thematic analysis. *Int J Ment Health Nurs.* (2017) 26:32–40. doi: 10.1111/inm.12296

4. Papachristou Nadal I, Cliffton C, Chamley M, Winkley K, Gaughran F, Ismail K. (2019). Exploring healthcare professionals' perspectives of barriers and facilitators to supporting people with severe mental illness and type 2 diabetes mellitus. *Health Soc Care Commun.* 28(2):690–7. doi: 10.1111/hsc.12903

5. Butler J, de Cassan S, Turner P, Lennox B, Hayward G, Glogowska M. Attitudes to physical healthcare in severe mental illness; a patient and mental health clinician qualitative interview study. *BMC Fam Pract.* (2020) 21:243. doi: 10.1186/s12875-020-01316-5

6. Owens C, Crone D, Kilgrour L, El Ansari W. The place and promotion of well-being in mental health services: a qualitative investigation. *J Psychiatr Ment Health Nurs.* (2010) 17(1):1–8. doi: 10.1111/j.1365-2850.2009.01480.x

7. Hughes E, Gray R. HIV Prevention for people with serious mental illness: a survey of mental health workers' attitudes, knowledge and practice. *J Clin Nurs.* (2009) 18:591–600. doi: 10.1111/j.1365-2702.2007.02227.x

8. Onwumere J, Howes S, Shiers D, Gaughran F. Physical health problems in people with psychosis: the issue for informal carers. *Int J Soc Psychiatry.* (2018) 64(4):381–8. doi: 10.1177/0020764018763684

9. NICE. Psychosis and schizophrenia in adults: prevention and management [CG178], Psychosis and schizophrenia in adults: prevention and management (nice.org.uk) (2014).

10. Twycross A, Shorten A. Service evaluation, audit, and research: what is the difference? *Evid Based Nurs.* (2014) 17(3):65–6. doi: 10.1136/eb-2014-101871

11. SLaM (2022, November 7th). About us. South London and Maudsley NHS Foundation Trust. https://slam.nhs.uk/about

12. SLaM (2022, November 29th). 2021–2022 Workforce Equality and Diversity Report. https://slam.nhs.uk/equality-reports

13. Dawson S, Banister K, Biggs K, Cotton S, Devane D, Gardner H, et al. Trial forge guidance 3: randomised trials and how to recruit and retain individuals from ethnic minority groups—practical guidance to support better practice. *Trials.* (2022) 23:672. doi: 10.1186/s13063-022-06553-w

14. SLaM (2022, November 29th). Meeting the Public Sector Equality Duty at South London and Maudsley NHS Foundation Trust: 2021/2022 Trust-wide Equality Information Report. https://slam.nhs.uk/equality-reports

15. SLaM (2022, November 7th). Aiming High, Changing Lives (2021-2026). South London and Maudsley NHS Foundation Trust. https://slam.nhs.uk/strategy

16. Belling R, Whittock M, McLaren S, Burns T, Catty J, et al. (2011). Achieving continuity of care: facilitators and barriers in community mental health teams. *Implementation Sci* 6(23):1–7. doi: 10.1186/1748-5908-6-23

17. Tabvuma TS, Stanton T, Browne G, Happell B. Mental health consumer's perspectives of physical health interventions: an integrative review. *Int J Ment Health Nurs.* (2022) 31:1046–89. doi: 10.1111/inm.13000

18. NHS England (2019). The Community Mental Health Framework for Adults & Older Adults [v1.0]. https://www.england.nhs.uk/publication/the-community-mental-health-framework-for-adults-and-older-adults/

19. Hannigan B, Simpson A, Coffey M, Barlow S, Jones A. (2018). Care coordination as imagined, care coordination as done: findings from a cross-national mental health systems study. *Int J Integr Care*, 18(3):12, doi: 10.5334/ijic.3978

20. Singh SP. Running an effective community mental health team. *Adv Psychiatr Treat.* (2000) 6(6):414–22. doi: 10.1192/apt.6.6.414

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Patient satisfaction in inpatient psychiatric treatment compared with inpatient equivalent home treatment in Germany: an in-depth qualitative study

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Background: Inpatient treatment (IT) is the predominant form of psychiatric care in Germany and worldwide, whereby forms of psychiatric treatment have mainly evolved in the direction of home services. Inpatient equivalent home treatment (IEHT) is a new and additional pillar of psychiatric acute care provision legally embedded since 2018 in Germany.

Objective: The aim of this study was to conduct an in-depth exploration as little qualitative research has been performed so far in Germany to examine possible differences in patient satisfaction with IT compared with IEHT.

Methods: In the current qualitative study, $N = 9$ patients of a German hospital providing IT and IEHT were interviewed with the problem-centered interview. Inclusion criteria were IT or IT with subsequent IEHT. The theoretical sampling method was applied to select test persons in the research process. The experiences of the participants during their psychiatric treatment were analyzed using a qualitative content analysis.

Results: The results of both types of psychiatric treatment refer to different satisfaction factors during the treatment period. The function of fellow patients, the setting of the treatment, the conditions in place, and the relationship to relatives turn out to be pivotal for patient satisfaction. In addition, the quality of the therapy and relationship to caregivers itself can have an impact on patient satisfaction, particularly by shared decision making. During the IEHT, patient satisfaction can be strengthened by the possibility to handle daily tasks, to be close to relatives, while not so close to fellow patients, whereas IT patients are mostly satisfied because of the distance to their everyday life and the closeness to fellow patients. The choice of the form of psychiatric treatment according to the individual needs of the patients seems to be one key driver that can in turn increase patient satisfaction. In addition, a clean and hygienic environment seems to be critical for our respondents as a lack of it is one of the reasons to drop out of treatment.

Conclusions: Despite its limitations, this hypothesis-generating study is one of the first investigating German IEHT in comparison with IT in an in-depth qualitative approach contributing to a patient-oriented and cost-effective psychiatric treatment. Although hospitals are highly complex organizations and therefore not directly comparable, other German and international providers of IEHT may derive several generic success factors from this study for the development and improvement of patient satisfaction.

KEYWORDS

home treatment, psychiatric inpatient treatment, psychiatric inpatient equivalent home treatment, patient satisfaction, qualitative study

1. Introduction

Inpatient treatment (IT) is still the predominant form of psychiatric treatment, but in the last decades, it has mainly evolved in the direction of home treatment (HT) (1–5). According to the recommendation of international and national guidelines (6–8), many high-income countries have successfully implemented outreach mental health services for acute psychiatric care. In 2018, a new German law enabled national mental healthcare providers to implement team-based crisis intervention services on a regular basis, allowing for different forms of inpatient equivalent home treatment (IEHT) (9–11). The German IEHT is in parts related to the internationally known home treatment or crisis resolution teams (CRT). It provides acute psychiatric treatment with a similar intensity and flexibility to IT, but delivered in the home of the users by mobile, multi-professional, and permanently available teams (e.g., from nursing care, ergotherapy, psychotherapy) (12). The key elements are daily home visits, medical rounds by mental health specialists, regular multi-professional team meetings, and a round-the-clock availability of the team or the hospital (13). The patients in Germany receive IEHT either as alternative or following an IT (10). Moreover, in adherence to the systemic therapeutic approach (14), close relatives are integrated as well into the IEHT (15).

Due to the short time period since the legal implementation of IEHT in Germany, there is a lack of detailed evaluation. Although there exist several studies on patient views (16, 17), as well as systematic reviews (18) on HT and CRT from other countries, their evidence is for limited use as IEHT is a unique construct within the German healthcare system and fulfills only some of the internationally defined criteria for HT or CRT (19). It differs, for example, from HT in Great Britain as it is less flexible and requires at least one personal contact with the users per day, cannot be gradually phased out, and is associated with strict criteria for reimbursement. Moreover, it cannot be compared with the assertive community treatment as these services have been constructed for long-term support, in contrast to the limited scope of IEHT, which is restricted for acute crisis (18–20).

To the best of our knowledge, there exist currently only two published German studies on this topic based on one data set. The first published study is the one of von Peter and colleagues (21) exploring IEHT on patients, informal caregivers, and staff in 12 psychiatric hospital departments. In their mixed-method process evaluation, the authors found that the evaluations of the patients were largely influenced by the advent of continuous forms of care, better accessibility, and by their degree of autonomy in steering of their services. Specifically, their qualitative analysis (21) did show that the patients valued IEHT for its potential to deal with “embedded and real-life problems,” instead of receiving treatment “in a greenhouse” (on a ward), perceived to be “normalizing and de-stigmatizing” although at the risk of having the potential to “disrupt a person’s or family’s privacy” (21, p. 9). Moreover, continuity of care was highly valued and being experienced as leading to “more trustful relationships” between staff, patients, and their families as well as to a “more solid and nuanced understanding” between them. Also, autonomous steering of services and flexible care management were both perceived to lead to more “need-adapted forms of treatments.” Being able to “choose ones’ own treatment setting” was perceived to increase “personal empowerment” (21, p. 9). The same research group published more details of the qualitative part of their study with $N = 13$ patients in a German journal (22): IEHT seems to strengthen the integration of the everyday life of the patients and the treatment flexibility as it is more focused on the individual needs of the patients. Also, the quality of therapy was perceived, e.g., more on “eye level” with the therapist, and therapy time was sensed more intensively. After having experienced IEHT once, the patients generally rated it better. The disadvantages named by the patients were, e.g., the lack of daily structure, lack of contact with fellow patients, and being alone with themselves. Moreover, both family members and patients experienced the therapists being in their homes, in some cases, as “crossing a border” (22, p. 4–5).

The study protocol by Baumgart and colleagues (19) describes a similar research aim: a naturalistic, quasi-experimental cohort study to evaluate IEHT in 10 German hospitals within a multi-method research approach to evaluate the experiences of the stakeholders of care, service use, efficacy, costs, treatment processes, and implementation processes of IEHT from different perspectives. However, the results of this study are not published yet. A further interesting study protocol is the one of Reinke and colleagues (23). In their randomized controlled trial, IEHT with peer support (i.e., the people with lived experience of a mental illness are trained to support others on their way toward recovery) is compared with IEHT without peer support within a network of eight psychiatric clinical centers in Germany. The authors (23) give also an overview of studies on peer support in psychiatric care with promising results for patient-reported outcomes (PROs).

An older German quantitative study on a model project—before the new German IEHT law was introduced in

2018—comparing patient satisfaction in adolescents with mental illness and their parents in IT and IEHT concludes that adolescents are more satisfied with the IT compared with patients with IEHT. However, the adolescents with treatment experience of both IEHT and IT report significantly higher satisfaction with IEHT compared with preceding IT (24), similar as in (22).

Nevertheless, as more and more psychiatric departments in Germany and worldwide are expected to include forms of IEHT into their treatment options, evidence on its effectiveness, i.e., also on PROs (25), are of high relevance (18) for their acceptance. Batbaatar and colleagues (26, 27) conclude in their systematic reviews that patient satisfaction is a crucial and multidimensional PRO and a widely measured indicator in the evaluation of healthcare service quality as the patients have contributor, target, and reformer roles in quality assurance. The results of patient satisfaction surveys allow the healthcare providers to identify problems and service factors that need improvement. It also enables the policymakers to understand the needs of the patients and, consequently, to make strategic plan for effective and better-quality services, e.g., improves service management and behavior of health professionals. Moreover, a high level of satisfaction results in the decision of the patients to choose a health service and to have an intention to return to a particular hospital (26).

Furthermore, a higher patient satisfaction with healthcare services changes the behavioral intentions of the patients, such as compliance with the doctor's recommended treatment and appointments to follow-up, which results in better health outcomes (27). Satisfaction may be strengthened through participation opportunities in the decision-making process that match individual preferences (28). However, the strongest determinants of patient satisfaction across studies in the review of Batbaatar and colleagues (27) were the quality of the interpersonal skills and competence of the healthcare providers and the physical environment of the facility, accessibility, continuity of care, hospital characteristics, and outcome. Among them, the interpersonal care quality of the health providers was the essential determinant of patient satisfaction.

In summary, patient satisfaction is seen as an important criterion in the evaluation of (psychiatric) healthcare (29) since an appreciative relationship between patients and caregivers is not only associated with patient satisfaction (24) but seems to be vital for successful treatment results and for utilization of the services (once again).

2. Aim of the study

The forms of IEHT are of high importance in an innovative and cost-effective psychiatric healthcare, and patient satisfaction plays on several levels a significant role for the quality of care and thus for patients' acceptance and utilization of (forms of) IEHT. Since the introduction of the new German IEHT law in 2018, in-depth comparisons of IEHT in contrast to IT are rare in Germany: Although there exists the mixed-method process evaluation of von Peter et al. (21, 22) containing a qualitative part, but they are not comparing IT vs. IEHT and not providing a comprehensive report on their qualitative results. Therefore, the aim of the present study was to close this research gap and conducting in-depth qualitative research to examine possible differences in patient satisfaction from the subjective perspective of two groups of German patients experiencing IT and IEHT.

3. Methods

3.1. Study design

This qualitative study was designed to gain a profound understanding and overview of interpersonal differences in intrapersonal perceptions, experiences, and feelings in connection with the research aim mentioned above. Moreover, a qualitative study is particularly appropriate given that the research topic has been scarcely researched. We chose a descriptive phenomenological research perspective (compare a detailed overview in 30): for an appropriate consideration of subjective meanings, individual interpretations, and the context of actions and opinions as described by the participants. That means specifically, we "describe the phenomena phenomenologically, rather than explaining them" (30). In accordance with this approach, it was decided to conduct semi-structured interviews based on Witzel and Reiter (31) and to apply an inductive qualitative content analysis according to Mayring (32).

The authors of this paper are following the Standards for Reporting Qualitative Research (SRQR) guidelines (33).

3.2. Interview guideline and data collection

The approval for this qualitative study was obtained from the ethics committee of Witten/Herdecke University (Germany) prior to the interviews (application no. 43/2019). In addition, the test persons signed informed consent declarations to participate in the research project. Individual code numbers were assigned to each test person as requested by the ethics committee.

The interview guide was drawn up according to Helfferich (34) with the aim to register individual differences in patient satisfaction with the different treatment forms of IT and IEHT as accurately as possible. The focus in the interview for both groups was, e.g., on positive and negative experiences with therapy, caregivers, fellow patients, and family; also on expectations, recommendations of the form of treatment, suggestions for improvement, etc. (for complete interview guideline, see **Supplementary Material**).

The interviews were conducted based on the "problem-centered interview" that according to Witzel and Reiter (31) takes place, e.g., in the own home of the patients or a room at Witten/Herdecke University (see **Table 1**). The aim of the guideline-based problem-centered interview is an unbiased recording of the individual actions as well as subjective perceptions and processing modes. Its main features are the following: (1) narrative-generating communication strategies including conversation starters, guiding questions, and *ad hoc*

TABLE 1 Sample description.

	Inpatient treatment (IT)	Inpatient equivalent home treatment (IEHT)
Female	4	5
Male	0	0
Range of age	20–30	30–65
Duration of therapy	Between 3 and 51 days	Between 11 and 38 days
Average interview duration	55 min	70.8 min
Diagnoses	Obsessive-compulsive disorder, recurrent depression, combined personality disorder, bulimia	Schizoaffective disorder, psychosis, depression, anxiety and panic disorder, complex PTSD, eating disorder, ADHS

PTSD, post-traumatic stress disorder; ADHS, attention deficit/hyperactivity syndrome.

questions and (2) comprehension-generating communication strategies allowing, e.g., for reflections back to the statements of the interviewees, comprehension questions, and confrontations in case of contradictions and/or evasive answers.

From 13 August to 26 November 2019, the interviews were conducted and recorded on audio equipment. The study persons were offered subsequent support by their therapists in the IT/IEHT in case of distress caused by the interview.

3.3. Recruitment of test persons

As a part of our inclusion criteria, we recruited people who had utilized IT or IT with subsequent IEHT at least once, were of the age of legal majority, able to speak and read the German language, could furnish written consent to participate, and had a physical and mental condition permitting conversation. The theoretical sampling method (35) was applied to select test persons in the research process. This means that first interviews provided indications of more or less satisfied patients who were then successively included in the study. This heterogeneity of patient satisfaction was meant to ensure increased information value. However, during recruitment, only the female respondents expressed interest to participate in the research project, and therefore, the sample was kept homogenous regarding gender throughout. The test persons were recruited via a notice board in the hospital and also via caregivers, who were informed prior by NA about the study, its aims, and the inclusion criteria.

The aim was to recruit $N = 14–16$ test persons for this qualitative study, but despite great efforts, only $N = 9$ female individuals indicated their interest in the research project (see **Table 1**). As a result, data saturation could not be ensured as we could only recruit female patients, thus missing data from a male perspective.

3.4. Sample description

The sample examined consists of nine women aged between 20 and 61 years, five of whom report experience with IEHT (and prior IT experience) and four with IT (without IEHT experience) of approximately the same treatment duration (see **Table 1**). No further sociodemographic data are reported here to preserve the anonymity of the participants.

3.5. Qualitative analysis

The interviews were fully transcribed using the transcription scheme of Dresing and Pehl (36). Data analysis was done with the German transcripts, and only the selected citations for the results section were translated into English, whereby the first authors did doublecheck its accuracy.

An inductive data analysis was performed using the qualitative content analysis method according to Mayring (32). That means, that the first author (NA) began by identifying text passages relating to the topic that were subsequently summarized and paraphrased to reduce data material to a practicable proportion without altering the main content. The main categories and subcategories were created successively and filled with quotations from transcribed interviews. The category system drawn up in this way was then applied to the entire data set to ensure a coherence of results.

The other first author (MN) conducted the same analyzing steps, and the last author (FE) independently reviewed the analyses of the first authors and conclusions. This involved careful review of the transcripts, themes, and results to ensure accurate formulation of conclusions from the individual interview data (investigators triangulation) (37). All disagreements over conclusions were intensively discussed in a group setting and adequately resolved. All authors were trained and experienced in qualitative data analysis as well as conducting and publishing qualitative research.

3.6. Personal reflexivity

A research based on a qualitative methodology recognizes the importance of locating and highlighting the central opinions informing the research process according to the Standards for Reporting Qualitative Research (33) and the APA Style JARS (38). Moreover, as we chose a descriptive phenomenological research perspective, reflexivity of the authors is especially of high importance.

This paper has been heavily informed by the standpoint of the first authors (NE and MN). The role of the last author (FE) was rather to assist the other authors throughout the research process and to also reflect and critically engage in their relationship and motivation for conducting the study and assess the ways in which it has informed the study aims, design, and analysis.

The two first authors (NA and MN) are both clinical psychologists and experienced qualitative researchers at the University of Witten/Herdecke, Germany. MN is also adequately skilled in qualitative evaluations and quantitative research and has practical knowledge in the German healthcare system due to her work as a nursing assistance for several years. Before the research project started, NA worked for a few months at the investigated ward/hospital, and MN had no prior connection to the research field. The last author (FE) is a neurologist and a qualitative and quantitative researcher with practical knowledge in the German healthcare system due to his work as a physician for nearly 30 years. He had no prior connection to the research field.

4. Results

The following sections describe the main and subcategories, and **Figure 1** provides a graphical overview of the results.

4.1. Satisfaction with the physical environment

Design factors of the physical environment constitute an important element of patient satisfaction when analyzing data obtained from the respondents.

4.1.1. Facility

A warm, welcoming and comfortable design of the IT setting seems to be important to test persons:

> … well, because this is […] a hospital where you go. And that […] it should […] convey a sense of warmth despite the circumstances. Some sense of welcome (I5 receiving IT and IEHT, p. 10 l237–240).

The test persons criticized that the ward design should more be adapted to their need, e.g., window grids in particular are seen as “unhomely” and evoke feelings of being imprisoned. In contrast, the test persons in IEHT are in charge of designing their own home.

4.1.2. Hygiene and cleanliness

A clean and hygienic environment contributes as well to the sense of well-being of the test persons, and a lack of it is one of the reasons to drop out of treatment. On the other hand, an exaggerated cleanliness can impair the sense of normality.

Regular visits from the caregivers in the context of IEHT induce the test persons to pay more attention to cleanliness and order at home and to “arrange things nicely for themselves as well” (I9 receiving IT and IEHT, p. 10 l249), so that “you feel more at ease” (I5 receiving IT and IEHT, p. 10 l249).

4.1.3. Atmosphere

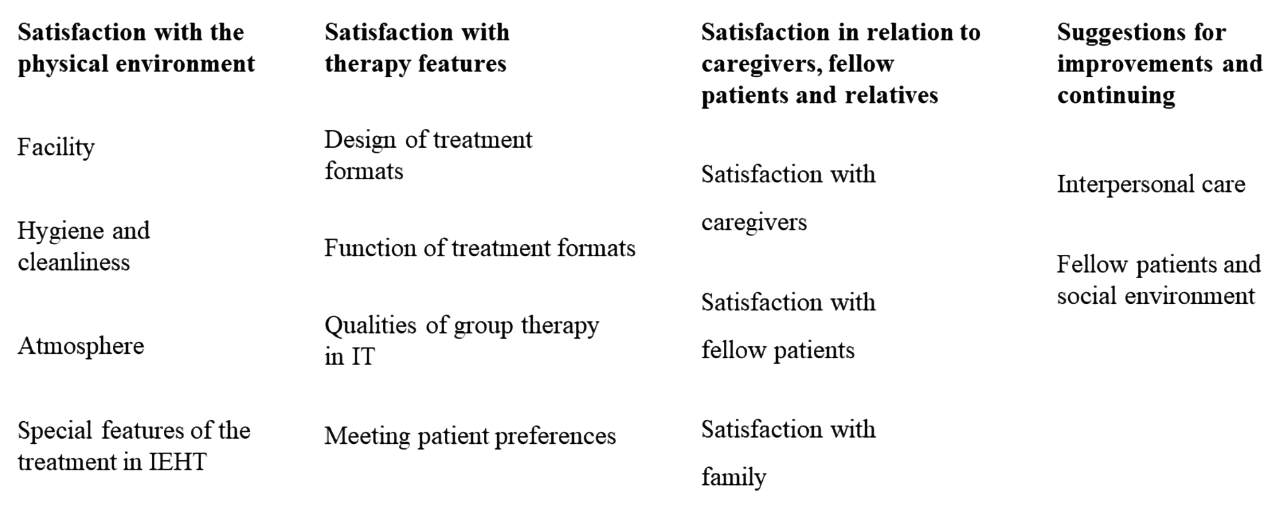
The atmosphere in IT is positively impacted by cleanliness, hygiene, a freshly renovated ward, and a relaxed climate:

> But the people there and the social encounters made it better. The outward appearance of the clinic […], they have these cozy sitting areas, quite comfortable […] really help to create a relaxed atmosphere (I6 receiving IT, p. 5, l. 120–123).

Informal gatherings for shared meals are mentioned specifically as valuable and a quiet ambiance is much appreciated on these occasions.

On the other hand, own pressure of expectation of a test subject can lead to a tense atmosphere at home (in IEHT):

> … this additional pressure, so that I think: Okay, this is something I want. So, I must […] become actively engaged. This means “creating framework conditions” so that my life and home circumstances will have the lowest possible



Satisfaction with the physical environment	**Satisfaction with therapy features**	**Satisfaction in relation to caregivers, fellow patients and relatives**	**Suggestions for improvements and continuing**
Facility	Design of treatment formats	Satisfaction with caregivers	Interpersonal care
Hygiene and cleanliness	Function of treatment formats	Satisfaction with fellow patients	Fellow patients and social environment
Atmosphere	Qualities of group therapy in IT	Satisfaction with family	
Special features of the treatment in IEHT	Meeting patient preferences		

FIGURE 1
Overview of main categories and their subcategories.

> negative impact on the therapy situation […] or the therapy conversation. This has put me under a lot of pressure (I7 receiving IT and IEHT, p. 17–18, ll. 442–446).

On the IEHT ward[‡] the breakfast atmosphere depends on the fellow patients present and on their mood. The respondents also mentioned the colors and smells on that ward helping to create a warm and welcoming impression.

4.1.4. Special features of the treatment in IEHT

“There is no place like home” (I3 receiving IT and IEHT, p. 4, l. 76): This is where the test persons generally feel good, “more familiar” (I4 receiving IT and IEHT, p. 3, l. 70), not cut off from their usual surroundings, and freer. Or they plan to create their own home, where there are fewer places with negative associations:

> … when I was really ill, I was on the intensive ward and was not permitted to leave […], but whenever I saw that door [entrance to the intensive ward] then I […] always took distance. […] Now it is better (I3 receiving IT and IEHT, p. 21, ll. 515–519).

At the same time, there may be worries to create negative associations in one’s own home:

> …. if now for example there were a trigger somewhere to remind me of my couch at home, then I will later have a problem with my couch (I7 receiving IT and IEHT, p. 15, ll. 372–374).

It may also become challenging to meet the demands of several roles simultaneously in IEHT, such as the roles of the patient and of the mother. Building up a positive relation to the caregivers can help to reduce the stress involved. Nevertheless, the prospect of being accepted into the IEHT program in the near future has a relieving effect on the test subjects.

4.2. Satisfaction with therapy features

This category is frequently connected with the question as to which activities are conducted in which manner and to which purpose in the course of treatment. Therefore, this main category constitutes an important basis for the analysis of patient satisfaction.

4.2.1. Design of treatment formats

In both formats of treatment, invigorating experiences play an important role in the healing process, such as learning new strategies and methods:

> … this is […] valuable, when you see progress and can feel it (I5 receiving IT and IEHT, p. 25, l. 602), I have actually had positive experiences throughout (I5 receiving IT and IEHT, p. 29, l. 709).

Both forms of interventions aim to improve the quality of life, as one possible way toward normality. A clearly formulated and transparent therapy plan helps to achieve this objective. Other supportive elements can be an overview about which therapy targets the individual patient can reach over which treatment period, and a jointly planned schedule for a daily structure. Such a plan offers the test subjects a valuable structure:

> … there also was a very clear professional distance with the clear understanding: Look, these […] are the points we discussed, right from the start, in the preliminary talks, this is what we aim to achieve […]… care was always taken to ensure that (I9 receiving IT and IEHT, p. 6, ll. 144–148).

All the test persons who defined treatment targets in consultation with their caregivers continued the treatment. Self-determined treatment objectives may therefore be assumed to be important factors for successful treatment. Another significant conclusion from the data analysis is that the expectation of positive results of the test persons is frequently associated with the actual treatment results.

4.2.2. Function of treatment formats

The function of IT is to consciously provide a protected space away from the home setting and the opportunity:

> … just to take a step back from daily life and the obligations involved […], […] that you listen to yourself and do something for yourself (I8 receiving IT, p. 12, ll. 284–286).

Where these functions are not fulfilled, the test persons may be inclined to break off the treatment prematurely and be discouraged from resuming treatment at a later time. In contrast, IEHT is rather intended to:

> … make it easier to return home […], not to fall back into old patterns of behavior (I5 receiving IT and IEHT, p. 1, ll. 12,13).

The test persons describe IEHT as a highly individual form of intervention that can be adapted to their personal situation and circumstances. The focus is on the individual to be treated, and IEHT is therefore perceived as an intensive form of therapy:

> … in IEHT you feel positively challenged to work on yourself all the time. You […] need not concern yourself with others

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[‡] There exist rooms for the IEHT in the investigated hospital, because they offer every Friday morning a shared breakfast as an opportunity for exchange between IEHT patients.

> because there is nobody else, I mean no other patients. […] You are very much faced with yourself (I9 receiving IT and IEHT, p. 25 l618–621).

IEHT provides a kind of support that is relevant to everyday life. However, coping simultaneously with daily life and treatment may present a particular challenge. It is therefore essential to keep an eye on the individual degree of challenge of the patients and achieve a positive completion of therapy:

> … the time I was in therapy was more than enough and shouldn't have lasted longer. I think the effect would have been reversed. […] It is too open and too intensive, and then I was really glad to be […] well within the time limit […] because […] it felt like a wound you reopen every day (I7 receiving IT and IEHT, p. 46, ll. 1171–1182).

4.2.3. Qualities of group therapy in IT

Group therapies form part of IT (but not of IEHT) and are perceived as central elements in this treatment format. It enables the test subjects to express their emotions in different ways and switch their thoughts to different things. At the same time, the physical closeness to fellow patients in this setting encourages the impression of being understood, of being not alone:

> There are others who feel the same way, although you would not think so judging them by appearance, people who understand you and, well, who can […] give helpful tips (I8 receiving IT, p. 11, ll. 268–270).

On the other hand, closeness to fellow patients may also cause difficulties in one's own therapy process:

> In group therapies you get an idea of other people's innermost thoughts, and sometimes it is hard to keep your distance and […] remain true to yourself (I8 receiving IT, p. 6, ll. 147–149).

Cancellation of group therapy sessions by the hospital organization is, however, one of the most frequent points of criticism.

4.2.4. Meeting patient preferences

In the context of therapy, a pattern among the test subjects becomes apparent with regard to patient satisfaction: the patients in IT are particularly satisfied when they hope for some degree of freedom from responsibility, when they leave their daily lives behind including the obligations involved, and when they develop a wish to be close to like-minded persons and fellow patients. In contrast, the test persons in IEHT are most satisfied with the option to recover at home in their familiar domestic surroundings and to receive psychiatric care while meeting responsibilities for close persons.

4.3. Satisfaction in relation to caregivers, fellow patients, and family

A third key category in the analysis of differences in patient satisfaction is the relationship with all persons connected to the therapy.

4.3.1. Satisfaction with caregivers

In both treatment formats, the time and effort invested by caregivers and the patients' sense of being appreciated as a human being on a personal level have a favorable effect on patient satisfaction:

> … obviously this […] can only work in a functioning relationship (I7 receiving IT and IEHT, p. 39–40, ll. 1008–1010).

Professionality is mentioned as a specific factor in this context —on the personal as well as the therapeutic level. Both levels are required for good cooperation. IT therapy should offer patients the chance to become actively involved in obtaining their treatment goals, in collaboration with their caregivers. A lack of opportunity for active participation generates discontent in the test subjects and may even induce them to early terminate the treatment. A sense of being abandoned despite the presence of caregivers—for example, due to shortage of time—can also enhance the feelings of dissatisfaction.

IEHT in contrast gives the test subjects the impression of being key agents:

> … this is an entirely different approach […], where the affected person takes the lead, or becomes something like the ordering party […] where affected individuals […] are seen as experts on their own behalf (I7 receiving IT and IEHT, p. 42, ll. 1069–1073).

However, the staff usually rotates in IEHT, so that the patients need to build up relationships to unfamiliar caregivers, and this takes time. This may create a feeling in the patients that they cannot work on their objectives with a maximum of efficiency, which reduces the perceived therapeutic success and degree of patient satisfaction.

Evident dissatisfaction therefore requires that potential problems are openly addressed in both types of treatment in order to keep the patients satisfied and ultimately to ensure successful treatment results.

4.3.2. Satisfaction with fellow patients

Physical proximity to fellow patients is perceived as essential specifically in IT, as their support may enhance patient satisfaction. "True friendships" (I1 receiving IT, p. 5, l. 124)—like in a "surrogate family" (I1 receiving IT, p. 8, l. 184)—may be retained after the hospital stay. The shared experience of a group during the therapeutic process may be a key factor for successful treatment. At the same time, close proximity to fellow patients may have adverse effects on patients:

> … well in some respects it was good to have these contacts to fellow patients, but less so in others because […] certain fellow patients tended to trigger particular behaviors such as self-injury (I6 receiving IT, p. 11, ll. 251–254).

Strong feelings of compassion for others in IT therapy can create additional distress and distract the attention of the patients from tackling their own problems. They may also evoke detrimental thoughts about their personal situation. On the other hand, IT creates physical distance and offers the opportunity to enjoy peace and quiet, which again enhances patient satisfaction. In contrast, contacts with fellow patients in the context of IEHT—in the investigated IEHT ward only on Fridays during a breakfast—are described as comparatively reserved:

> I met fellow patients only once, at that shared breakfast (…). I personally do not need that (I7 receiving IT and IEHT, p. 20, ll. 494, 495).

The greater distance in IEHT results in less compassion with fellow patients. This is one reason why the test subjects in IEHT wish for more contacts with others in the same situation.

4.3.3. Satisfaction with family

IT perceived as challenging can serve to strengthen relations between the test persons and their family members and be used as an occasion to frankly discuss the disorder in question. Frequently, IT is intended to relieve the family:

> … I would not wish to burden my family with this responsibility (I2 receiving IT, p. 9, ll. 224, 225).

In contrast, the patients in IEHT often feel the urge to meet obligations to immediate family or dependents even in stages of illness:

> … therefore, it is extremely valuable for a mother […] to be there for the family and get the help you need yourself (I5 receiving IT and IEHT, p. 28, ll. 693–694).

4.4. Suggestions for improvement and continuing

We found useful suggestions for improvement and continuing on different levels in IT and IEHT, which may contribute to higher patient satisfaction.

4.4.1. Interpersonal care

The IT patients derive specific satisfaction from the proximity and support of fellow patients, and regular offers of group and individual therapies enhance patient satisfaction in general:

> There are people who think the same way, […] who can understand that and […] give tips (I8 receiving IT, p. 11, ll. 267–269)

Thus, there is a wish for sufficient personnel to ensure the provision of such interventions.

In the context of IEHT, the test subjects report specific satisfaction with regular support from their caregivers. They appear to feel most content with caregivers who are familiar with their individual problems, which permits efficient cooperation in the form of personalized assistance and advice. Assigning a permanent and not rotating team to each individual patient might help to reinforce this positive effect:

> … when I really work with one person who […] knows what the problem is around me, that they could help me much more concretely […], then I realized that it would be good if […] two employees would always take care of one patient and not all employees […] of all patients. always take care of one patient and not all employees […] take care of all patients […]. (I9 receiving IT & IEHT, p.18, ll. 431–437)

Particularly gratifying elements, so the test subjects in both types of therapy, are friendly treatment by caregivers, a sense of being taken seriously, and the chance to become actively involved in the therapy process:

> … where you are more the tone setter, or the contracting authority (I7 receiving IT and IEHT, p. 42, ll. 1070–1071)

A therapy plan providing a firm structure in daily life and a jointly drawn-up time schedule to reach individual therapy objectives offer valuable orientation and also contribute to patient satisfaction.

4.4.2. Fellow patients and social environment

Some IEHT respondents wish for more contact with fellow patients and would welcome a wider range of collective activities, for example, after the shared breakfast on Fridays.

> If you could perhaps offer one or two […] talk groups per week, where you could also go if you wanted to. So, on a voluntary basis, if all patients […] could exchange information. Like a self-help group perhaps within IEHT. (I9 receiving IT and IEHT, p. 29, ll. 720–723)

Continued adherence to the daily time schedule in IEHT would also contribute to patient satisfaction and successful therapy outcome because it helps the patients to be better prepared for visits from caregivers. Other ideas to improve IEHT refer to the following:

- The option of a meeting with the persons primarily involved in the therapy after the first half of the treatment period for a joint reflection on relations
- Increased networking with social services such as domestic help or “meals on wheels”
- Employment of more caregivers who have undergone psychiatric treatment themselves (peer support).

Another suggestion is an arrangement with IEHT patients prior to the start of the therapy as to which persons from their domestic environment (e.g., neighbors, acquaintances) should be allowed to know that the visiting caregivers are providing psychiatric care. Here, the idea is to avoid unintentional stigmatization.

5. Discussion

This hypothesis-generating qualitative study on patient satisfaction reveals three crucial differences comparing IT with IEHT. These concern, firstly, the different environments, secondly, the role of fellow patients, and thirdly, the role of family members. IT offers a protected environment away from daily life and the obligations involved, whereas the test subjects in IEHT feel freer and more familiar in their own domestic surroundings. In IT, relations to fellow patients are characterized by special proximity and have a significant supportive effect (due to regular group therapy sessions), whereas the patients in IEHT report a more reserved relationship and less compassion to fellow patients (due to breakfast meetings only on Fridays at the investigated facility) as a result, which can also mean a lower degree of distress and distraction. IEHT is probably perceived as very intensive and individual because contacts with fellow patients are limited. The family members of the patients in IT have less responsibility to bear, whereas the patients in IEHT can meet obligations to family and dependents in their habitual domestic surroundings. In terms of relations to caregivers, both the interpersonal (e.g., relationship, continuity of care) and the professional therapeutic (e.g., shared decision making) levels are described as essential for the quality of collaboration in both types of treatment, for patient satisfaction and ultimately for the treatment success. As a result, the choice of the form of psychiatric treatment according to the individual needs of the patients seems to be one key driver that can in turn increase patient satisfaction, which is similar to the results of (22). A second decisive factor for patient satisfaction in IT is ensuring a clean and hygienic environment as a lack of it is one of the reasons to drop out of treatment in our sample.

Besides these comparative results, the present study corresponds in most aspects to the qualitative research results of the study group of von Peter and colleagues (21) process evaluation: in both studies, the patients perceived IEHT to be normalizing, dealing with problems close to real life, but having the risk to harm private life in different ways. The participants of both studies highly valued continuity of care as leading to more trustful relationships between staff, patients, and family. Also, need-adapted forms of treatments to choose ones' own treatment setting, i.e., shared decision making and active participation, increased patient satisfaction in both studies. Similar to the German published study of the research group of von Peter and colleagues (22), our IEHT respondents perceived the IEHT as more intense and rated it better as IT (compare also 24). Parallel are the named disadvantages as, e.g., lack of contact with fellow patients in IEHT (22).

In contrast to the quantitative study by Kirchmann and colleagues (24), our findings do not allow the conclusion that IT generally creates a higher degree of satisfaction. Rather, the results indicate a need to identify those aspects that are important to the individual patient in order to find the most appropriate type of treatment. The findings from this qualitative study indicate rather—based on their individual circumstances—that the test persons in IEHT seem to report more satisfaction with this type of therapy compared with IT. All the respondents with experience in IEHT had previously undergone IT and consider this experience as valuable, too.

Our analysis also shows that patient satisfaction in IT and IEHT is not only strengthened by a desired level of participation in decision making (28), but also seems to result in early treatment termination when not sufficiently fulfilled. Particularly with regard to staff, it is obvious that the coordination and continuity of treatment also plays an important role in patient satisfaction, while communication with staff is particularly relevant in the short term (39). This is also shown by our results regarding IT. However, we cannot conclude from our results better (mental) health outcomes due to higher patient satisfaction neither in IT nor in IEHT. But we could see that the expectations of the study participants seem to be associated with positive treatment results, which is not commonly found in recent systematic reviews (27).

The results in this qualitative study correspond almost completely to the systematic review of Batbaatar and colleagues (27) where particularly the quality of the interpersonal skills and competence of the healthcare providers and the physical environment of the facility, accessibility, and continuity of care were essential determinants with the highest influence on patient satisfaction. Nevertheless, as mentioned above, a clean and hygienic environment seems to be critical for our respondents as a lack of it is one of the reasons to drop out of treatment.

Beyond that, the participants in our study wished for peer support in their therapy, which corresponds to the study protocol of Reinke and colleagues (23) comparing home treatment with and without peer support.

5.1. Implications for practice

As hospitals and their wards are highly complex organizations, we cannot generalize the results of our study to other German or international hospitals. However, even small studies such as this offer important insights into potential promising practices for the delivery of patient-centered, respectful psychiatric treatment. In addition, due to the similar results of our research to those of the study group of von Peter and colleagues (21, 22) and the systematic reviews on patient satisfaction by Batbaatar and colleagues (26, 27), there seem to exist some generic issues from which German hospitals and caregivers offering IT as well as IEHT may benefit from in order to identify and better utilize existing potentials and strengths. Those are (1) continuity of care resulting in better interpersonal care and improved relationships between patient, caregiver, and family, (2) taking the needs of the patients into consideration to choose their own form of treatment, and (3) shared decision making and active participation between the patient and the caregiver, also in the process of treatment. Considering these generic issues seems to be advisable as a high level of satisfaction results in the decisions of the patients to choose a health service and in an intention to return to a particular hospital (26). However, fulfilling point (1) is currently a very critical issue as staff shortage is one of the biggest problems for all healthcare providers in Germany.

5.2. Strengths and limitations of the study

Certain elements of this study limit the generalization of findings. One potential factor influencing the sample is that the test persons were recruited who might have a higher satisfaction with IEHT and IT. This might bias the heterogeneity of the sample. The same applies to the fact that only women were interviewed about treatment experience. Since recruitment proved to be difficult in view of the sensitive topic explored in the study, all the test persons were included in the sample who met the inclusion criteria and showed an interest in sharing their personal experience with treatment. In line with the theoretical sampling method (35), this dominance of the female gender was therefore transferred to the sample of respondents with IEHT experience to ensure better comparability.

The qualitative, hypothesis-generating, and explorative character of the study calls for due caution in interpreting the results. But this weakness is also a strength since the qualitative approach provides an in-depth and comprehensive view on the experiences of the patients and also encourages openness for unexpected results. Moreover, this is one of the first comprehensive and profound qualitative investigations in Germany to explore and compare patient satisfaction with IT and IEHT. Nevertheless, our study suffers probably from a retrospective and social desirability bias of respondents.

Another point of criticism is the sample size of $N = 9$, which is even small also for a qualitative study. However, it proved impossible to recruit more test persons for the study, because at the time of data collection, the investigated facility had only a relatively small number of patients in IEHT.

A further weakness of our research is that we could not recruit patients with IEHT alone, i.e., without prior experience of IT. This would have added possibly more and interesting information as, e.g., some unknown "basics" are missing when patients have not previously undergone IT.

Nevertheless, the strengths of our study are that data were analyzed by multiple researchers, ensuring investigator triangulation. Moreover, two researchers had a neutral view on the data as they were not involved in the field of IT and IEHT, which is also a strength of this study. Finally, we used an interview technique that was problem-centered, which is a theory-based and long-established scientific interview method.

5.3. Implications for future research

Future research should compare qualitative or mixed-method studies with bigger sample sizes and a higher gender heterogeneity ideally patients in three groups of treatment: IT, IEHT with prior experience of IT, and IEHT without prior experience of IT. However, it seems to be questionable if the test subjects from various psychiatric hospitals and regions in Germany should be summarized in one data set in future studies, as hospital/wards are highly complex organizations and not directly comparable.

Beyond that, a valuable future research, particularly for healthcare practice, would be to accurately identify the different needs of the patients in IT and IEHT in larger samples in order to identify different types of patients. Resulting needs profiles and questionnaires for measuring them (40) in practice might help to better meet the needs of the patients and thus enhance patient satisfaction.

Data availability statement

The data sets presented in this article are not readily available because the authors did not include sensitive transcripts of the qualitative interviews, for the reason that the authors must preserve the anonymity of the study participants according to the German and European Data Protection Law. Requests to access the data sets should be directed to: neleadam@gmx.de.

Ethics statement

The studies involving human participants were reviewed and approved by the ethics committee of the University of Witten/Herdecke, Germany. The patients/participants provided their written informed consent to participate in this study.

Author contributions

Conceptualization, literature research, methodology, and organization of the study: NA and MN; interviews: NA; interpretation of reported studies: NA, MN, and FE; figure preparation: NA; funding acquisition: FE; writing—original draft preparation: NA and MN; writing—review and revising: MN and FE; writing—editing: MN and FE; and writing. All authors gave final approval for all aspects of the work, agreed to be fully accountable for ensuring the integrity and accuracy of the work. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frhs.2023.1195614/full#supplementary-material.

References

1. Weissenau CN. StäB—eine neue Art der Behandlung, nicht nur für unsere Patienten [Ward-equivalent psychiatric treatment—a new kind of treatment, not only for our patients] (2018). Available online at: https://docplayer.org/111154833-Staeb-eine-neue-art-der-behandlung-nicht-nur-fuer-unsere-patienten-dr-n-corpus-weissenau.html (accessed March 28, 2023).

2. Stationsäqusivalente Behandlung [Home Treatment] (without author, 2018). Available online at: https://www.zfp-web.de/news-media/pressemitteilungen/stationsaequivalente-behandlung-auf-einem-guten-weg (accessed March 28, 2023).

3. Karow A, Bock T, Daubmann A, Meigel-Schleiff C, Lange B, Ohm G. The Hamburg-model of integrated care for patients with psychosis: part 2: results of the clinical course over 2- and 4-years of treatment. *Psychiatr Prax.* (2014) 41:266–73. doi: 10.1055/s-0033-1349496

4. Schöttle D, Ruppelt F, Karow A, Lambert M. Home treatment—a treatment model of integrated care in Hamburg. *Psychother Psych Med.* (2015) 65:140–5. doi: 10.1055/s-0034-1390424

5. Vendsborg PB. Community psychiatry in Copenhagen. Services and resource utilization. *Ugeskr Laeg.* (1995) 157:6261–4. (no doi available).

6. NICE. In: Health NCCfM, editor. *Psychosis and Schizophrenia in Adults: prevention and management* [CG178]. London: National Institute for Health and Care Excellence (UK) (2014).

7. Murphy S, Irving CB, Adams CE, Driver R. Crisis intervention for people with severe mental illnesses. *Cochrane Database Syst Rev.* (2012) 16(5):CD001087. doi: 10.1002/14651858.CD001087.pub4

8. DGPPN. S3-Leitlinie Psychosoziale Therapien bei schweren psychischen Erkrankungen. [S3-guideline Psychosocial therapies in severe psychiatric diseases] Berlin, Heidelberg: Springer (2019).

9. Längle G, Holzke M, Gottlob M, GmbH WK. *Psychisch Kranke zu Hause versorgen—Handbuch zur Stationsäquivalenten Behandlung.* [Caring for mentally ill at home—Manual for IEHT] Stuttgart: Kohlhammer (2018).

10. Bühring P. Stationsäquivalente psychiatrische Behandlung: Neues Element zur Flexibilisierung. [Ward-equivalent psychiatric treatment: New element for flexibilization] *Dtsch Arztebl* (2017) 114: A-2132/B-1795/C-1753.

11. Munk I. Stationsäquivalente Behandlung Zur Entwicklungsgeschichte des Begriffs in diesem Netzwerk. [Ward-equivalent treatment: On the development history of the term in this network] (2016). Available online at: https://silo.tips/download/netzwerk-steuerungs-und-anreizsysteme-fr-eine-moderne-psychiatrische-versorgung–3 (Accessed March 28, 2023).

12. Vereinbarung zur Stationsäquivalenten psychiatrischen Behandlung nach § 115d Abs. 2 SGB V vom 01.08.2017, 2020 (2017).

13. Gesetz zur Weiterentwicklung der Versorgung und der Vergütung für psychiatrische und psychosomatische Leistungen (PsychVVG), (2016).

14. Schlippe von A, Schweitzer J. Lehrbuch der systemischen Therapie und Beratung I und II. [Textbook of systemic therapy and counselling I and II]. Göttingen: Vandenhoeck & Ruprecht (2016).

15. Greve N. Home Treatment in Deutschland—Konzepte und Modelle der Gemeindepsychiatrie. [Home Treatment in Germany—Concepts and Models of Community Psychiatry] (2017). Available online at: https://www.dvgp.org/fileadmin/user_files/dachverband/dateien/Doku_Jahrestagung_2017/Pr%C3%A4sentation_Greve.pdf (Accessed March 28, 2023).

16. Stulz N, Wyder L, Maeck L, Hilpert M, Lerzer H, Zander E, et al. Home treatment for acute mental healthcare: randomised controlled trial. *Brit J Psych.* (2020) 216:323–30. doi: 10.1192/bjp.2019.31

17. Lloyd-Evans B, Osborn D, Marston L, Lamb D, Ambler G, Hunter R, et al. The CORE service improvement program for mental health crisis resolution teams: results from a cluster-randomised trial. *Brit J Psych.* (2020) 216:314–22. doi: 10.1192/bjp.2019.21

18. Wheeler C, Lloyd-Evans B, Churchard A, Fitzgerald C, Fullarton K, Mosse L, et al. Implementation of the crisis resolution team model in adult mental health settings: a systematic review. *BMC Psychiatry.* (2015) 15:74. doi: 10.1186/s12888-015-0441-x

19. Baumgardt J, Schwarz J, Bechdolf A, Nikolaidis K, Heinze M, Hamann J, et al. Implementation, efficacy, costs and processes of inpatient equivalent hometreatment in German mental health care (AKtiV): protocol of a mixed-method, participatory, quasi-experimental trial. *BMC Psychiatry.* (2021) 21:173. doi: 10.1186/s12888-021-03163-9

20. Nugter MA, Engelsbel F, Bähler M, Keet R, van Veldhuizen R. Outcomes of FLEXIBLE assertive community treatment (FACT) implementation: a prospective real life study. *Community Ment Health J.* (2016) 52:898–907. doi: .org/10.1007/s10597-015-9831-2

21. von Peter S, Ignatyev Y, Johne J, Indefrey S, Kankaya OA, Rehr B, et al. Evaluation of flexible and integrative psychiatric treatment models in Germany: a mixed-method patient and staff-oriented exploratory study. *Front Psychiatry.* (2019) 22:785. doi: 10.3389/fpsyt.2018.00785

22. Schwarz J, Zeipert M, Ignatyev Y, Indefrey S, Rehr B, Timm J, et al. Implementierungsstand und erfahrungen der stakeholder mit der zuhause-behandlung in psychiatrischen modellvorhaben (nach §64b SGB V)—eine mixed-methods untersuchung [implementation and stakeholders' sxperiences with home treatment in Germany's Integrative and flexible psychiatric care models—a mixed-methods study]. *Psychother Psychosom Med Psychol.* (2020) 70:65–71. doi: 10.1055/a-0942-2163

23. Reinke B, Mahlke C, Botros C, Kläring A, Lambert M, Karow A, et al. Study protocol of a randomized controlled trial evaluating home treatment with peer support for acute mental health crises (HoPe). *BMC Psychiatry.* (2022) 22:619. doi: 10.1186/s12888-022-04247-w

24. Kirchmann F, Schepker R, Corpus N, Fegert JM, Keller F, Boege I. Patienten- und elternzufriedenheit bei intensiver klinikvernetzter zu-hause-behandlung. [patient and parent satisfaction with intensive, hospital-networked home treatment]. *Psychother.* (2014) 59:371–7. doi: 10.1007/s00278-014-1075-z

25. Deshpande PR, Rajan S, Sudeepthi BL, Abdul Nazir CP. Patient-reported outcomes: a new era in clinical research. *Perspect Clin Res.* (2011) 2:137–44. doi: 10.4103/2229-3485.86879

26. Batbaatar E, Dorjdagva J, Luvsannyam A, Amenta P. Conceptualisation of patient satisfaction: a systematic narrative literature review. *Perspect Pub Health.* (2015) 135:243–50. doi: 10.1177/1757913915594196

27. Batbaatar E, Dorjdagva J, Luvsannyam A, Savino MM, Amenta P. Determinants of patient satisfaction: a systematic review. *Perspect Pub Health.* (2017) 137:89–101. doi: 10.1177/1757913916634136

28. Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, Lakhani I, et al. Satisfaction with surgery outcomes and the decision process in a population-based sample of women with breast cancer. *Health Serv Res.* (2005) 40:745–68. doi: 10.1111/j.1475-6773.2005.00383.x

29. Bermejo I, Kriston L, Härter M. Patient satisfaction with inpatient treatment of depressive disorders: sociodemographic, clinical, and treatment-related predictors. *Z med Psychol.* (2008) 17:97–105. doi: 10.3109/13651501.2014.988272

30. Alhazmi Ahmed A, Kaufmann A. Phenomenological qualitative methods applied to the analysis of cross-cultural experience in novel educational social contexts. *Front Psychol.* (2022) 13:785/143. doi: 10.3389/fpsyg.2022.785134

31. Witzel A, Reiter H. *The problem-centred interview: Principles and practice.* Los Angeles: Sage Publications. doi: 10.4135/9781446288030 (2012).

32. Mayring P. *Qualitative inhaltsanalyse [qualitative content analysis]*. Weinheim: Beltz (2015).

33. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med*. (2014) 89:1245–51. doi: 10.1097/ACM.0000000000000388

34. Helfferich C. *Leitfaden- und Experteninterviews* [guideline and expert interviews]. in: *Handbuch methoden der empirischen sozialforschung*. Baur N, Blasius J (eds.), Wiesbaden: Springer Fachmedien. doi: 10.1007/978-3-531-18939-0_39 pp. 559–74 (2014).

35. Glaser BG, Strauss AL. *Grounded theory: strategien qualitativer forschung [grounded theory: strategies of qualitative research]*. Göttingen: Hogrefe (2010).

36. Dresing T, Pehl T. *Transkription* [transcription]. In: *Handbuch qualitative forschung in der psychologie, band 2: designs und verfahren*. Mey G, Mruck K. (eds.), Wiesbaden: Springer Fachmedien. doi: 10.1007/978-3-658-26887-9_56 pp. 835–54 (2020).

37. Patton MQ. *Qualitative research and evaluation methods*. Los Angeles: Sage Publications (2002).

38. Levitt HM, Bamberg M, Creswell JW, Frost DM, Josselson R, Suárez-Orozco C. Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: the APA publications and communications board task force report. *Amer Psychol*. (2018) 73:26–46. doi: .org/10.1037/amp0000151

39. Anderson RT, Weisman CS, Camacho F, Scholle SH, Henderson JT, Farmer DF. Women's satisfaction with their on-going primary health care services: a consideration of visit-specific and period assessments. *Health Serv Res*. (2007) 42:663–81. doi: 10.1111/j.1475-6773.2006.00620.x

40. Neumann M, Wirtz M, Ernstmann N, Ommen O, Längler A, Edelhäuser F, et al. Identifying and predicting subgroups of information needs among cancer patients: an initial study using latent class analysis. *Supp Care Cancer*. (2011) 19:1197–209. doi: 10.1007/s00520-010-0939-1

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Establishing community mental health clinics increased the number of patients receiving care in rural Western Uganda

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Background: Mental, neurological, and substance-use disorders cause medium to long term disability in all countries. They are amenable to treatment but often treatment is only available in hospitals, as few staff feel competent to give treatment. The WHO developed the "Mental Health GAP" (mhGAP) course to train non-specialist clinical staff in basic diagnosis and treatment. At Bwindi Community Hospital, in south-west Uganda, mental health care was initially only provided at the hospital. It was extended outside the hospital in two implementation phases, initially by establishing 17 clinics in the community, run by qualified mental health staff from the hospital. In the second implementation phase staff in 12 health centers were trained using mhGAP and ran their own clinics under supervision.

Methods: Using routine data the defined data variables for the individuals attending the clinics was extracted.

Results: A total of 2,617 people attended a mental health care clinic in the study period between January 2016 and March 2020. Of these 1,051 people attended more than once. The number of patients attending clinics increased from 288 during the baseline to 693 in the first implementation phase then to 839 patients in the second implementation phase. After mhGAP training, about 30% of patients were seen locally by mhGAP trained healthcare personnel. The average number of mental health patients seen each month increased from 12 to 65 over the time of the study. The number of patients living >20 km from the hospital increased from 69 in the baseline to 693 in the second implementation phase. The proportion of patients seen at the hospital clinic dropped from 100% to 27%.

Conclusions: Providing mental health care in the community at a distance from the hospital substantially increased the number of people accessing mental health care. Training health center-based staff in mhGAP contributed to this. Not all patients could appropriately be managed by non-specialist clinical staff, who only had the five-day training in mhGAP. Supplies of basic medicines were not always adequate, which probably contributed to patients being lost to follow-up. About 50% of patients only attend the clinic once. Further work is required to understand the reasons.

KEYWORDS

mhGAP training, community-based mental health care, rural mental health care, task sharing, mental health gap, patient retention

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Abbreviations
BCH, Bwindi Community Hospital; HCII, health center level ll; HCIII, health center level lII; mhGAP, Mental Health Gap Action Program, developed by the World Health Organization; PNFP, Private-Not-For-Profit.

1. Introduction

Mental, neurological, and substance use disorders contribute about 10% (258 million) Disability Adjusted Life Years to the Global Burden of Disease in both high-income countries and low-and-middle-income countries (1). While some individuals may die from mental, neurological, and substance use disorders, and some die early from neglect of their physical health (2), the majority of those with mental illness suffer from life-inhibiting illnesses that may result in poverty and discrimination that affects future generations as well. In some countries, including Uganda, children with uncontrolled epilepsy may be prevented from attending school due to fear of other children "catching the infection" (3). Treatment of many mental illnesses is available, but may not be accessible for a number of reasons (4).

Primary health care (health care outside of hospitals) should include mental health care if it is to be accessible to those who need it (5–8). The main barriers to accessing mental health services include centralization of mental health services in hospitals, lack of available medicines, inadequate number of mental health trained staff, mental health not being a priority for policy makers, and beliefs around the causation and appropriate treatment of mental illness which result in seeking alternative treatments such as from religious and traditional healers (4, 8–11).

There is a scarcity of specialized mental health workers in many countries (5), including Uganda (12). The World Health Organization (WHO) has developed programs such as the Mental Health Gap Action Program (mhGAP), to bridge this gap by training non-specialized clinical staff in basic skills to diagnose and treat or refer those with mental illness (13). This is not about "task shifting" but "task sharing" (6), with the intention of increasing the number of staff with these basic skills. The mhGAP program has been piloted in Uganda and shown to be effective in increasing access to mental health care to some extent (14).

It has been estimated that up to 35% of Ugandans suffer from a mental disorder and 15% would benefit from treatment (12, 13). Provision of mental health care in Uganda is a component of the national minimum healthcare package, which should be available at all levels of the health system (15). It is expected to be integrated into outpatient services at hospitals and health centers to improve access to mental health care (14, 15).

Despite having a national policy framework and the encouragement of programs such as the mhGAP in Uganda, there are marked gaps in mental health service delivery in Uganda, especially at health centers (16). Mental health care is largely provided by specialist psychiatric workers at national and regional referral hospitals, with little being offered at district hospitals or health centers (17). Relatively few of the private-not-for-profit (PNFP) hospitals provide mental health care (18).

Bwindi Community Hospital (BCH) has been offering hospital-based mental health care since 2013. From January 2018 a two phased approach was adopted to expand the service into the community with monthly clinics across the catchment area. The intention was to increase access to mental health care in the area.

This study aimed to assess if the establishment of clinics away from the hospital, and training of non-specialist clinical staff from health centers in mental health care, increased the number of patients accessing mental health care and if any contributing factors could be identified.

2. Methods

2.1. Design

This was a retrospective cohort study using routinely collected data.

2.2. Setting

2.2.1. General setting

Uganda is a land-locked East African country. In 2020 it had an estimated population of 45 million people, 84% of whom lived in rural areas and 21% living in poverty. Life expectancy at birth was 63 years in 2017 (19). Health care is provided by both government and private providers. Rural areas are mainly served by health centers supported by hospitals.

2.2.2. Specific setting

The study was carried out in the catchment of BCH, which is a PNFP Hospital in Kanungu District in Southwestern Uganda. Its main catchment area covers 17 parishes, with a total population of about 70,000, living in 101 villages (20).

BCH has been providing mental health care services since 2013. Their initial focus was on providing care at the hospital, with most of this being for outpatients. From 2013 there were ongoing discussions between the BCH senior management team, the lead for mental health care and the trustees of Jamie's Fund, a small UK charity working to improve access to mental health care in Uganda (https://jamiesfund.org.uk). This resulted in the staff at BCH trying out different ways to use their resources to increase the number of clinics in the community. Once some progress had been made in two different models it was suggested we should carry out a more formal evaluation to see if the models worked.

The mental health qualified staff at BCH were 1.5 whole time equivalent psychiatric clinical officers, a psychiatric nurse and a counsellor employed by the hospital. Patients were treated as outpatients as far as possible, but when necessary disturbed patients were admitted to the acute medical ward for management. We took as our baseline, the last two-year period when all mental health care services were hospital-based.

Both oral tablets and depot injections were available to manage mental illnesses. The main diagnoses (*with the available treatments*) were: schizophrenia (*chlorpromazine, haloperidol, benzhexol, depot fluphenazine)* severe depression, (*amitriptyline, imipramine),* bipolar affective disorder (*sodium valproate chlorpromazine, carbamazepine)*, epilepsy (*phenytoin, phenobarbitone, sodium valproate, carbamazepine)* and alcohol use disorder (*diazepam, thiamine and vitamin B complex*). These are old, well established treatments. Compared to treatments for other diseases they are relatively cheap, but they may be too costly for people to afford.

Counselling is provided when appropriate and accessible. Educational sessions were run in the community to inform about aspects of mental illness, its treatment and ways to remain healthy.

BCH operates "eQuality", a voluntary health insurance scheme which for a payment of about US$5 per adult per year allows the family to access subsidized health care and treatment. Other patients pay the costs out of pocket. Unlike some other health insurance schemes, patients with chronic conditions such as mental illness are allowed to be members of the scheme.

There were 12 health centers in the catchment area. Of these, four are health center IIIs (HCIII), three government run and one PNFP. At an HCIII there are supposed to be 14 staff, led by a senior clinical officer. The other eight health centers are health center lls (HCIIs), one government and seven PNFP. BCH runs two of the private HCIIs. At an HCII there are supposed to be 3 staff, led by an enrolled nurse.

MhGAP training is encouraged by the Ugandan Ministry of Health. The five-day training course was run at BCH and used the mhGAP intervention guide training materials (21). It combined didactic lectures with role plays, communication exercises and discussions. It was led by one of the experienced national trainers for mhGAP. He had also run the "training the trainers" course attended by the three other trainers who were all qualified in mental health. Twenty two nurses and midwives from health centers were trained and ten staff from BCH.

Government health centers are given a limited supply of medicine monthly, for which there is no charge to patients. HCIIIs receive a greater quantity and range of medicines than HCIIs. Patients attending the health centers run by BCH and other private providers have to pay for medicines.

In the first implementation phase, mental health clinics were established in each of the 17 parishes, and held at local health centers, churches or local administrative headquarters. The sites were selected by the clients through their 5-member parish mental health committees.

These clinics were run by mental health qualified staff from BCH once every four-weeks, travelling by motorcycle on bumpy, dusty and sometime muddy roads. The staff also visited patients at home, to provide some of the psycho-social elements of the care packages, and engaged with people in the village to raise awareness that mental, neurological, and substance use disorders could be treated. This could require two mental health staff staying for a working week in each of two sub-counties, since many of these centers were too far to travel to daily.

At each clinic, patients were assessed for their physical and psychosocial needs. Activities at the venues include talks and discussion on aspects of mental ill health and maintaining good health, and reviews of individuals. Treatments offered included counselling, medication (both oral and depot injections), discussing way to reduce stress and promote social support (including promoting social support and resettling patients who are neglected) and promoting activities of daily living and livelihood activities. Medicine refills were given if medicines were available. Mental health staff from the hospital were not permitted by hospital procedures to provide medicines at the venues in villages other than health centers, so patients were encouraged to get them from the nearest health center or pharmacy.

In the second implementation phase, after the mhGAP training, the number of clinics was reduced to 12, one in each of the health centers where non-specialist clinical staff had been trained in mhGAP. Those clinics at churches or local administrative headquarters which had been run by the staff from the hospital were closed. Additional arrangements were also made to try to ensure better availability of medicines at these health centers.

As the staff at the health centers were full time, it was expected that this would increase access to mental health care. They were also given regular mentoring by the more experienced hospital-based staff who attended each health center once a month. After a clinic, patients requiring a home visit would be seen by qualified mental health workers from BCH. The BCH team also continued to provide some of the psycho-social elements of the care packages via village visits to patients and families that required them.

2.3. Participants

All patients with mental, neurological and substance misuse disorders who attended BCH or outreach clinics between January 2016 and March 2020.

2.4. Data variables

Data was obtained from routinely collected information in health center registers and electronic databases at BCH. Data on an individual's clinic attendances was linked across time in the databases, using a combination of identifier variables, to provide patient mental health clinic histories in terms of their frequency and time intervals.

Variables collected included patients' demographic characteristics, clinic attendance before and after establishment of mental health services in the community, year of first diagnosis with a mental illness and the type of clinic attended. Unfortunately, some data relating to home visits and other outreach work by BCH based staff in the last half of the 2nd implementation phase was lost due to an information technology problem.

Patients were counted as being a more consistent attender of the clinic in the following 12-month period if they did not have a gap in attendance of six months or more during the 12 months. They were counted as lost to follow-up if, at the end of the 12 months, they had not attended for at least the last 6 months (22).

Data taken from the main hospital databases was validated at the original point of data entry. All data from health center and mental health electronic registers were subjected to consistency checks, and discrepancies were investigated as far as possible.

2.5. Analysis and statistics

The data were analyzed in EpiData (version 2.2.2.186, EpiData Association, Odense, Denmark) using frequencies and proportions.

Correction for the missing data in the second implementation phase was done on the assumption that the missing data were similar to those that were not missing for that period. Sensitivity analysis was done to test the robustness of the resulting estimates with regard to this assumption.

To assess the effectiveness of the service, we focused on those patients who attended the clinic more than once in one of the three time periods (January 2016 to December 2017 [baseline], January 2018 to February 2019 [first implementation phase], March 2019 to March 2020 [second implementation phase) as they had established a relationship with the clinic. Those who attended only once did not necessarily have a mental illness.

Assessing the frequency of attendance as part of this evaluation was complicated by the fact that the length of the time periods varied. For existing patients, all attendances in any of the three time periods were counted. For new patients, reattendance within six months was used to enable comparison between periods. It was assumed that the proportion of new patients who re-attended within 6 months of their first attendance was the same in both the first six months and the final six month of the second implementation phase, to compensate for missing data. Again, sensitivity analysis was done to test the estimates based on this assumption.

We investigated factors associated with patients' repeated clinic attendance patterns in each period. For this analysis, an individual may be counted in more than one of the three time periods. Demographic and clinic characteristics of patients were compared with clinic attendance variables using multivariate logistic regression with results presented as odds ratios (OR) and 95% confidence.

3. Results

A total of 2,617 people attended a mental health care clinic in the study period between January 2016 and March 2020. Of these 1,051 people attended more than once. The three time periods, together with the number of clinics and who ran them, are summarized in **Table 1**.

The characteristics of the patients who attended more than once in each of the three periods of the study are shown in **Table 2**. There was little difference between the study periods in the patient demographics, with about 60% being male, and about 60% aged between 18 and 59. Most were subsistence farmers.

TABLE 1 The time periods in the study and number of mental health clinics in the catchment area of Bwindi community hospital, Uganda.

Time period	Number of clinics	Staff running clinics
Base line, Jan 2016 to Dec 2017	1	Mental health qualified staff from hospital
Implementation phase 1, Jan 2018 to Feb 2019	17	Mental health qualified staff from hospital
Implementation phase 2, Mar 2019 to Mar 2020	12	Health centre staff trained in MhGAP and Mental health qualified staff from hospital

The number of patients increased in each successive time period, from 288 to 693 to 839 patients, excluding those who attended only once. This was due to increased recruitment of new patients, as the proportion of patient retained between the periods remained the same at about 75%. The average number of patients seen each month increased steadily (**Table 3**). The main three diagnoses were the same in each time period, epilepsy, depression and bipolar affective disorder.

Attendance at the different types of clinics changed markedly following the establishment of clinics outside the hospital (**Table 3**). Initially everyone had to attend the BCH hospital-based clinic. In the first implementation phase, when services were provided by staff from BCH working in the community, only 229/693 (33%) were seen at the hospital and the rest seen either in the village 267/693 (39%) or at clinics 160/693 (23%). A few (5%) were seen in more than one place.

In the second implementation phase, after the mhGAP training, only 233/839 (27%) of patients were seen at the hospital, and 253/839 (30%) were seen by the mhGAP-trained health center staff. The remainder were seen by BCH staff in the village 218/839 (26%) or a community clinic 38/839 (4%) with 96/839 (11%) seen at more than one location.

During both the first and second implementation phases, many of the patients seen at a community-based clinic run by staff from BCH or a lower Health Center were also seen during a home (or village) visit, reflecting the fact that the BCH team was continuing to provide some of the psycho-social elements of the care.

The number of patients attending clinics who lived more than 20 km from BCH was six times higher in the second implementation phase (following the mhGAP training) than in the baseline period. The number who lived <10 km from BCH was similar changed very little. At the same time the proportion of patients not enrolled in BCH's eQuality health insurance increased from 8% to 48% and 49% in the first and second implementation phases.

In the second implementation phase, following the mhGAP training, three of the twelve health centers saw the majority of the patients (69%) seen at Health Centers. Two were over 20 km from BCH and the other one was just under the 20 km.

Around half of the patients attending the service only attended once: 46% (241) before clinics were established outside the hospital, 54% (829) in the first implementation phase, and 37% (496) in the second implementation phase, following the mhGAP training. Many of these were diagnosed with a mental illness but we have no data as to why they did not re-attend.

Regular clinic attendance is important to maintain a supply of medicine and support. Around 30% of new patients attended four or more times in the first six months, while over 50% of those who had continued to attend from the previous period attended four or more times in the next period (**Table 3**).

Factors associated with a patient being a more consistent attender of the clinic in the following 12-month period (i.e., neither lost to follow up nor having a gap in attendance of six months or more during the period) were: being aged between 18 and 59, having eQuality insurance (both $p < 0.001$), having

TABLE 2 Characteristics of patients attending mental health services in the catchment area of Bwindi community hospital, Uganda between 2016 and 2020.

Characteristics	Base line, Jan 16 to Dec 17	First implementation phase, Jan 18 to Feb 19	Second implementation phase, after mhGAP training Mar 19 to Mar 20
Total number of patients (excluding first time attenders in each period who only attended once)	288	693	839
Age (in years)			
0–17	64 (22%)	143 (21%)	160 (19%)
18–35	107 (37%)	207 (30%)	267 (32%)
36–59	70 (24%)	215 (31%)	265 (32%)
60 + years	46 (16%)	125 (18%)	147 (18%)
Not recorded	1 (0%)	3 (0%)	0 (0%)
Sex			
Male	178 (62%)	450 (65%)	515 (61%)
Female	110 (38%)	240 (35%)	322 (38%)
Not recorded	0 (0%)	3 (0%)	2 (0%)
eQuality insurance status			
All of the period	112 (39%)	188 (27%)	255 (30%)
Some of the period[a]	153 (53%)	172 (25%)	175 (21%)
None of the period	23 (8%)	333 (48%)	409 (49%)
Distance from home to BCH			
Near (<10 Km)	90 (31%)	94 (14%)	88 (10%)
Far (10–20 Km)	129 (45%)	288 (42%)	298 (36%)
Very far (>20 Km)	69 (24%)	311 (45%)	453 (54%)

[a]Patients who are only members of the "eQuality" health insurance scheme for part of a year, as they did not continue the subscription for the full year. Probably as they could not afford it.

psychosis or epilepsy rather than one of the other mainly shorter-term conditions ($p < 0.01$).

4. Discussion

This study shows that in a poor, very rural area of a low income country, staff with very limited resources succeeded in substantially increasing the number of individuals attending mental health clinics. This was sustained over a two year period by opening clinics in the community and training health centre staff in mhGAP. Furthermore, this was done as part of normal service development, with only the costs of the two mhGAP courses being sponsored externally, but with supportive senior management and well motivated staff. We have not found any other studies describing this achievement.

About half of all the patients attending the service in each of the three study periods only attended once, and a further significant proportion were lost to follow up. A Rwandan study found 35% of patients only attended once (23). This is about two thirds the rate in our study.

Elsewhere in Uganda (14) an increase in patient numbers was seen in a six month pilot study when health center staff were trained in mhGAP. That study was generously funded by an external donor. They report an increase of 35% (670 to 1016) in attendance in the six months follow the training. However, their data is based on that reported the Ugandan National Health Information Management System. This only records attendances, not cases, so although the numbers increased it is not clear if any patient attended more than once. The increase they describe would be accounted for by 346 patients attending one extra time in the second six months. Due to their data source, there is no information on patient retention or frequency of attendance.

Until we analyzed our data for this study, we were unaware of the high number of patients attending only once, as previously the data focus was counting the number of patient attendances, as required by the Ugandan National Health Information Management System.

This shows the importance of both collecting the relevant data and also analyzing it. The data to show that many patients who would benefit from treatment were not attending regularly, or even more than once, had been collected by the mental health services at BCH, but not used. As has been said elsewhere "We are drowning in information but starved for knowledge" (24).

Around 30% of new patients attended four or more times in the first six months. This is likely to be adequate for them to have enough medication to be able to take it regularly, but we have no data on concordance with medication.

One of the challenges accessing health care when living in a rural area is the distance to the nearest appropriate facility (25). The main increase in patient numbers accessing mental health care came in those living at a distance from BCH. As stated above, the number living more than 20 km from the hospital increased six-fold over the study period, while the percentage of patients from more than 20 km doubled: from 69 (24%) to 453 (54%). This is probably simply because the service became easier to access for those living further from the hospital. This finding is similar to the study in Rwanda (23) which reported that the majority of patients attended health centers which were <5 km from home, rather than travelling further to the main clinic at the hospital.

TABLE 3 Patients' utilization of mental health services in the catchment area of Bwindi community hospital, Uganda, between 2016 and 2020.

Variable	Base line Jan 16 to Dec 17		First implementation phase Jan 18 to Feb 19		Second implementation phase Mar 19 to Mar 20	
	N (%)	Average monthly attendance	*N* (%)	Average monthly attendance	*N* (%)	Average monthly attendance
Total number of patients (excluding first time attenders in each period who only attended once)	288	12.0	693	49.5	839	64.5
Existing and new patients						
Patients from previous period	168 (58%)	7.0	221 (32%)	15.8	548 (65%)	42.2
New patients	120 (42%)	5.9	472 (68%)	33.7	291 (35%)	22.4
Frequency of patient attendance						
a) New patients (in 6 months from 1st attendance)						
Attended twice	50 (42%)	1.8	194 (41%)	12.8	142 (49%)	6.1
Attended 3 times	28 (23%)		99 (21%)		70 (24%)	
Attended 4 times or more	42 (35%)		179 (38%)		79 (27%)	
b) Existing patients (in full period)						
Attended once	31 (18%)	4.8	46 (21%)	9.2	137 (25%)	21.1
Attended twice	13 (8%)		29 (13%)		88 (16%)	
Attended 3 times	10 (6%)		17 (8%)		49 (9%)	
Attended 4 times or more	114 (68%)		129 (58%)		274 (50%)	
Clinical diagnosis						
Epilepsy	137 (48%)	5.7	264 (38%)	18.9	307 (37%)	23.6
Depression	59 (20%)	2.5	188 (27%)	13.4	237 (28%)	18.2
Bipolar affective disorder	25 (9%)	1.0	66 (10%	4.7	79 (9%)	6.1
Psychosis	35 (12%)	1.5	38 (5%)	2.7	56 (7%)	4.3
Child and adolescent disorder, SUD[a] & Self-harm	7 (2%)	0.3	16 (2%)	1.1	25 (3%)	1.9
Other mental illness	23 (8%)	1.0	70 (10%)	5.0	79 (9%)	6.1
Condition not recorded	2 (1%)	0.1	51 (7%)	3.6	56 (7%)	4.3
Type of clinic attended by patient						
Hospital-based BCH-run clinic[b]	288 (100%)		229 (33%)		233 (28%)	
Community-based BCH-run clinics[b]	-		160 (23%)		38 (5%)	
Health center-based & run clinics[b]	-		-		253 (30%)	
Combinations of the above clinics	-		37 (5%)		96 (11%)	
BCH home visits only	-		267 (39%)		219 (26%)	
Distance from home to BCH						
Near (<5 Km)	90 (31%)	3.8	94 (14%)	6.7	88 (10%)	6.8
Far (5–10 Km)	129 (45%)	5.4	288 (42%)	20.6	298 (36%)	22.9
Very far (>10 Km)	69 (24%)	2.9	311 (45%)	22.2	453 (54%)	34.8

[a] SUD, Substance Use Disorders.

[b] Many patients were also seen on home visits.

In many low income countries, access to a reliable, affordable supply of appropriate medicines is a major barrier to mental health care (9, 11, 26). This was certainly a problem in our study. Government HClll are supposed to receive a monthly stock of psychotropic medication so may have slightly more reliable supplies of free medication. The private HClls have to charge for medication and often do not have adequate supplies. The two HClls run by BCH offered subsidized mental health medication through the eQuality health insurance scheme but this requires families to have enough money to be part of the insurance scheme (27). It is discouraging for patients to make the effort to attend a clinic to be told their medication is out of stock, or it may be that they cannot afford the ongoing expense of the medication when attending private health centers. This is likely to contribute to the loss to follow up.

Three of the twelve health centers saw the majority (239, 69%) of the patients reviewed by health center staff in the second implementation phase. These were two government HCllls and one private HCll run by BCH. The reasons for this higher demand are not known. Contributing factors may be the availability of medicines, which were free at two of the clinics, the greater number of trained staff at a HCIII, or the level of enthusiasm and/or confidence of the staff. Population density or accessibility were not appreciably different from other clinics. Anecdotally, some of the health center staff did not consider it part of their role to provide care for those with mental illness and have been known to request payment per patient from their employer for them to do this. This was also found elsewhere in Uganda (14).

People were more likely to continue to attend a clinic if they had a major mental illness or epilepsy and were of working age, or were enrolled in BCH's eQuality insurance, suggesting that cash-flow or access to funds is an important determinant of access to continuing care. For those with a major mental illness or of working age, the beneficial effect of medication probably gave an adequate incentive to continue to take the medicine. Those with epilepsy may be more likely to continue to attend the clinic as the positive impact of treatment is more marked and may be more valued. Others have found that some people with mental, neurological or substance use disorders, live socio-economically and psychologically chaotic lives, so attending a clinic may not be a priority (28). Those with depression in India were found not to see depression and anxiety as necessarily being suitable for medical treatment (29). This has been described for all mental illnesses in Uganda (30). An interesting paper from Ghana (31) describes how many people with psychosis discontinued their medication as they found the side effects such as drowsiness, restlessness, and movement abnormalities unpleasant and these conflicted with concepts of health, healing, and wellness. The patients felt that failure to achieve a permanent cure cast doubt on the medication's long term efficacy and further suggested to them that spiritual factors might also be at play. This may well also true in Uganda.

The percentage of people with eQuality insurance fell over the three periods, although the total number insured increased. This was not surprising as it has been observed previously (32) that people living closer to BCH are more likely to be in the insurance scheme. As more people living further from the hospital attended the new clinics they would be less likely to be part of the insurance scheme. However, access to effective treatment may have contributed to the increased number of patients joining the insurance scheme. Encouraging mental health patients to enroll in the scheme could possibly improve compliance with treatment and be worth pursuing.

The number of new patients fell in the second implementation phase while the number retained increased. This might mean that there were fewer people left who needed to attend the clinic.

The Programme for Improving Mental Health Care (PRIME) was an international programme researching ways to improve mental health care (33). They have worked in five countries and recommend a comprehensive planning approach. However, even this does not guarantee success, as they reported that in Uganda, India and Ethiopia they found a small non-significant improvement in treatment coverage of depression and a significant improvement in diagnosis of depression and alcohol use disorder, but this improvement was not sustained over the longer term in Uganda (34).

Their Ugandan study was undertaken on a much larger scale than ours, with multiple focus groups and coordination groups, and yet the impact was not sustained. We found better long term results in increasing treatment coverage in a program run without extra (external) funding. Introducing service developments with motivated local leadership, using existing funding, and which can be evaluated from routinely collected local data, must be a more appropriate and sustainable approach than the studies that are often published. Such published studies often depend on significant, but short term, international funding to "pilot" a model, which may have been shown to work elsewhere already. The conclusion of these "pilots" is too often that the model should be implemented on a wider basis in that country. But that expansion usually has to await further external funding, which often is not forthcoming. PNFP hospitals may be able change service models more easily than government hospitals, as they usually have more autonomy, flexibility and, perhaps, more motivated staff.

A study in Malawi (35) where 43 primary health care workers were trained for two days in mhGAP found that there was an increase in the numbers of patients with a diagnosis of mental illness attending the 18 health centers but the numbers were very low, increasing from a total of about 15 cases per month pre-training to a total of about 31 per month. It is not clear if these are cases or patient-contacts. This is a much smaller number and increase than we found (**Table 3**).

One of the benefits of this provision of mental health care in the community was seen during the subsequent COVID-19 lockdowns, as patients were able to receive care from these health centers even when staff from BCH were limited in their travel.

Strengths of this study include that it has been carried out using routine data, much of which has been collected electronically, which is unusual in a very rural poor community in much of Africa. It is unlikely that we could have undertaken this study with paper-based records. Also, the clear step-changes in attendances in the two implementation phases and the fact that data was collected over several years give credence to the findings.

Weaknesses include the following. We were only able to report on attendances by individuals but do not know the accuracy of the diagnoses or the reasons for people not returning to the clinic. Some of the data on clinical workload in the community was lost due to an IT issue. Both these weaknesses reflect that this project was operational research carried out in rural Africa in a small non-academic hospital without external funding.

Analysis of what treatment was prescribed has not been done due to lack of resources, nor do we have data on when and how much medication patients received. This would have enabled us to see if they had enough medication to take at the recommended dosage until their next appointment. Outcome data, particularly in terms of control of their illness would have been helpful to assess the effect on peoples' lives. In the other studies as part of the PRIME initiative (34) they recruited full time staff to assess the impact of treatment. We did not have the resources to do this.

4.1. Practical implications

Providing more clinics in the community, nearer where people live resulted in many more patients attending mental health care clinic which was continued over time.

Training non-specialist staff in mhGAP adds to the workforce able to diagnose and treat or refer people with mental health conditions (36). This increases the likelihood that patients will access care. Care for mental ill-health is much more accessible if it is provided by staff based in a health center each day, not just at a monthly clinic. This has been achieved at the minimal cost of running two mhGAP training courses with the motivation and supervision coming from the mental health qualified staff in the hospital as part of their service development work.

These non-specialist staff complement, rather than replace, the mental health qualified staff, who are still required. It is not appropriate that all the care of patients with a mental illness should be transferred to non-specialist clinicians who have undergone a five-day training in mhGAP. There is still a need for mental health-qualified staff to review and manage some of the more complex patients, though the workload of the mental health staff has been reduced as they no longer have to see all patients. Due to data loss, this reduction in workload cannot be reported in detail.

BCH has relatively well-developed electronic records, with data from both its hospital and community programs facilitating this retrospective study. We recommend that the hospital systems are refined to enable routine data to be used to identify patients' failures to attend a clinic on a real-time basis. This could significantly improve the standard of service provided to those with mental illness and other non-communicable diseases that benefit from regular follow up. Text messages could then be used to remind patients before their appointments, or to check with patients if they do not attend. This is already used in other patient programs.

Gathering data routinely on the quantities of drugs prescribed and dispensed would enable a much clearer understanding of how patients were using the service. We do not have data on what medication patients actually received as opposed to what was prescribed, so we have little idea if they were able to take their medicines continuously. As the routine treatment of all non-communicable diseases becomes more established, it would be helpful to be able to monitor more effectively how well patients are being managed in routine care.

Further qualitative research would be helpful to understand why the loss to follow up rate was so high. It could be due to socioeconomic factors and the cost of medication from some clinics, local health beliefs and expectations, (such as an expectation of a cure rather than long term medication) and/or the stigma that remains around mental health disorders.

4.2. Lessons learned

Robust backup systems for electronic data and appropriate training are important. We thought there was a good system in place to back up our data but we still managed to lose six months of data that had been entered on the system which recorded the work the hospital staff had done in the community.

5. Conclusion

We have shown that providing community mental health care in a rural Ugandan setting resulted in substantially higher numbers of patients both starting and continuing to attend clinics. We also identified that a large number of our patients only attend a mental health clinic once or twice and do not return. This requires further research to understand the reasons for this loss and to help develop appropriate services to enable this disadvantaged group to receive appropriate treatment.

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 human participants were reviewed and approved by The Mbarara University of Science and Technology – Research Ethics Committee. Mbarara, Uganda. Ref: MUST-2022-468. Written informed consent for participation was not required for this study in accordance with the national legislation and the institutional requirements.

Author contributions

Conceptualization, KY, EW, AD, AS, and BM; methodology, KY, EW, AD, AS, and BM; software AD.; validation, AD and KY; formal analysis, AD, KY, AS, and EW; writing—original draft preparation KY, AD, and EW; writing—review and editing KY, AD, AS, EW, and BM. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

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References

1. Whiteford HA, Ferrari AJ, Degenhardt L, Feigin V, Vos T. The global burden of mental, neurological and substance use disorders: an analysis from the global burden of disease study 2010. *PloS One*. (2015) 10(2):e0116820. doi: 10.1371/journal.pone.0116820

2. WHO. Management of physical health conditions in adults with severe mental disorders. (cited 2022 Oct 13). Available at: https://www.who.int/publications-detail-redirect/978-92-4-155038-3 (2018).

3. Duggan MB. Epilepsy and its effects on children and families in rural Uganda. *Afr Health Sci*. (2013) 13(3):613–23. doi: 10.4314/ahs.v13i3.14

4. Hailemariam M, Fekadu A, Prince M, Hanlon C. Engaging and staying engaged: a phenomenological study of barriers to equitable access to mental healthcare for people with severe mental disorders in a rural African setting. *Int J Equity Health*. (2017) 16 (1):156. doi: 10.1186/s12939-017-0657-0

5. Saxena S, Thornicroft G, Knapp M, Whiteford H. Resources for mental health: scarcity, inequity, and inefficiency scarcity, inequity, and inefficiency. *Lancet*. (2007) 370(9590):878–89. doi: 10.1016/S0140-6736(07)61239-2

6. Abdulmalik J, Thornicroft G. Community mental health: a brief, global perspective. *Neurol Psychiatry Brain Res*. (2016) 22(2):101–4. doi: 10.1016/j.npbr.2015.12.065

7. Angdembe M, Kohrt BA, Jordans M, Rimal D, Luitel NP. Situational analysis to inform development of primary care and community-based mental health services for severe mental disorders in Nepal. *Int J Ment Health Syst*. (2017) 11(1):1–16. doi: 10.1186/s13033-017-0176-9

8. Bailey J. The issues affecting mental health nursing in Uganda. *J Psychiatry*. (2014) 17(6). doi: 10.4172/1994-8220.1000158

9. Ali SH, Agyapong VI. Barriers to mental health service utilisation in Sudan-perspectives of carers and psychiatrists. *BMC Health Serv Res*. (2015) 16(1):1–10. doi: 10.1186/s12913-015-1254-9

10. Ma Z, Huang H, Chen Q, Chen F, Abdullah AS, Nie G, et al. Mental health services in rural China: a qualitative study of primary health care providers. *BioMed Res Int*. (2015) 2015. doi: 10.1155/2015/151053

11. Badu E, O'Brien AP, Mitchell R. An integrative review of potential enablers and barriers to accessing mental health services in Ghana. *Health Res Policy Syst*. (2018) 16 (1):1–19. doi: 10.1186/s12961-018-0382-1

12. Molodynski A, Cusack C, Nixon J. Mental healthcare in Uganda: desperate challenges but real opportunities. *BJPsych Int*. (2017) 14(4):98–100. doi: 10.1192/S2056474000002129

13. mhGAP: Mental Health Gap Action Programme. *Scaling up care for mental, neurological and substance use disorders*. Geneva: World Health Organization (2008). (cited 2021 Aug 26). (WHO Guidelines Approved by the Guidelines Review Committee). Available at: http://www.ncbi.nlm.nih.gov/books/NBK310851/.

14. Kigozi FN, Kizza D, Nakku J, Ssebunnya J, Ndyanabangi S, Nakiganda B, et al. Development of a district mental healthcare plan in Uganda. *Br J Psychiatry*. (2016) 208(Suppl 56):s40–6. doi: 10.1192/bjp.bp.114.153742

15. Ministry of Heath. Health Sector Development Plan 2015/16 - 2019/20 Uganda government, (cited 2021 Aug 26). Available at: http://extwprlegs1.fao.org/docs/pdf/uga179615.pdf (2015).

16. Ssebunnya J, Kigozi F, Kizza D, Ndyanabangi S. Integration of mental health into primary health care in a rural district in Uganda. *Afr J Psychiatry*. (2010) 13(2). doi: 10.4314/ajpsy.v13i2.54359

17. Kigozi F, Ssebunnya J, Kizza D, Cooper S, Ndyanabangi S, Mental Health and Poverty Project. An overview of Uganda's mental health care system: results from an assessment using the world health organization's assessment instrument for mental health systems (WHO-AIMS). *Int J Ment Health Syst*. 2010;4(1):1. doi: 10.1186/1752-4458-4-1

18. Mwesigwa J, Wilkinson E. Report on mental health services provided by Health Facilities affiliated to the Uganda Protestant Medical Bureau in 2018 (2018).

19. Life expectancy at birth, total (years) - Uganda | Data (cited 2022 Oct 13). Available at: https://data.worldbank.org/indicator/SP.DYN.LE00.IN?locations=UG.

20. Kuule Y, Dobson AE, Woldeyohannes D, Zolfo M, Najjemba R, Edwin BMR, et al. Community health volunteers in primary healthcare in rural Uganda: factors influencing performance. *Front Public Health*. (2017) 5. doi: 10.3389/fpubh.2017.00062

21. World Health Organization. World Health Organization. mhGAP training manuals for the mhGAP intervention guide for mental, neurological and substance use disorders in non-specialized health settings, version 2.0. World Health Organization (2017). p. 57–418. Available at: https://apps.who.int/iris/handle/10665/259161 (Accessed 3 July, 2023).

22. Geng EH, Bangsberg DR, Musinguzi N, Emenyonu N, Bwana MB, Yiannoutsos CT, et al. Understanding reasons for and outcomes of patients lost to follow-up in antiretroviral therapy programs in Africa through a sampling-based approach. *JAIDS J Acquir Immune Defic Syndr*. (2010) 53(3):405–11. doi: 10.1097/QAI.0b013e3181b843f0

23. Nyirandagijimana B, Edwards JK, Venables E, Ali E, Rusangwa C, Mukasakindi H, et al. Closing the gap: decentralising mental health care to primary care centres in one rural district of Rwanda. *Public Health Action*. (2017) 7(3):231–6. doi: 10.5588/pha.16.0130

24. Mooney M. Megatrends—ten new directions transforming our lives, by john naisbitt. New York: Warner books, 1982. 290 pages. $15.50. *Natl Product Rev*. (1983) 2(2):215–6. doi: 10.1002/npr.4040020216

25. Arcury TA, Gesler WM, Preisser JS, Sherman J, Spencer J, Perin J. The effects of geography and spatial behavior on health care utilization among the residents of a rural region. *Health Serv Res*. (2005) 40(1):135–55. doi: 10.1111/j.1475-6773.2005.00346.x

26. Parry SJ, Wilkinson E. Mental health services in Cambodia: an overview. *BJPsych Int*. (2020) 17(2):29–31. doi: 10.1192/bji.2019.24

27. Haven N, Dobson AE, Yusuf K, Kellermann S, Mutahunga B, Stewart AG, et al. Community-Based health insurance increased health care utilization and reduced mortality in children under-5, around bwindi community hospital, Uganda between 2015 and 2017. *Front Public Health*. (2018) 6:281. doi: 10.3389/fpubh.2018.00281

28. Ross LE, Vigod S, Wishart J, Waese M, Spence JD, Oliver J, et al. Barriers and facilitators to primary care for people with mental health and/or substance use issues: a qualitative study. *BMC Fam Pract*. (2015) 16(1):1–13. doi: 10.1186/s12875-014-0212-7

29. Roberts T, Shrivastava R, Koschorke M, Patel V, Shidhaye R, Rathod SD. Is there a medicine for these tensions?" barriers to treatment-seeking for depressive symptoms in rural India: a qualitative study. *Soc Sci Med*. (2020) 246:112741. doi: 10.1016/j.socscimed.2019.112741

30. Nsereko JR, Kizza D, Kigozi F, Ssebunnya J, Ndyanabangi S, Flisher AJ, et al. Stakeholder's perceptions of help-seeking behaviour among people with mental health problems in Uganda. *Int J Ment Health Syst*. (2011) 5(1):5. doi: 10.1186/1752-4458-5-5

31. Read U. "I want the one that will heal me completely so it won't come back again": the limits of antipsychotic medication in rural Ghana. *Transcult Psychiatry*. (2012) 49(3–4):438–60. doi: 10.1177/1363461512447070

32. Agasha DB, Edwin BMR, Baine SO. Effect of the eQuality health bwindi scheme on utilization of health services at bwindi community hospital in Uganda. *Front Public Health*. (2019) 7:71. doi: 10.3389/fpubh.2019.00071

33. Lund C, Tomlinson M, De Silva M, Fekadu A, Shidhaye R, Jordans M, et al. PRIME: a programme to reduce the treatment gap for mental disorders in five low- and middle-income countries. *PLoS Med*. (2012) 9:e1001359. doi: 10.1371/journal.pmed.1001359

34. Marx M, Hanslo G. PRIME impact report: improving mental healthcare in low and middle income countries. University of Cape Town; (cited 2023 May 16). Available at: https://zivahub.uct.ac.za/articles/book/PRIME_impact_report_improving_mental_healthcare_in_low_and_middle_income_countries/8058788/1 (2019).

35. Kokota D, Lund C, Ahrens J, Breuer E, Gilfillan S. Evaluation of mhGAP training for primary healthcare workers in mulanje, Malawi: a quasi-experimental and time series study. *Int J Ment Health Syst*. (2020) 14(1):3. doi: 10.1186/s13033-020-0337-0

36. Keynejad R, Spagnolo J, Thornicroft G. WHO Mental health gap action programme (mhGAP) intervention guide: updated systematic review on evidence and impact. *Evid Based Ment Health*. (2021) 24(3):124–30. doi: 10.1136/ebmental-2021-300254

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MOSAIC, an example of comprehensive and integrated social and health care: care and practices oriented towards personal recovery

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Background: The Mosaic project is a socio-health integration model that promotes the personal recovery of people with severe mental illness in a territory of Central Catalonia: the Bages region. The recovery approach in mental health care promotes meaningful activities and social inclusion for people with mental health disorders. The aim of this study is to examine the relationship between the level of meaningful activities and other factors associated with the mental health recovery model.
Methods: A cross-sectional design was used. Participants ($n = 59$) signed an informed consent and completed the following standardized instruments: Engagement in Meaningful Activities Survey; The Connor-Davidson Resilience Scale; Hert Hope Scale; and Recovery Assessment Scale.
Results: A Pearson correlation test was performed between the level of meaningful activities and life satisfaction, resilience, hope, and recovery. These data indicate that the amount of meaningful activities are strongly associated with variables related to the personal recovery process from mental health problems.
Conclusions: The integration process of MOSAIC confirms the need to accompany the recovery processes through significant occupations.

KEYWORDS

mental health recovery, personal recovery, integrated care, meaningful occupations, life project

1. Introduction

Social and health integration is a growing concern for governments, in a context of social and economic crises that demands efficiency (1–3).

Kodner and Spreeuwenberg defined the integration process as “a set of methods and models of financing, administration, organization, provision of services and clinical care designed to create connectivity, alignment and collaboration within and between the sector dedicated to caring [the social] and the sector dedicated to curing [health]” (4). Leutz (5) also emphasized this dimension of integrated care as a process, defining it as “the search to connect the health system”.

Integration processes between health and social services facilitate a continuum in the care of the population, focusing the intervention on the person's needs (person-centered care). In addition, it demonstrates a special interest in accompanying the person from a paradigm of the social determinants of health (relationships between the environment, habits and routines, and personal health). Finally, a basic preventive and promotional care has been promoted (6).

1.1. Recovery model: a new approach to mental health

Personal recovery refers to the ways in which a person manages a mental health problem trying to restore or develop a meaningful life project, as well as a sense of belonging and a positive perception of identity that is independent of a mental health problem (7, 8). Recovery is a process of change by which individuals improve their health and well-being, lead their lives autonomously and strive to achieve their full potential. This approach has its origins in the historic "recovery movement", which promoted, in the 1960s, the rights of people with mental health problems to receive decent therapeutic care as well as the consideration of the person with mental health problems as a competent individual that can make decisions about their life project and community functioning (9). At first, the initiatives focused on mental health laws, especially those that sanctioned involuntary and coercive interventions, but later changes were also proposed in the practice of mental health, especially from the appearance of new therapeutics, which would allow people with mental health problems to live in the community, and started the creation of rehabilitative resources in the community in order to cover the psychosocial needs of the affected people. Unfortunately, this historical context has often been overlooked in the transformation of services towards a recovery orientation, and thus that the concept has begun to lose its inspiration and ultimate goal, which is simply to restore people with severe mental disorders their sense of dignity, respect, self-esteem and citizenship (10). However, in recent decades, the concept of initial recovery has grown strongly in the treatment of people with mental health problems, mainly due to two pieces of scientific evidence: (a) 33% of people who show a severe mental health problem, such as schizophrenia, can recover without suffering any negative consequences and 67% show significant improvements over time; and (b) different studies have indicated that care focused on recovery (mainly, the positive expectation of having a meaningful life) predicts clinical improvement and adequate community functioning (11). In this way, in the first definitions of recovery, developed by Patricia Deegan and William Anthony, recovery implies the development of a new meaning and purpose in life, regardless of the limitations derived from the mental health problem (9).

Although this definition of recovery, due to its subjective nature, has usually been measured qualitatively, in recent years, objective instruments have emerged that assess this level of recovery (12), with an increasing number of studies that have identified the factors underlying this conceptualization. Factors, including sociodemographic (gender and age) or clinical (level of symptomatology) factors or more rehabilitative aspects, such as social functioning or cognition, would not be sufficient, although would, to a certain degree, be necessary, to achieve subjective or personal recovery, having identified the psychosocial variables that would have a main role in explaining recovery, such as empowerment, hope, quality of life, internalized stigma, perceived social support, social satisfaction, degree of recognition, loneliness and self-esteem (12, 13).

In the recovery model, the care provided by mental health professionals is characterized by a main function of supporting the affected person's life project in such a way that they provide integrated care, aimed at promoting personal (2, 14) recovery through techniques based on the evidence of shared decision making, advance directives in mental health, the peer strategy, and training and self-care in the physical, mental and social spheres. It is a model that promotes active citizenship in the defense and is aimed at claiming the rights of people with mental illness.

1.2. MOSAIC: care and practices oriented towards personal recovery

MOSAIC is a social initiative, coordinated with health, that promotes the quality of life of people who suffer from mental health problems and addictions in Central Catalonia. Specifically, the project is located in Manresa, capital of the Bages region, with its own idiosyncrasy: a semi-urban area dependent on the capital in a territorially dispersed territory. It is a pioneering initiative in Catalonia, and although the project has impacted a small number of people (due to the very capacity of the services), we believe that it can promote similar experiences in Catalan territory and generate more evidence.

The Mosaic legally depends on the Tomàs Canet Foundation and is managed with the participation of four other entities: the Germanes Dominiques de Santa Clara, the Order of Sant Joan de Déu, Manresa City Council and the Althaia Foundation.In the Convent of Santa Clara, the headquarters of the project, different social and health services come together with the aim of improving people's quality of life: (1) Work Program (WP), specialized social service that offers support and individualized advice in the search, access and maintenance of work; (2) Social Club (SC), a specialized social service that aims to increase participation and connection with the community; (3) Community Rehabilitation Service (CRS) is a specialized health service that develops different actions aimed at the psychosocial rehabilitation of people with mental disorders, which integrate the individual, group, family and community care levels to respond to their needs and personal characteristics; And (4) Individualized Service Plan (ISP) is a specialized health service that works according to an organizational model of case management and an assertive community intervention model, in order to guarantee the continuity of care and the maximum possible recovery in relation to people with a severe mental health disorders.

The fact that we can all recover does not mean that we will all do so at the same pace or following the same path (15). Mosaic adapts to the rhythm of the person. Each person must construct the meaning of his own life, he must find the resources that serve him for his well-being, he must strengthen or build an identity that is not defined by the pathology. The services are oriented towards recovery, defined as a process, that is to say, a whole set of small everyday actions that, done over time, help the person.

To better understand what Mosaic is and what its distinctive characteristics are, we can follow the US Substance Abuse and Mental Health Services Administration (SAMHSA), which proposes 10 Basic Principles of Recovery (16):

1. It comes from hope.
2. It is person-centered.
3. It occurs through many pathways.
4. It goes beyond professional care.
5. It is enriched with mutual support.
6. It assumes community.
7. It requires a comprehensive approach.
8. It is sensitive to diversity.
9. It is based on respect.
10. It requires addressing the trauma.

The last point is a very important one. Throughout our lives, people can experience painful situations that lead to a personal process that can be difficult to navigate (17, 18). A possible path towards acceptance of situations that have caused us suffering consists of facing some challenges. First of all, we need to become aware of our own experience and the possible changes that may arise in the social and relational sphere. Secondly, it is very important to have a space for the expression and management of the different emotions that can appear and overwhelm us such as sadness, anger, frustration, etc. Thirdly, we will often need to reset ourselves and not cling to the past. It is about adopting a hopeful vision of the new situation, of the present and the future, of strengthening the capacity for resilience to emerge strengthened and transformed from adversity.

1.3. Integrated care, a necessary challenge to address in mental health

As already mentioned, integrated care is a challenge for the world population (1–3) of which care for people with mental health problems is very present. There are two recent systematic reviews (2017 and 2022) that address the challenge. The first one (19) highlighted the efficacy demonstrated in the 172 experiences analyzed. However, it concluded with the need to obtain quality indicators, aimed at improving implementation.

In this line, Chan and his research team (20) exposed the precariousness of existing services in all health care for people with mental health problems. A very important detail of his research is the need for multidisciplinary teams with the aim of promoting transversal knowledge in the team. Finally, there is an Australian experience of integrated mental health care, designed on the personal recovery model (21). The need to promote evidence-based psychosocial interventions is highlighted, and to collaborate permanently with community organizations.

In this context, of the need to generate evidence on integration processes, in the paradigm of the personal recovery model, our study and the Mosaic project are of great importance. The need to identify quality indicators is vital to implement improvements in services and to be able to respond to a global public health problem.

1.4. Current context: a window of opportunity

The implementation of the perspective of recovery in the care of people with mental health problems is limited in our environment, but it is strongly considered in other countries, receiving the support of governments and public administrations, such as in the United States, New Zealand, Australia, England or Canada (22). This fact is mainly due to the fact that transformations must take place in mental health devices, and this implies that not only must the results be measured through recovery, but also that changes must be produced that promote recovery in the attitudes of professionals and in those of the people affected, so that resistance to change is softened (23–25). It is important to encourage citizen participation and orientation to the rights of people with mental illness (26).

In Catalonia, the community psychiatry resources that are using recovery-focused care characteristics, such as the Individualized Service Plan teams, use a modification of the assertive community treatment model, which provides comprehensive care (housing, socialization, symptoms, training, work, spirituality, among others); however, all Community Rehabilitation Services are prepared to provide it. On the other hand, programs, such as Activa't per la Salut Mental, promote the personal recovery model in the social and professional fabric of the country (26, 27). The objective of this program is to (1) accompany people with mental health problems in the construction of a life project and (2) promote social support networks.

At present, in Catalonia, there is a very propitious context to promote mental health interventions using the personal recovery model: the National Pact for Mental Health (PNSM). The PNSM (28) is the interdepartmental and intersectoral instrument of the Generalitat de Catalunya that, in line with the recommendations of the World Health Organization (29), promotes mental health from all spheres of action by the government and society. Among the objectives of the PNSM, we highlight that it (1) guarantees a comprehensive, responsible and community approach, placing people and their families at the center; (2) promotes a paradigm shift in public policies related to mental health so that it is concerned with the mental health of people at different stages of life and guarantees the right of affected people to full citizenship, community inclusion and job placement; and (3) includes the conclusions of the United Nations Convention on the Rights of Persons with Disabilities (30).

This article culminates the implementation project of the personal recovery model in Central Catalonia. The result of the project was three articles aimed at promoting practice and intervention models centered on the will of the people.

2. Materials and methods

2.1. Study design

A cross-sectional non-controlled follow-up study with ex post outcomes measurements was used. This is the third study of a 5-year investigation into the recovery model. This article was preceded by a (1) systematic review and (2) mixed methods approach. In this paper we focus on a quantitative approach.

This study examined the relationship between the level of meaningful activities and other factors associated with the mental health recovery pattern. The objective this study was to assess the effectiveness of the implementation of the recovery model in a sample of people with serious mental health problems treated at MOSAIC. Our hypothesis is that the implementation of the recovery model will lead to the correlation of meaningful occupation with recovery-oriented variables. The recommendations of the Declaration of Helsinki (WMA, 2015) were followed. All persons participating in the trial signed an informed consent for their participation. This project was evaluated by the Research Ethics Committee of the participating center: Fundació Unio Catalana Hospitals, CEI 19/09.

2.2. Participants

The study participants were people between 18 and 65 years of age; with a diagnosis of severe mental disorder (Schizophrenia and Psychotic Disorders Cluster; Bipolar Disorder and Major Affective Disorders Cluster; Personality Disorders); no gender difference; it is linked in the 4 services of Mosaic simultaneously; and willing to participate voluntarily. Exclusion criteria: ages under 18 years and over 65 years of age; present levels of high dependency and acute destabilization of the mental health problem; language difficulties in terms of understanding and expression of the Spanish or Catalan language; presence of head trauma, dementia or severe physical disability (disabling diseases that cause a disability greater than 80%) or intellectual disability ($IQ < 70$); not wanting to participate in the study voluntarily. Presenting comorbidity with substance use disorders, personality disorders and organic disorders were not reasons for exclusion.

A reference professional from each device assessed the suitability to participate of the people who meet the inclusion criteria and invited them to do so. This person also facilitated the documentation of the study and had the affected person sign the informed consent. Once the person signed the informed consent, they were entered into a database, where another professional outside the study carried out the coding.

2.2.1. Creation of a new structure

Integration processes require joint and coordinated work, in which professionals feel that they are part of the reorganization process. Therefore, three levels of coordination were defined in which all services were represented. (1) Driving group: Its role in the process is that of the design, start up and evaluation of the process. It is a multidisciplinary space, free for reflection, which is marked by a horizontal work dynamic. Its role, especially in the design and the first steps, was to define and mark the phases of the process. The participants in this group were: coordination project; WP; SC; CRS and ISP. Monthly meetings were held (2) Case management: Space in which all the referrals that reach MOSAIC are shared. It is a place where the first interview is reflected on based on the needs detected by the colleagues at the mental health center. It is a coordination space in which all the professionals who can potentially accompany the person are present: from professionals from the mental health center to colleagues from the social club. The frequency of the meetings was weekly. (3) Activities Commission: Place from where the joint activities of MOSAIC are designed. It follows the same multidisciplinary dynamic and the objective is to offer a range of occupations to the person from a broad perspective of recovery: health and healthy habits; work and active life; community; functioning. The existence of an internal management commission is responsible for optimizing communication channels. A periodicity of bimonthly meetings was maintained.

2.3. Intervention

The MOSAIC intervention is an example of support for people in the construction of their life project. The project's strategy focuses on comprehensive and integrated care, which revolves around a single entry mechanism for 4 services. Below we detail the actions of each service and how they integrate with each other.

- Work program. Resources that are available to users with the will and ability to work. It is important for job placement and training. The labor technical offices work to reduce the obstacles that hinder the insertion and permanence in the labor market of people diagnosed with a mental health disorder. The work methodology is based on individualized monitoring and support, and group work actions.
- Social Club. Self-managed voluntary resources for users with commissions, where different activities (workshops, outings …) are carried out according to their own will to promote social and community inclusion. The word “club” refers to a group of people who are organized collectively with common rules and objectives (sporting, recreational, cultural, etc.) in relation to shared hobbies. In the case of clubs for people with mental illness, there is a care aspect that is shaped by the work of a professional team and the rehabilitative orientation of their activity. The social club service is a program of support for integration and community insertion through leisure aimed at people with mental illness in a situation of dependency. It is based on the creation and

stimulation of relational links to improve the sense of belonging of the collective in the fight against social stigmatization.

- Community Rehabilitation Service. The community rehabilitation service is a public and free community rehabilitation service that offers care to older people with severe mental disorders where the personal, family and social rehabilitation and normalization of the user is worked on. The service is that therapeutic space, located at the heart of the community, which allows the user to remain integrated in their environment. It is aimed at the psychosocial rehabilitation of those people with a certain degree of autonomy and stability, and who do not present situations of acute decompensation. Different areas of the person served are worked on: social skills; the body; cognitive skills; occupational skills; the organization of leisure and free time; work skills; the family sphere; health education. Individualized service plan.
- Individualized care program aimed at the community of people who have a severe mental disorder. The professionals who make up these teams help the user connect to the health and social services he needs in his place of residence. Thus, the affected person learns to use existing resources of all kinds in an appropriate way to have their needs covered. Each professional will take about fifteen cases and will do so until the person has their deficiencies resolved.

In addition, a training program was designed based on the principles of the recovery model (11), specifically including recovery education training sessions (31, 32): emotional and material well-being of the participants; skills for the search and maintenance of meaningful occupations: work and leisure; promotion of social support networks and the care environment; and perspective of rights in the exercise of their citizenship (see **Table 1**).

In the recovery model, a basic premise is the participation of people with psychiatric life experience, as active agents in the process (11). At Mosaic they play an active role as facilitators of activities in the community rehabilitation service and in the social club: healthy habits, leisure and free time, culture. They are self-managed spaces where the presence of the professional is very reduced or absent and where the professional remains in the background.

TABLE 1 Education training sessions.

Health	
Emotional well-being	Material well-being
Satisfaction	Housing
Self-concept	Work placement
Absence of stress	Income
	Physical well-being
	Health care
	Sleep
	Health and its alterations
	Activities of daily life
Work and active life	
Personal development	Leisure
Limitations/capabilities	Relational
Access to new technologies	Cultural
Learning opportunities	Digital play
Work skills	
Functional skills	
Community	
Interpersonal relationships	Social inclusion
Social relations	Integration
Have clearly identified friends	Participation
Positive social relationships	Accessibility
Partner relationships and sexuality	Support
Family relationships	
Autonomous development	
Self-determination	Rights
Personal goals and preferences	Privacy
Autonomy	Knowledge and exercise of rights
Decisions	Respect
Elections	

2.3.1. Design of a single referral process

As has been commented, the existence of a motor group centralized the design of the project. However, a horizontal work environment was generated in which all decisions were agreed upon (equal power relations). The number of participants, between 6 and 8 people, represented all MOSAIC services. The function of the group, in addition to designing and structuring the implementation phase, was in charge of ensuring the correct implementation. The group as a whole has a long experience and connection to the project, which made it easier to adhere to the new proposed changes. The team is oriented in a perspective of accompanying recovery processes based on respect for the rights of the person.

Traditionally, to access MOSAIC services, mental health center professionals, mostly psychiatrists, activate a referral. With this model, it may be the case that a person has different references with the corresponding access interviews. The model we propose is to create a single referral channel to MOSAIC, reflecting personal needs (**Figure 1**). To achieve this, a new referral sheet (single) was designed in which the needs of the person in all their personal and social spheres were reflected. Once the referral reaches MOSAIC, it is the professionals who, based on a motivational interview, explore the person's needs. It will be at this time when, by mutual agreement, the inclusion of the person in one of the programs becomes effective. A single database is created, accessible to all workers, where the singularities of the person and their environment are widely collected (see **Supplementary Material S1**).

2.4. Outcome variables and measures

The objectives of this study were: Engagement in Meaningful Activities Survey; The Connor–Davidson resilience scale; Hope; Recovery. The measuring instruments were selected according to variables of the recovery model. A fact of great significance is that all instruments are self-applied.

(1) The Engagement in Meaningful Activities Survey (EMAS) (Cronbach's $\alpha = 0.91$) reflects multiple proposals for occupational therapy and occupational science that address

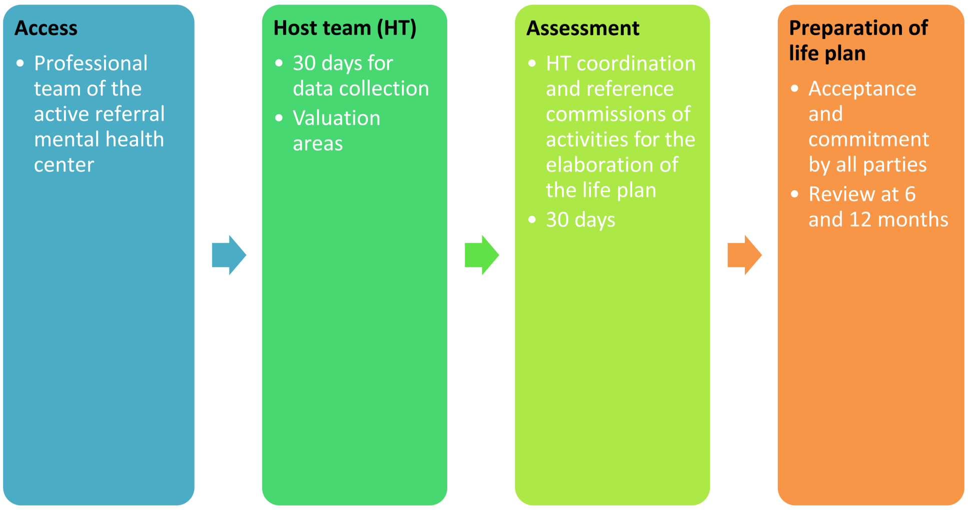

FIGURE 1
Access MOSAIC services.

constituents of meaningful engagement. The EMAS addresses the assessment of the meaning of an occupation by bringing together diverse viewpoints on meaning and employment (33).

(2) The Connor–Davidson Resilience Scale (CD-RISC) (34) consists of 25 items with a Likert-type response format with five response options ("not at all", "rarely", "sometimes", "often" and "almost always"), scored from 0 ("not at all") to 4 ("almost always"). The Spanish version of the 10-item CD-RISC has a Cronbach α coefficient of 0.85 and the test–retest intraclass correlation coefficient of 0.71 (35).

(3) General Self-Efficacy Scale (GAS) (Schwarzer, 1993), in the Baessler and Schwarzer (1996) version. It consists of 10 items with responses on Likert-type scales of 5 points between 1 (totally disagree) to 5 (totally agree). Scores between 27 and 38 points show an average of general self-efficacy. This is reliable with values of $\alpha = .87$ for the Spanish version (36).

(4) The Herth Hope Scale (37) was designed to measure goal-directed thinking across different situations. It is composed of 12 items that measure pathways and agency components by means of 4 items each, and 4 more filler items are added. In the validation studies, it had a high internal consistency ($\alpha = .97$) and adequate divergent validity with hopelessness of −.77 (38).

(5) The Recovery Assessment Scale-revised (RAS-R) (Cronbach's alpha ranging between $\alpha = 0.93$ and $\omega = 0.95$) is a self-applied instrument that measures personal recovery, developed over 20 years ago by Gifford and colleagues in the United States. The RAS-R consists of 24 items on a five-level scale "strongly disagree," "disagree," "not sure," "agree," and "strongly agree" (39).

2.5. Data collection procedures

Over the course of 12 months (September 2019–June 2020) a cross-sectional sample was identified by professionals, with prior training to unify data collection criteria, from all the participants included in the study. The team of researchers explained the research project to all the participants of Mosaic, a meeting where the inclusion criteria and the different phases of the research were detailed. Next, the reference professionals will explain again only to those people who met the inclusion criteria. Finally, their consent was collected in case of expressing a will to continue with the investigation. The reference professionals explained each of the measures (self-applied) to the study participants, giving them the opportunity to fill them in at home. Once the study participants had the measurements, the reference professional followed closely, where he accompanied the person in any doubts. Once the scales were completed, they handed them to their referral professional. The measures were shielded in order to maintain the anonymity of the responses. Finally, these were delivered to the research team and were entered into the database.

2.6. Data analysis

Two researchers (G.P. and I.C.) used the SPSS software (version 28.0). Pearson correlation tests were carried out to study the relationship between significant employment and the different factors using the statistical package SPSS/PC + (v. 28.0). Bonferroni correction was used to adjust the alpha to the multiple correlations.

3. Results

3.1. Demographic characteristics of the participants

The basic characteristics of the participants are shown in Table 2. A total of 59 participants were included, with a mean

TABLE 2 Sociodemographic and clinical profile.

Characteristics	Participants ($N = 59$)
Age (mean, SD)	49.0 (±11.0)
Gender (% women)	47
Diagnosis (% psychosis)	42
Civil status (% single)	67.3
Family unit (% alone)	36
Income (% disability benefit)	40
Education (% basic)	60

TABLE 4 Correlation coefficients with meaningful activities ($n = 59$).

Variable	r	p	B	t	95% CI
1. Self-efficacy	0.349	0.012	−0.012	0.134	(0.049, 0.584)
2. Personal recovery	0.414	0.003*	−0.010	0.128	(0.140, 0.628)
3. Hope	0.400	0.004*	−0.001	0.109	(0.175, 0.605)
4. Resilience	0.360	0.009	−0.011	0.150	(0.038, 0.605)

R, Pearson correlation; B, Bias; t, standard error; CI, confidence interval.
*Correlation is significant at the 0.005 level.

age of 49.0 ± 11.0 years. Of these, 47% were women, 67.3% were single, 42% had a diagnosis of psychosis, 60% had a basic level of education and 40% received income from disability benefits. Despite having a small sample, responses were collected from 80% of people who met inclusion criteria.

3.2. Correlation analysis

The correlation matrix for the key variables is presented in Table 3.

The scores obtained from EMAS reflect a perception of the meaning of their activities as moderate (39.76). Meaningful activities was significantly correlated with self-efficacy ($r = 0,112$, $p < 0,05$); recovery ($r = 0,414$, $p < 0,01$); hope ($r = 0,400$, $p < 0,01$); resilience ($r = 0,360$, $p < 0,01$).

On the other hand, the GSE results place the perception of self-efficacy at an intermediate point (24.25), on a scale from 10 to 40, which indicates more self-efficacy. Self-Efficacy was significantly correlated with meaningful activities ($r = 0,349$, $p < 0,01$); empowerment ($r = 0,437$, $p < 0,05$); hope ($r = 0,480$, $p < 0,01$); resilience ($r = 0,384$, $p < 0,01$); and self-stigma ($r = 0,396$, $p < 0,01$).

Continuing with the description of the results, a RASR score of 76.90 is observed. Recovery was significantly correlated with meaningful activities ($r = 0,014$, $p < 0,01$); hope ($r = 0,439$, $p < 0,01$); resilience ($r = 0,294$, $p < 0,05$.

Continuing with the analysis, HHS stood at a score of 21.21 out of 48, with higher scores indicating greater hopefulness. Hope was significantly correlated with self-efficacy ($r = 0,480$, $p < 0,01$); meaningful activities ($r = 0,400$, $p < 0,01$); recovery ($r = 0,439$, $p < 0,01$); resilience ($r = 0,333$, $p < 0,01$).

Finally, a CD-RISC score of 50.55 out of 100 can be observed, with higher scores corresponding to higher levels of resilience. Resilience was significantly correlated with self-efficacy ($r = 0,384$, $p < 0,01$); meaningful activities ($r = 0,360$, $p < 0,01$); recovery ($r = 0,294$, $p < 0,01$); and hope ($r = 0,333$, $p < 0,05$).

After applying the Bonferroni correction ($p < 0,005$), significant positive relationships were observed between meaningful employment and the personal recovery scale ($p = 0,003$); hope ($p = 0,004$); life satisfaction ($p = 0,002$); perceived social support ($p = 0,005$); and empowerment ($p = 0,001$). The correlation coefficients with meaningful activities are presented in Table 4.

4. Discussion

The work addresses a topic of special relevance in the context of Catalonia (28), given a problem of global interest: the care of the person in an integral and holistic way (1–3, 19, 20). The document has identified quality indicators aimed at personal recovery (21). We believe that despite the small sample in which the project has impacted, the study facilitates the promotion of health and social integration experiences. Especially in semi-urban and rural environments, which are the usual norm except for the metropolitan area of Barcelona.

Our article contributes to the construction of evidence and to consolidate the paradigm of personal recovery in comprehensive care in Catalonia. There is evidence of the recovery model that is in tune with the results obtained (40, 41). People in recovery must be involved in all aspects and phases of the process. Thus, recovery-oriented care is characterized by:

(1) Contemplating the promotion of a positive self-concept and identity;
(2) The development of a life project beyond the mental health problem;
(3) With the hope of being able to carry it out;
(4) The promotion of self-responsibility regarding both the life project and its therapeutic process;

TABLE 3 Descriptive statistics and correlations among the key variables ($n = 59$).

Variable	Mean (SD)	1	2	3	4	5	6	7	8	9
1. Self-efficacy	24.25 (4.53)		0.349*	0.222	0.437*	0.480**	0.228	0.384**	0.396**	0.152
2. Meaningful activities	39.76 (7.03)	0.112*		0.414**	0.489**	0.400**	0.368**	0.360**	0.415**	0.385**
3. Personal recovery	76.90 (13.50)	0.117	0.014**		0.465**	0.439**	0.231	0.294*	0.272	0.438**
4. Hope	21.21 (3.53)	0.480**	0.400**	0.439**	0.440**		0.082	0.333*	0.126	0.106
5. Resilience	50.55 (11.71)	0.384**	0.360**	0.294*	0.419**	0.333*	0.407**		0.054	0.189

SD, standard desviation.
*Correlation is significant at the 0.05 level.
**Correlation is significant at the 0.01 level.

(5) Facilitating the creation of support and a social network;
(6) Providing tools and fostering skills to manage the disease; and
(7) Increase resilience to stressful life situations and the stigma associated with the disease (42).

All human beings are occupational beings who interact in an environment. One of the objectives of all humans is to develop occupations that are interesting to us and afford value to our existence. The results obtained in this study are in line with those of Meyer (precursor of occupational therapy), who noted the need to accompany the person through meaningful occupations (43). Contemporary authors, such as Simó-Algado and Guzmán (44), have emphasized the need to weave a life project through meaningful occupations.

4.1. In search of meaningful activities

Hope in moments of fragility is a transformative mechanism that promotes change and recovery, and is a pillar of the personal recovery model. Many individuals with mental health problems show confusion in the initial phases, families lack tools and the associated stigma in our communities has an impact on the recovery process (45).

Studies such as the one by Nuslang commented on the need to incorporate hope as a central element of the intervention (46), and in the pilot peer to peer test, the participants' narratives highlighted the importance of having a meaningful occupation (47).

However, how do we promote it in our services? In the study by Hayes (48), the levels of hope between the community population and people with mental health problems were compared, obtaining significantly lower results in the study group. The conclusions they reached is that it is difficult to foster hope if the person with mental health problems has serious symptoms.

Next, we reflected on how we can generate a feeling of hope in people. As we observed in our systematic review, mutual support networks, sharing with an equal weight, are a cross element (49). MOSAIC promotes an occupational environment in which to share and forge bonds and increase social support networks. Another important aspect that the research has shown is the impact of meaningful occupations on the perception of quality of life and resilience of the participants. Both aspects have a great impact on the recovery process and are interrelated. In a study carried out in Canada (50), a direct relationship was observed: the higher the quality of life, the higher the levels of resilience. In addition, Hadebe and Ramakumba noted the importance of social networks, which influence a greater resilience in people (51).

Participation in meaningful occupations affords meaning to the recovery process and promotes resilience strategies in the face of a possible traumatic situation (52). Additionally, we found studies that support the results regarding the existing correlation between EMAS and the perception of self-efficacy (53).

This is fully consistent with the MOSAIC project and the need to establish integration processes between health and social services. It is also an opportunity to generate multidisciplinary projects and interventions, with professionals who carry in their essence a critical reflection on their praxis. These new figures are essential, as we showed, to promote an atmosphere of hope in the recovery process (54).

In addition, the construction of a meaningful life process based on meaningful occupations is key, not only because it gives hope (the basis of recovery), but also because it is essential for the person to develop full citizenship and contribute to their society as a citizen of law (55). The exercise of citizenship entails the freedom to participate in society and to be able to decide one's life. A dignified life for each person and that corresponds to the possibilities of personal fulfillment and access to opportunities to live in health. It is a process of construction of identity and belonging (13, 26, 29).

A transcendental factor to promote full citizenship, and personal recovery, is to co-create together with the community. Studies such as the systematic review of Chan et al. (20) strongly recommend generating synergies with community assets. For this, it is essential to co-create community mental health interventions (26, 27) with the objective that people become health assets. Participating in the community and having a meaningful life project is a human right (25, 30).

4.2. Limitations

The present study has, of course, some limitations. The first of these is the small sample size. Mosaic's target population is a small *n* (compared to the studies cited), and the number of participants with inclusion criteria is low. This is related to the reference population of the different services that participate in Mosaic. Another situation that marked (and surely conditioned the study) was the COVID19 pandemic. The data collection process was inactive for a few weeks due to the impossibility of monitoring. This means that not all participants are in the same recovery process.

4.3. Recommendations for practice and research

In the midst of a debate on the reformulation of the mental health care system for citizens, this study shows a case of success in the territory. The results obtained are a weighty argument to replicate and generate more integration experiences. The potentiality of relevant activities (significant occupations) with the personal recovery process indicates the need to plan interventions from a holistic and comprehensive perspective.

Future research needs to quantify the impact of the intervention on the outcomes described. The project lays the foundations for an RCT, which will make it possible to build evidence around integration processes from a perspective of personal recovery in mental health. RCTs of mixed methods are recommended that allow the triangulation of the results and a better understanding of the reality analyzed. Finally, it is crucial to incorporate the perspective of territorial equity and propose projects in urban areas with high population density.

5. Conclusions

These data indicate that the number of meaningful activities is strongly associated with variables related to the process of personal recovery from mental health problems. Subsequent studies should determine the functional weight of these variables in the performance of significant occupations.

The integration process of MOSAIC confirms the need to accompany the recovery processes through significant occupations. Variables, such as hope and resilience, are pillars in the personal recovery model, both closely related to the performance of meaningful occupations.

Finally, we highlighted the processes of social and health integration as an opportunity to include professionals with a critical vision (occupational therapists and social workers) and complement the prevailing clinical view of the health system.

The study has connected significant occupation as a human right to exercise full citizenship, in which hope is the pillar of personal recovery.

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 study was conducted in accordance with the Declaration of Helsinki, and approved by the Ethics Committee of Fundació Unio Catalana Hospitals (CEI 19/09, 03/04/2019). The patients/participants provided their written informed consent to participate in this study.

Author contributions

Conceptualization, IC-P, GP-V, and SS-A; methodology, IC-P and GP-V; software, IC-P and GP-V; validation, IC-P, GP-V, and SS-A; formal analysis, IC-P and GP-V; investigation, IC-P; resources, IC-P, GP-V, RV-M, GL-F, AG-C, and RGP; data curation, IC-P, GP-V, RV-M, GL-F, AG-C, and RGP; writing—original draft preparation, IC-P; writing—review and editing, IC-P, GP-V, and SS-A; visualization, IC-P, GP-V, SS-A, RV-M, GL-F, AG-C, and RGP; supervision, GP-V and SS-A. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

Publisher's note

Supplementary material

The Supplementary Material for this article can be found online at: https://www.frontiersin.org/articles/10.3389/frhs.2023.1174594/full#supplementary-material

References

1. Gröne O, Garcia-Barbero M, WHO European office for integrated health care services. Integrated care: a position paper of the WHO European office for integrated health care services. *Int J Integr Care.* (2001) 1:e21. doi: 10.5334/ijic.28

2. Frost BG, Tirupati S, Johnston S, Turrell M, Lewin TJ, Sly KA, et al. An integrated recovery-oriented model (IRM) for mental health services: evolution and challenges. *BMC Psychiatry.* (2017) 17:1. doi: 10.1186/s12888-016-1164-3

3. Baxter S, Johnson M, Chambers D, Sutton A, Goyder E, Booth A. The effects of integrated care: a systematic review of UK and international evidence. *BMC Health Serv Res.* (2018) 18:1. doi: 10.1186/s12913-018-3161-3

4. Kodner DL, Spreeuwenberg C. Integrated care: meaning, logic, applications, and implications–a discussion paper. *Int J Integr Care.* (2002) 2:e12. doi: 10.5334/ijic.67

5. Leutz WN. Five laws for integrating medical and social services: lessons from the United States and the United Kingdom. *Milbank Q.* (1999) 77:77-v. doi: 10.1111/1468-0009.00125

6. Valentijn PP, van Es Institute J, Opheij W, Gudde T, Bruijnzeels MA. Understanding integrated care: a comprehensive conceptual framework based on the integrative functions of primary care. *Int J Integr Care.* (2013) 13:e010. doi: 10.5334/ijic.886

7. Davidson L. Recovery, self management and the expert patient—changing the culture of mental health from a UK perspective. *J Ment Health*. (2005) 14:25–35. doi: 10.1080/09638230500047968

8. Slade M, Williams J, Bird V, Leamy M, Le Boutillier C. Recovery grows up. *J Ment Health*. (2012) 21:99–103. doi: 10.3109/09638237.2012.670888

9. Anthony WA. Recovery from mental illness: the guiding vision of the mental health service system in the 1990s. *Psychosoc Rehabil J*. (1993) 16:11–23. doi: 10.1037/h0095655

10. Rowe M, Davidson L. Recovering citizenship. *Isr J Psychiatry Relat Sci*. (2016) 53:14–20. https://cdn.doctorsonly.co.il/2016/08/04_Rowe_Recovering-Citizenship.pdf

11. Slade M, Amering M, Farkas M, Hamilton B, O'Hagan M, Panther G, et al. Uses and abuses of recovery: implementing recovery-oriented practices in mental health systems. *World Psychiatry*. (2014) 13:12–20. doi: 10.1002/wps.20084

12. Slade M. Measuring recovery in mental health services. *Isr J Psychiatry Relat Sci*. (2010) 47:206–12. https://doctorsonly.co.il/wp-content/uploads/2011/12/2010_3_6.pdf

13. Slade M. Mental illness and well-being: the central importance of positive psychology and recovery approaches. *BMC Health Serv Res*. (2010) 10:26. doi: 10.1186/1472-6963-10-26

14. Davidson L, White W. The concept of recovery as an organizing principle for integrating mental health and addiction services. *J Behav Health Serv Res*. (2007) 34:109–20. doi: 10.1007/s11414-007-9053-7

15. Rubashkin N, Warnock R, Diamond-Smith N. A systematic review of person-centered care interventions to improve quality of facility-based delivery. *Reprod Health*. (2018) 15(1):169. doi: 10.1186/s12978-018-0588-2

16. Substance Abuse and Mental Health Services Administration (USA). SAMHSA's working definition of recovery. 10. Guiding principles of recovery. (2012).

17. Fenwick-Smith A, Dahlberg EE, Thompson SC. Systematic review of resilience-enhancing, universal, primary school-based mental health promotion programs. *BMC Psychol*. (2018) 6(1):30. doi: 10.1186/s40359-018-0242-3

18. Chuang SP, Wu JYW, Wang CS. Resilience and quality of life in people with mental illness: a systematic review and meta-analysis. *Neuropsychiatr Dis Treat*. (2023) 19:507–14. doi: 10.2147/NDT.S392332

19. Sunderji N, Ion A, Ghavam-Rassoul A, Abate A. Evaluating the implementation of integrated mental health care: a systematic review to guide the development of quality measures. *Psychiatr Serv*. (2017) 68(9):891–8. doi: 10.1176/appi.ps.201600464

20. Chan V, Toccalino D, Omar S, Shah R, Colantonio A. A systematic review on integrated care for traumatic brain injury, mental health, and substance use. *PLoS One*. (2022) 17(3):e0264116. doi: 10.1371/journal.pone.0264116

21. Frost BG, Tirupati S, Johnston S, Turrell M, Lewin TJ, Sly KA, et al. An integrated recovery-oriented model (IRM) for mental health services: evolution and challenges. *BMC Psychiatry*. (2017) 17(1):22. doi: 10.1186/s12888-016-1164-3

22. Weaver N. Recovery and care continuity experiences of people in mental health care: a conciliatory approach to the challenge of implementing recovery-based services. *Sociol Health Illn*. (2021) 43:1996–2014. doi: 10.1111/1467-9566.13373

23. Khan N, Tracy D. The challenges and necessity of situating "illness narratives" in recovery and mental health treatment. *BJPsych Bull*. (2022) 46:77–82. doi: 10.1192/bjb.2021.4

24. Dubreucq J, Plasse J, Gabayet F, Faraldo M, Blanc O, Chereau I, et al. Stigma resistance is associated with advanced stages of personal recovery in serious mental illness patients enrolled in psychiatric rehabilitation. *Psychol Med*. (2022) 52:2155–65. doi: 10.1017/S0033291720004055

25. Onocko-Campos R, Davidson L, Desviat M. Salud mental y derechos humanos: desafíos para servicios de salud y comunidades mental health and human rights: challenges for health services and communities. *Salud Colect*. (2021) 17:e3488. doi: 10.18294/sc.2021.3488

26. Sampietro HM, Gavaldà Castet C. Manual per a la recuperació i l'autogestio del benestar [Manual for recovery and self-management of well-being]. Activa't per la Salut Mental (2018). Available at: https://activatperlasalutmental.org/wp-content/uploads/2023/06/salut_mental_cat_LF_web-1.pdf

27. Rojo Rodés E, San Pío Tendero MJ, Eiroa Orosa F, Marcet G. Get active for mental health: a project evaluated for active involvement of families and users. *Int J Integr Care*. (2019) 19:419. doi: 10.5334/ijic.s3419

28. Generalitat de Catalunya. *ACORD GOV/176/2021, de 9 de novembre, pel qual es crea el Programa per a l'elaboració del Pacte Nacional de Salut Mental [AGREEMENT GOV/176/2021, of November 9, which creates the program for the preparation of the national mental health pact]*. Barcelona: Departament de la Presidència (2021). https://portaldogc.gencat.cat/utilsEADOP/PDF/8540/1877946.pdf

29. Funk M, Drew N. WHO QualityRights: transforming mental health services. *Lancet Psychiatry*. (2017) 4:826–7. doi: 10.1016/S2215-0366(17)30271-7

30. United Nations. Convention on the rights of persons with disabilities (2006). Available at: http://www.un.org/esa/socdev/enable/rights/convtexte.htm

31. Hutchinson DS, Gagne C, Bowers A, Russinova Z, Skrinar GS, Anthony WA. A framework for health promotion services for people with psychiatric disabilities. *Psychiatr Rehabil J*. (2006) 29(4):241–50. doi: 10.2975/29.2006.241.250

32. Foster G, Taylor SJ, Eldridge SE, Ramsay J, Griffiths CJ. Self-management education programmes by lay leaders for people with chronic conditions. *Cochrane Database Syst Rev*. (2007) 4:CD005108. doi: 10.1002/14651858.CD005108.pub2

33. Prat G, Ribot A, Recoder S, Muñoz F. Psychometric properties of the Spanish version of the engagement in meaningful activities survey in people with serious mental illness. *Br J Occup Ther*. (2019) 82:743–9. doi: 10.1177/0308022619856557

34. Connor KM, Davidson JR. Development of a new resilience scale: the connor-davidson resilience scale (CD-RISC). *Depress Anxiety*. (2003) 18:76–82. doi: 10.1002/da.10113

35. Notario-Pacheco B, Solera-Martínez M, Serrano-Parra MD, Bartolomé-Gutiérrez R, García-Campayo J, Martínez-Vizcaíno V. Reliability and validity of the Spanish version of the 10-item connor-davidson resilience scale (10-item CD-RISC) in young adults. *Health Qual Life Outcomes*. (2011) 9:63. doi: 10.1186/1477-7525-9-63

36. Sanjuán Suárez P, Pérez García AM, Bermúdez Moreno J. Escala de autoeficacia general: datos psicométricos de la adaptación para población española the general self-efficacy scale: psychometric data from the Spanish adaptation. *Psicothema*. (2000) 12:509–13. https://www.psicothema.com/pdf/615.pdf

37. Herth K. Abbreviated instrument to measure hope: development and psychometric evaluation. *J Adv Nurs*. (1992) 17:1251–9. doi: 10.1111/j.1365-2648.1992.tb01843.x

38. Sánchez-Teruel D, Robles-Bello MA, Camacho-Conde JA. Validity of the spanish version of the herth hope index and the beck hopelessness scale in people who have attempted suicide. *Actas Esp Psiquiatr*. (2020) 48:163–8. https://www.actaspsiquiatria.es/repositorio//22/126/ENG/22-126-ENG-163-8-562420.pdf

39. Saavedra J, Vázquez-Morejón AJ, Vázquez-Morejón R, Arias-Sánchez S, González-Álvarez S, Corrigan P. Spanish validation of the recovery assessment scale. *Psicothema*. (2021) 33:500–8. doi: 10.7334/psicothema2021.52

40. Pérez-Corrales J, Huertas-Hoyas E, García-Bravo C, Güeita-Rodríguez J, Palacios-Ceña D. Volunteering as a meaningful occupation in the process of recovery from serious mental illness: a qualitative study. *Am J Occup Ther*. (2022) 76(2):7602205090. doi: 10.5014/ajot.2022.045104

41. Leamy M, Bird V, Le Boutillier C, Williams J, Slade M. Conceptual framework for personal recovery in mental health: systematic review and narrative synthesis. *Br J Psychiatry*. (2011) 199:445–52. doi: 10.1192/bjp.bp.110.083733

42. Lipskaya-Velikovsky L, Krupa T, Silvan-Kosovich I, Kotler M. Occupation-focused intervention for in-patient mental health settings: pilot study of effectiveness. *J Psychiatr Res*. (2020) 125:45–51. doi: 10.1016/j.jpsychires.2020.03.004

43. Meyer A. The philosophy of occupational therapy. *Arch Occup Ther*. (1922) 1:1–10.

44. Simó-Algado S, Guzman S. Construyendo proyectos de vida con personas supervivientes de enfermedad mental [Building life projects with survivors of mental illness.] *RevistaTOG*. (2014) 11:1–25. http://www.revistatog.com/num19pdfs/maestros.pdf

45. Boehnlein JK, Kinzie JM. Experiencing mental illness: suffering, hope, and healing. *Narrat Inq Bioeth*. (2021) 11:189–94. doi: 10.1353/nib.2021.0070

46. Naslund JA, Aschbrenner KA, Marsch LA, Bartels SJ. The future of mental health care: peer-to-peer support and social media. *Epidemiol Psychiatr Sci*. (2016) 25(2):113–22. doi: 10.1017/S2045796015001067

47. Prat Vigué G, Cano Prieto I, Del Río Sáez R, Vilanova Masana R, Simó Algado S. Training peer support workers in mental health care: a mixed methods study in central catalonia. *Front Psychiatry*. (2022) 13:791724. doi: 10.3389/fpsyt.2022.791724

48. Hayes L, Herrman H, Castle D, Harvey C. Hope, recovery and symptoms: the importance of hope for people living with severe mental illness. *Australas Psychiatry*. (2017) 25:583–7. doi: 10.1177/1039856217726693

49. Cano-Prieto I, Simó-Algado S, Prat-Vigué G. Peer interventions in severe mental illnesses: a systematic review and its relation to occupational therapy. *Occup Ther Ment Health*. (2022) 39(2):99–136. doi: 10.1080/0164212X.2022.2085645

50. Mejia-Lancheros C, Woodhall-Melnik J, Wang R, Hwang SW, Stergiopoulos V, Durbin A. Associations of resilience with quality of life levels in adults experiencing homelessness and mental illness: a longitudinal study. *Health Qual Life Outcomes*. (2021) 19:74. doi: 10.1186/s12955-021-01713-z

51. Hadebe NF, Ramukumba TS. Resilience and social support of young adults living with mental illness in the city of Tshwane, Gauteng province, South Africa. *Curationis*. (2020) 43:e1–e7. doi: 10.4102/curationis.v43i1.2084

52. Frankl VE. *Man's search for meaning*. Boston, MA: United States: Beacon Press (1959).

53. Strong S. Meaningful work in supportive environments: experiences with the recovery process. *Am J Occup Ther*. (1998) 52:31–8. doi: 10.5014/ajot.52.1.31

54. Kovic M, Algado SS. Hope. *Interinst Braz J Occup Ther*. (2020) 4:131–6. doi: 10.47222/2526-3544.rbto32876

55. Eiroa-Orosa FJ, Rowe M. Taking the concept of citizenship in mental health across countries. Reflections on transferring principles and practice to different sociocultural contexts. *Front Psychol*. (2017) 8:1020. doi: 10.3389/fpsyg.2017.01020

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The role of self-endangering cognitions between long-term care nurses' altruistic job motives and exhaustion

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Background: Due to demographic change and staff shortages nurses suffer under high work strain. As a consequence, caregivers' absenteeism due to mental stress, in particular burnout, is high. To explain the development of nurses' burnout more research is needed on nurses' individual resources and coping strategies. Self-endangering is a potentially harmful coping strategy.

Objective: To expand the perspective of the Job Demand-Resources Model by including caregivers' intraindividual resources and the coping construct of self-endangering as a mediator between personal resources and nurses' emotional exhaustion.

Methods: A longitudinal questionnaire survey was conducted between July 2020—March 2021 among nurses in long-term care in Germany. The final analysis sample consisted of *wave 1* = 416 and *wave 1,2* = 50. Data were analysed by a multiverse analytic strategy using regression analysis with measurement repetition and cross-lagged-panel design for waves one and two. Variables used for regression analysis and cross-lagged-panel were: Independent variables: An altruistic job motivation, team identification and self-esteem, dependent variables: Exhaustion and disengagement, and mediators: Self-endangering cognitions and behavior tendencies.

Results: A highly altruistic job motivation leads to more self-endangering cognitions and to more self-endangering behavior tendencies. Mixed model analysis and cross-sectional path analysis confirmed mediation effects from altruism over self-endangering to exhaustion.

Conclusion: Our findings are at odds with some research findings about altruism in nursing, such that too much altruism can lead to harmful self-endangering. We also introduce a new instrument to capture self-endangering in nursing care. Future research should investigate various facets of self-endangering in nursing. We assume that leadership behavior could have influence on self-endangering. New health policy structures are needed to improve working conditions in nursing and thus prevent self-endangering.

KEYWORDS

self-esteem, self-endangering behavior, altruim, coping, burnout, self-endangering cognitions, nursing

Introduction

Even before the coronavirus disease (COVID-19) pandemic, there was a known global shortage of nursing staff in the health care system (1). Nevertheless, the pandemic has made it even clearer: The staff shortage in nursing as a result of overwork and poor working conditions is enormous. Further, the pandemic put nurses under overwhelming pressure and in consequence has led to increasing numbers of nurses leaving the profession (2). As a result of nurses' working conditions, the increased workload, and extra work due to a lack of staff, burnout is rampant (3), and there is mass trauma among nurses (4). In addition, the number of people in need of care has been rising for years; this development alone has resulted in an increasing demand for nurses in the coming decades (1).

Due to these and future developments in the health care system, the importance of a motivated and healthy nursing staff is greater than ever, because this is the only way to meet the demographic challenges. What can be done to protect the mental health of remaining nurses and to maintain their ability to work?

Shift work, frequent overtime and filling in on days off, and the difficulty of separating oneself from work (5) are just a few examples of the highly demanding working conditions in nursing. Due to this, nurses need to have very high levels of self-directed action, communication skills, and self-organization abilities (6), which is why both individual prevention and organization of work are particularly important in protecting nurses' health. Various research projects have already developed prevention action guidelines and training programs for individual resources (7) and organization structures (8) in everyday nursing care, such as in Germany "Working happily and healthy in geriatric care" (8), "Healthy working conditions in care facilities" (8), "Care for caregivers: Development and anchoring of an empathy-based relief concept in care work (empCARE)" (7). However, considering the still high number of stresses, absenteeism from work due to mental disorders (9), and career interruptions (2), the question arises as to what care institutions are aware of, using, and successfully implementing these programs and guidelines. We therefore argue that the continuous high level of nurses' burnout (3) as a result of high demands calls for new strategies in dealing with the challenges for nurses and care organizations that go beyond previous findings in the area of demands and resources.

Regarding individual resources, studies have found that organizational interventions that ignore nurses' individual factors cannot sustainably reduce exhaustion and that coping strategies and improving nurses' resilience are important for decreasing burnout (10). As for other individual factors, recent studies found that although being altruistically motivated (11) or highly identified with the team (12) leads to improvements in nurses' burnout, qualitative results show divergent trends (13).

By considering self-endangering as an important coping strategy in nursing, we see great potential for a broader perspective for nurses' training programs (13). Self-endangering is a coping strategy when employees are confronted with high workloads and demands for self-organization; the strategy is functional for reaching work goals but dysfunctional for health (14). There are only few studies available on the long-term effects of self-endangering, but Baeriswyl et al. (2014) (15) found detrimental effects on teachers' well-being, and Knecht et al. (2017) (16) found that self-endangering work behaviors might partly explain the association between work demands and exhaustion.

We hope to contribute to research on nurses' occupational health by expanding the job demands-resources model (JD-R) (17) to include personal characteristics and the construct of self-endangering as a mediator between personal resources and nurses' emotional exhaustion. We thus hope that our results can also help make interventions for caregivers more effective by addressing individual characteristics and needs and strengthening coping strategies.

We investigated our hypotheses in a three-wave questionnaire survey of nurses in long-term care in Germany from June 2020 to April 2021. For this, we contacted nursing homes in Germany about participating in the study and in addition shared the online questionnaire link in various social media nursing groups.

For predicting employees' exhaustion, the JD-R theory appears relevant. According to the JD-R, job characteristics consist of two dimensions, job resources and job demands (18). Job demands in nursing are in general work pressure, work time or staff capacities, and emotional demands, such as having to deal with death and dying or generally to interact with patients and relatives (19). Meaningful job resources in nursing are social relations, management support, decision latitude, and task significance (19).

As personality patterns and coping strategies (20, 21) have a potentially great influence on the way people deal with stress, such that based on the transactional stress theory, coping reactions mediate the effect of stress on well-being (22), a nursing specific demand-resources model emphasizes the effects of individual characteristics and resources and the coping strategy self-endangering (13).

Antecedents of self-endangering in nursing care

Self-endangering work behavior can be understood as a coping strategy in highly demanding working situations (14). It is defined as "actions that aim to deal with work-related demands but simultaneously increase the likelihood of health problems and impede necessary recovery from work-related stress" (14).

We understand self-endangering in nursing as self-sacrificing cognitions and behavior, such that nurses have their "own inner beliefs with regard to having a moral obligation to fill in for colleagues at the expense of their own health" and in consequence have a "diminished ability to say no when asked to fill in or to do work overtime" (13). Therefore, self-endangering in nursing is a coping strategy for dealing with high demands in nursing care based on nurses' individual attitudes and values and personality traits, which in the long term worsens psychological well-being.

Although an interest in professional success justifies self-endangering behavior in the previous research (23), in the field of elderly care we posit that job motives and individual attitudes and values are the reasons for nurses' self-endangering. Altruism is nurses' most important work value (24–26), but recent research postulates improvements in nurses' burnout symptoms with altruistic work values (11). However, studies also found that in the sense of moral stress (27), the gap between professional ideals and working reality may lead to burnout (28, 29). We assume this gap between nurses' altruistic motives and the working conditions that do not allow helping others adequately. We conclude that: altruistic job motivation is highly pronounced in nurses (24–26), and the highly demanding working situation leads nurses to neglect their own health and go beyond their own boundaries because they focus on others and helping others and not themselves.

Based on these findings, we formulated the following hypotheses:

Hypothesis 1a: Altruistic job motivation affects self-endangering cognitions such that more altruism increases self-endangering cognitions.

Hypothesis 1b: Altruistic job motivation affects self-endangering behavior such that more altruism increases self-endangering behavior.

As a result of self-endangering developments in organizations, employees want their colleagues to reach the same degree of performance and engagement when working goals are based on team levels (23). We understand the working goal in nursing to be the patients' healing or caring process, so in consequence, due to shift systems and interdisciplinary cooperation, this can only be done through the joint work of the team. Here, the team or organization is the nurses' social identification (30), which is defined as "the positive emotional valuation of the relationship between self and ingroup" (31). As nurses often have to work 12 days in a row, they spend a lot of time with their teammates, and as the work content is often emotionally demanding, we assume a special connection between colleagues. And as a result of difficult working conditions, failures in care are very common (9). Peer pressure in cases of absences is especially high when organizations give employees the feeling that illnesses are not tolerated or when they do not provide temporary staff to fill in for personnel (23). We postulate that, when a nurse who identifies strongly with the team is asked to fill in, the probability that they cannot say no is very high, because, first, out of the emotional valuation of the relationship they feel a strong responsibility for their colleagues' well-being and, second, they might think that filling in for others is a necessary part of the team relationship. Of course, we could also assume an inverted u-shaped course at this point, such that low and high levels of team identification result in low levels of self-endangering and only a middle level of team identification results in high levels of self-endangering. However, due to social identification theories, we assume a linear progression and formulated the following hypotheses:

Hypothesis 2a: Team identification affects self-endangering cognitions such that more team-identification increases self-endangering cognitions.

Hypothesis 2b: Team identification affects self-endangering behavior such that more team-identification increases self-endangering behavior.

As described above, we posit that social identification plays a special role in the context of nursing. In addition to nurses' identification with their team, we consider social identity, as group-relevant behaviors are associated with an individual's self-definition (32). According to social identity theory, people strive for the establishment or enhancement of positive self-esteem and a part of a person's self-concept is based upon the person's group memberships (32). Based on these assumptions, we postulate that caregivers strive for positive self-esteem by being part of caring memberships characterized by relationships with residents and colleagues. If self-esteem is generally rather low, we see a potential risk for the nurses' well- being, as it could drive them to find their self-esteem affirmation in this group affiliation. If part of the nurses' work motivation is to strengthen their own self-esteem, it is obvious from our point of view that nurses cannot say no and have a guilty conscience if they do not fill in in cases of absences. A study in Poland found that self-esteem is a predictor for professional burnout in nursing and a key factor for preventing nurses' burnout (33). In line with previous research we therefore argue that the more nurses use their work to enhance their self-worth and feel validated, the more they will be willing to exceed their own health limits and show self-endangering:

Hypothesis 3a: Self-esteem affects self-endangering cognitions such that less self-esteem increases self-endangering cognitions.

Hypothesis 3b: Self-esteem affects self-endangering behavior such that less self-esteem increases self-endangering behavior.

Self-endangering and burnout in nursing care

Due to ongoing demographic changes and the additional shortage of skilled workers in nursing, the ever-decreasing number of existing nurses must care for the ever-increasing group of people requiring nursing care (34). In the long term, this intensification of work leads to work strain, so it is not surprising that a study revealed "body postures, handling heavy loads, time pressure, deadlines and pressure to perform as the main burdens" of nurses in geriatric care (35). Nurses' objective workload and their subjective perception of stress are above average compared to other occupational groups (28). Recent studies revealed that burnout is rampart among nurses (3, 36, 37), especially nurses in long-term care (38).

Based on the Oldenburger Burnout Inventory (OLBI) (39) the construct of burnout includes two core dimensions—exhaustion and disengagement from work—and covers affective, physical, and cognitive aspects. As we define self-endangering cognitions as "the nurses' own inner beliefs with regard to having a moral obligation to fill in for colleagues at the expense of their own health" (13) and behavior "as the nurses' missing ability to say no when asked to fill in or to do work overtime" (13), we postulate that nurses tend to go beyond their boundaries when filling in for others or doing extra work and that this is harmful to their health. We assume that this results in the long term in emotional exhaustion, as personal resources are depleted:

Hypothesis 4a: Self-endangering cognitions affect emotional exhaustion such that more self-endangering cognitions increase exhaustion.

Hypothesis 4b: Self-endangering behavior affects emotional exhaustion such that more self-endangering behavior increases exhaustion.

Work values influence the emotional exhaustion dimension of burnout (40), in that altruistic work values improve nurses' burnout symptoms (11). In contrast, we also found evidence for negative effects of being highly altruistically motivated or strongly identified with the team in the context of nursing (13). Although being altruistically motivated may lead to a high sense of meaning and value at work (41), we see altruistic job motivation more as a risk factor, in the sense that caregivers go beyond their own limits (self-endangering) and become exhausted in the long term.

As nurses frequently practice self-sacrificing (42–44) and this is associated with burnout (43), the question arises to why nurses show self-endangering so frequently when it is so harmful to their health. We see great potential in clarifying these questions and contradictions by evaluating self-endangering as a mediator in the context of nurses' individual resources and demands and burnout. We formulated the following hypotheses:

TABLE 1 Sample variables from measurement time 1.

Variable	*N* (*N* total T1 = 416)
Female sex	355
Having a child	250
Age	
15–20 years	10
21–25 years	42
26–30 years	57
31–35 years	58
36–40 years	68
41–45 years	42
46–50 years	37
51–55 years	43
56–60 years	36
61–65 years	14
➢ 65 years	4
Profession*	
Nurse	364
Assistant Social Care	20
Professional Social Care	7
In job training	44
Nursing profession group*	
Registered nurse	273
Nursing assistant (1 year certified)	33
Nursing assistant	32
Care setting*	
Stationary care setting	218
Outpatient care setting	94
Duration of nursing home affiliation*	
0–2 years	108
3–5 years	124
6–10 years	69
➢ 10 years	98
Duration of profession duration*	
0–2 years	22
3–5 years	81
6–10 years	83
➢ 10 years	212
Leadership position	124

*These variables include missing data.

Hypothesis 5a: Self-endangering cognitions mediate the relationship between altruistic job values and burnout.

Hypothesis 5b: Self-endangering behavior mediates the relationship between altruistic job values and burnout.

In line with previous findings on the positive effect of altruistic work values, team identification is also positively associated with health (12). The effect is particularly positive when employees help others cope with stressful events and thereby reduce their negative experience of stress (12), which we assume is especially the case in caring professions. Contrary to these findings, we found indications for a negative impact, such that strong identification with the team leads to self-endangering in highly demanding working situations and this leads in the long term to emotional exhaustion. We therefore hypothesized:

Hypothesis 6a: Self-endangering cognitions mediate the relationship between team identification and burnout.

Hypothesis 6b: Self-endangering behavior mediates the relationship between team identification and burnout.

Although to our knowledge no study has investigated the concept of self-endangering in nursing, self-sacrificing practices in nursing is probably frequent (42–44) and there is an association between nurses' self-sacrificing and burnout (43). It therefore seems necessary to take a closer look at the interrelationships in quantitative terms.

Methods

Sample

We collected data from nurses working in nursing homes and outpatient care services located in Germany in three follow-up waves over a period of nine months from June 2020 to March 2021. For this purpose, we recruited nursing homes for onsite paper-pencil surveys, and we also shared the link to an online survey in social media, e.g., facebook nursing groups and LinkedIn. Each participant created a unique ID and we tracked them over all three measurement points, so participants were the same over all three waves.

The original dataset consisted of 426 individuals at the first wave (starting in June 2020), 52 at the second (starting in November 2020) and 35 at the third wave (starting in January 2021). After we cleaned the data for missing code allocation information and double participation, the analysis sample consisted of *wave 1* = 416, *wave 1,2* = 50, *wave 1,2,3* = 26.

The sample description below refers to the 416 participants who completed the first wave (**Table 1**). The majority of participants were women (85.33%), and nearly 60% of participants had at least one child. The majority of participants were aged 36–40 years; 87.5% were nurses, and of these 75% were registered nurses. More than half worked in stationary care, and most had worked for 3–5 years at their current organization. The majority of participants had worked for more than 10 years in their profession; 29.80% had a leadership position in the nursing home.

Procedure

We developed a paper-pencil questionnaire as well as an online version and received ethical approval from University's IRB (institutional review board). We used a voluntary response sampling method, such that we contacted several nursing homes in Germany that we knew from various care projects and asked for their participation. Participating nursing homes could choose whether to use the paper-pencil or the online questionnaire. If the paper-pencil version was requested, we provided a locked box for collecting the questionnaires. The nursing homes' employees could voluntarily decide whether they wanted to participate in the survey.

In addition, we published the online link in multiple social media platforms, e.g., Facebook nursing groups, LinkedIn, and Xing. We informed participants about the aims and background of the study and, in the online version, about the university's privacy and data protection policy. The policy conforms to European and German data protection regulations and was deposited online for participants. Before starting the survey, participants had to give their consent and confirm that they were at least 18 years old. Each participant was asked to generate a pseudonym code. Upon finishing the questionnaire, participants were asked to voluntarily provide their email address for participating in further follow-ups. We stored the email addresses independently from the survey data. All questionnaires were time-stamped.

Measures

Burnout

We assessed burnout with the Oldenburger Burnout Inventory (OLBI) (39) using the exhaustion and disengagement dimensions. The OLBI consists of 16 items; eight items measure the exhaustion dimension of burnout, and eight items measure the disengagement dimension. Responses ranged from 1 (*strong rejection*) to 4 (*strong approval*). Internal validity for exhaustion was high (8 items, $\omega_{total1,2,3} = .90, .93, .94$). Internal validity for disengagement was high (8 items, $\omega_{total1,2,3} = .88, .90, .93$). To allow easy interpretation of the results we recoded the inverted items.

Self-endangering

Based on our experiences in qualitative research on self-self-endangering in nursing (blinded for peer review) we developed 14 items for self-endangering behavior that we divided into five facets: behavior trends (4 items, e.g., "If a duty shift needs to be covered, I would step in to save my colleagues' weekend/day off."), behavior (2 items, e.g., "In the last four weeks I have been asked to fill in for other colleagues"), behavior towards whom (2 items, e.g., "I find it difficult to say no to my superiors when I have to stand in for other colleagues"), distance (2 items, e.g., "I have a hard time saying no on the phone when asked if I can fill in"), and expectations of colleagues (4 items, e.g., "If a service needs to be covered, I expect my colleagues to step in to make sure the residents are well taken care of"). Responses ranged from 1 (*not true at all*) to 5 (*totally true*). Internal validity for self-endangering behavior was high (3items, $\omega_{total1,2,3} = .80, .86, .86$).

To measure self-endangering cognitions we developed three items for self-endangering cognitions, e.g., "I feel guilty towards my colleagues if I do not fill in". Internal validity was high (3 items, $\omega_{total1,2,3} = .75, .73, .84$).

Altruistic values

We assessed altruistic job values using the adapted short version of the Dutch version of the Work Importance Study instrument developed by Coetsier and Claes (1990) (45), e.g., "I think it's important to have a job where I can help other people". Responses ranged from 1 (*totally unimportant*) to 5 (*totally important*). Internal validity was high (7 items, $\omega_{total1,2,3} = .88, .90, .91$).

Identification with the team, the organization, the profession, occupational activity, and the leader

We assessed identification (with the team, organization, profession, occupational activity, and the leader) with the Four Item Measure of Social Identification (FISI) (31), e.g., "I identify with my team." Responses ranged from 1 (*not at all true*) to 7 (*very true of me*). Internal validity was high (6 items, $\omega_{total1,2,3} = .90, .92, .90$).

Self-worth

We assessed self-worth with the German version of the Single-Item Self-Esteem Scale (G- SISE) (46), e.g., "I have high self-esteem" .Responses ranged from 1 (*not at all true*) to 5 (*very true of me*).

Exploratory and confirmatory factor analysis

As recommended in Standards for Educational and Psychological Testing (47), we performed exploratory factor analysis (EFA) and confirmatory factor analysis (CFA). We therefore randomly split the dataset from wave one into subsets A ($N = 200$) and B ($N = 226$). We used subset A for conducting the exploratory and confirmatory factor analysis and subset B for testing our hypotheses.

Exploratory factor analysis

For determining the numbers of factors, we used parallel analysis (PA) and the comparison data approach (CD), as Goretzko et al. (2021) (48) recommended avoiding MAP-test or Kaiser-Guttmann rule as a criterion. The PA using minimum rank factor analysis (MRFA) (49) resulted in three factors. The CD approach (50) suggested six factors. Due to the different

TABLE 2 Intercorrelations among the factors of self-endangering and exploratory factor analysis using weighted least squares and oblimin rotation: factor loadings of the four factors of self-endangering (after deletion of three items due to crossloadings above 32).

	Factor	F1	F2	F3	F4	h^2
Intercorrelations						
F2		.31				
F3		.20	.18			
F4		.34	.47	.20		
Factor loadings						
F1: Self-endangering cognitions	1. I find it difficult to say no to my leaders when I have to fill in for colleagues.	**0.84**	0.02	0.01	0.08	0.78
	2. I find it difficult to say no to my colleagues when I have to fill in for them.	**0.88**	0.03	0.05	−0.08	0.77
	3. I have a hard time saying no on the phone when asked if I can fill in.	**0.92**	−0.04	−0.05	0.07	0.85
	4. I find it difficult in personal contact (e.g., directly at work) to say no when asked if I can fill in.	**0.96**	−0.02	0.02	−0.03	0.91
	5. I feel bad for the residents if I don't fill in.	**0.57**	0.00	0.07	0.16	0.46
	6. When I fill in for others and give up my free time, I feel guilty towards my family/friends.	**0.50**	0.14	−0.11	−0.12	0.26
F2: Self-endangering behavior	7. In the last four weeks I have been asked to fill in for other colleagues.	−0.02	**0.96**	−0.01	−0.02	0.90
	8. For the past four weeks, I've been filling in on my time-off days.	−0.01	**0.80**	−0.02	0.14	0.69
	9. In the last four weeks, I have had to switch shifts at short notice (e.g., instead of an early shift, I took on a late shift the next day).	0.10	**0.61**	0.12	−0.12	0.42
F3: Self-endangering expectations	10. In order to take good care of the residents, my colleagues should put their own physical and mental health second.	0.14	0.02	**0.73**	−0.07	0.57
	11. If a shift needs to be covered, I expect my colleagues to step in, even if they have to change private plans to do so.	−0.07	−0.03	**0.93**	0.11	0.91
	12. When staff is absent, my colleagues should step in to save other colleagues' weekends/time off.	0.03	0.08	**0.70**	−0.07	0.49
F4: Self-endangering behavior tendencies	13. If a shift needs to be covered, I would fill in to make sure the residents are well taken care of.	−0.01	0.00	−0.05	**0.79**	0.58
	14. If a shift needs to be covered, I would fill in, even if it means changing private plans.	0.06	0.04	0.08	**0.93**	0.99
	Eigenvalue	3.95	1.99	2.00	1.64	
	Proportion of total variance	0.28	0.14	0.14	0.12	

(Continued)

TABLE 2 Continued

The bold values makes it easier to identify the item's relationship to the factor.

results, we calculated analyses for both numbers of factors and subsequently compared the respective model fit.

As the data did not meet the criteria for normally distributed data, we used EFA using weighted least squares (WLS) (48). As the factors were assumed to be correlated, we used oblique rotation methods (51), e.g., oblimin and promax (48). The five factors solution (RMSEA 90% interval = 0.122–0.154) showed a better fit than the six factors solution (RMSEA 90% interval = 0.122–0.160) and the three factors solution (RMSEA 90% interval = 0.167–0.195).

The analysis for the five factors solution yielded a structure with item loadings from 0.52 to 0.96. Each item highly loaded on one factor, whereas one item cross loaded above 0.32 on two factors. We therefore deleted this item for rerunning EFA (52). Further analyses showed additional cross loadings above.32, so we deleted two more items. After deleting the three items, the PA using minimum rank factor analysis (MRFA) (49) resulted in three factors. The comparison data approach (50) suggested four factors. The four factors solution (RMSEA 90% interval = 0.114–0.157) showed a better fit than the three factors solution (RMSEA 90% interval = 0.157–0.193). The analysis for the four factors solution yielded a structure with item loadings from 0.50 to 0.96, and each item highly loaded on one factor (Table 2). Table 2 presents factor intercorrelations.

Confirmatory factor analysis

Due to the different results of PA and the CD approach, we performed CFA for the four and the three factors solution

TABLE 3 Results of confirmatory factor analysis for the relationships among the facets of self-endangering (after deletion of three items due to crossloadings above 32).

Model	χ^2	df	CFI	TLI	RMSEA 90% interval		SRMR
					LL	*UL*	
Higher order	123.910	73.000	.956	.945	.044	.083	.067
3-factor	218.273	74.000	.875	.846	.091	.123	.087
4-factor	123.568	71.000	.952	.942	.046	.085	.066

χ^2, chi-square statistic; SRMR, standardized root mean square residual; RMSEA, root mean square error of approximation; CFI, comparative fit index; TLI, Tucker-Lewis index.

(**Table 3**). The four factors solution (RMSEA 90% interval = 0.046–0.085, $df = 71.000$, $\chi^2 = 123.568$, CFI = .954, SRMR = .066) showed a better fit than the three factors solution (RMSEA 90% interval = 0.091–0.123, $df = 74.000$, $\chi^2 = 218.273$, CFI = .875, SRMR = .087). A model comparative ANOVA showed that the three-factor model fit significantly worse than the four-factor model, $\chi^2 = 218.27$, $p < .001$, $\Delta\ AIC = 88.7$.

After EFA and CFA, the final version of self-endangering behavior tendency consisted of two items, and self-endangering cognitions consisted of six items. Internal validity for self-endangering behavior tendency was high (2 items, $\omega_{total1} = .90$). Internal validity for self-endangering cognitions was high (6 items, $\omega_{total1} = .91$). See the supplemental online file for the final version of the self-endangering questionnaire.

Analytic strategy

To test our hypotheses, we originally wanted to calculate longitudinal mediation analyses using the independent variables (e.g., altruism, team identification, and self-worth) from wave 1, the mediation variables (e.g., subscales of self-endangering) from wave 2, and the dependent variable (e.g., burnout exhaustion) from wave 3. An *a priori* power analysis resulted in a sample size of 138. Due to the global COVID-19 pandemic in 2020 and 2021, our sample size decreased from wave one with 416 participants (July to August 2020) to 35 participants in wave three (January to March 2021). Therefore, a longitudinal evaluation including all three measurement points was no longer advisable.

In order to still gain maximum information from the collected data, we used a multiverse analytic strategy (53). We selected two approaches to test our hypothesis: (1) regression analysis with measurement repetition, and (2) cross-lagged panel design for waves 1 and 2. We conducted all analyses with RStudio Version 1.3.959 (54).

We provide descriptive statistics for the variables that describe the sample and the workstrain context of the participants in more detail in an additional online appendix: workload, emotional dissonance, psychological detachment, and self-care. Further, we describe descriptive statistics for the independent variables (IV), dependent variables (DV) and mediation variables (MV). To test hypothesis, we provide regression analysis statistics and path analysis models for variables: IV—altruism, team identification, self-esteem; DV—exhaustion and disengagement; and mediators—self-endangering cognitions and behavior tendencies.

Results

Descriptive statistics

Table 4 shows descriptive statistics and correlations among independent and dependent variables and mediators.

Regression analysis

To test hypotheses 1a—6b we computed a multiple regression model with repeated measurements. Due to the longitudinal design, the model had two levels, with individuals' repeated measurements nested in individuals. We followed recommendations by Bliese (2002, 2016) (55, 56) and calculated intraclass correlations (ICCs) (57) to test for potential non-independence justified by the hierarchical structure of the data, for exhaustion and disengagement (dependent variables) and self-endangering cognitions and behavior tendency (mediating variables).

Exhaustion was non independent in individuals, ICC(1) = .56, $F(215,\ 75) = 2.75$, $p < .001$. Individuals were also somewhat distinguishable by their average level of exhaustion, ICC(2) = .63. Disengagement was non independent in individuals, ICC(1) = .66, $F(215,\ 75) = 3.60$, $p < .001$. Individuals were also distinguishable by their average level of disengagement, ICC(2) = .72. Self-endangering cognitions were non independent in individuals, ICC(1) = .67, $F(214,\ 73) = 3.78$, $p < .001$. Individuals were also distinguishable by their average level of self-endangering cognition, ICC(2) = .73. Self-endangering behavior tendency was non independent in individuals, ICC(1) = .71, $F(215,\ 77) = 4.40$, $p < .001$. Individuals were also distinguishable by their average level of self-endangering behavior tendency, ICC(2) = .77. We tested our hypotheses with multilevel modeling.

We explored the random effect structure by testing random intercept models for the dependent variables exhaustion and disengagement and the mediators self-endangering cognitions and behavior tendency and measurement time as the independent variable. The calculation of random intercept and slope models was not possible, because too few people participated in several measurement points. We therefore tested the hypotheses with random intercept models using mean centered predictor variables.

Hypotheses tests using mixed models

Hypothesis 1 proposed that altruistic job motivation is positively related to self-endangering cognitions and self-endangering behavior tendency. To test, we investigated model 3 and 4; see **Table 5**. Tests revealed a significant effect of altruism on self-endangering cognitions, $b = 0.47$, 95% CI = [0.30, 0.63], and on self-endangering behavior tendency, $b = 0.54$, 95% CI = [0.36, 0.71].

Hypothesis 2 proposed that team identification is positively related to self-endangering cognitions and self-endangering behavior tendency. To test, we investigated model 3 and 4; see **Table 5**. There was no significant effect of team identification on self-endangering cognitions, $b = -0.02$, 95% CI = [−0.10, 0.05], but a significant effect of team identification on self-endangering behavior tendency, $b = 0.11$, 95% CI = [0.02, 0.19].

Hypothesis 3 proposed that self-esteem is negatively related to self-endangering cognitions and self-endangering behavior

TABLE 4 Descriptive statistics and correlations Among independent and dependent variables and mediators From analysis sample From Measurement time 1.

Variable	*M*	*SD*	1	2	3	4	5	6
1. Altruism	3.84	0.67						
2. Team identification	4.92	1.35	.22**					
			[.09,.35]					
3. Self-esteem	3.71	1.01	.04	.08				
			[−.09,.18]	[−.06,.21]				
4. Self-endangering behavior tendency	3.49	1.10	.36**	.18**	−.03			
			[.24,.47]	[.05,.31]	[−.17,.10]			
5. Self-endangering cognitions	2.94	1.03	.27**	.03	−.42**	.33**		
			[.14,.39]	[−.11,.17]	[−.52, −.30]	[.20,.44]		
6. Burnout Exhaustion	2.54	0.57	.07	−.14*	−.36**	−.04	.40**	
			[−.07,.20]	[−.27, −.01]	[−.47, −.23]	[−.17,.10]	[.28,.51]	
7. Burnout disengagement	2.08	0.57	−.04	−.18**	−.32**	−.19**	.28**	.67**
			[−.18,.09]	[−.31, −.05]	[−.43, −.19]	[−.32, −.06]	[.15,.40]	[.59,.74]

M and *SD* are used to represent mean and standard deviation, respectively. Values in square brackets indicate the 95% confidence interval for each correlation. The confidence interval is a plausible range of population correlations that could have caused the sample correlation (Cumming, 2014).
*Indicates $p < .05$.
**Indicates $p < .01$.

tendency. To test, we investigated model 3 and 4; see Table 5. There was a significant negative effect of self-esteem on self-endangering cognitions, *b* = −0.39, 95% CI = [−0.50, −0.28], but no significant effect of self-esteem on self-endangering behavior tendency, *b* = −0.01, 95% CI = [−0.14, 0.09].

Hypothesis 4 proposed that self-endangering cognitions and behavior tendency are positively related to emotional exhaustion. To test, we investigated model 5, see Table 6. This revealed a significant positive effect of self-endangering cognitions on emotional exhaustion, *b* = 0.19, 95% CI = [0.12, 0.26], and a significant negative effect of self-endangering behavior tendency on emotional exhaustion, *b* = −0.08, 95% CI = [−0.14, −0.01].

Hypothesis 5a/b proposed that self-endangering cognitions/behavior tendency mediate the relationship between altruistic job values and burnout. To test, we investigated mediation modeling; see Table 7. We found a significant indirect effect from altruism over self-endangering cognitions to exhaustion, b = 0.092, 95% CI = [0.04; 0.14] and from altruism over self-endangering behavior tendency to exhaustion, b = −0.044, 95% CI = [−0.08; −0.01].

Hypothesis 6a/b proposed that self-endangering cognitions/behavior tendency mediate the relationship between team identification and burnout. To test, we investigated mediation modeling; see Table 7. We found no significant indirect effect from team identification over self-endangering cognitions to

TABLE 5 Mixed models regressing repeated within-person measures of dependent variables and mediators on study variables.

	Model 1: DV = Burnout exhaustion				Model 2: DV = Burnout disengagement				Model 3: DV = Self-endangering cognitions				Model 4: DV = Self-endangering behavior tendency			
	b	SE	95% CI		b	SE	95% CI		b	SE	95% CI		b	SE	95% CI	
Direct Effect			LL	UL			LL	UL			LL	UL			LL	UL
Fixed effects																
Intercept	2.53	0.03	2.46	2.60	2.08	0.03	2.01	2.15	2.91	0.06	2.79	3.04	3.44	0.06	3.31	3.58
Altruism	0.07	0.05	−0.01	0.17	−0.02	0.04	−0.11	0.07	**0.47**	**0.08**	**0.30**	**0.63**	**0.54**	**0.08**	**0.36**	**0.71**
Team identification	**−0.05**	**0.02**	**−0.10**	**−0.009**	**−0.06**	**0.02**	**−0.11**	**−0.02**	−0.02	0.04	−0.10	0.05	**0.11**	**0.04**	**0.02**	**0.19**
Self-esteem	**−0.18**	**0.03**	**−0.25**	**−0.11**	**−0.16**	**0.03**	**−0.23**	**−0.10**	**−0.39**	**0.05**	**−0.50**	**−0.28**	−0.01	0.06	−0.14	0.09
Time	0.05	0.41	−0.02	0.14	0.02	0.03	−0.04	0.10	0.09	0.06	−0.02	0.22	−0.03	0.06	−0.16	0.09
Random effects																
Variance components																
Level 1 (Within-person)	0.14				0.15				0.51				0.69			
Level 2 (Between-person)	0.13				0.11				0.29				0.28			
Observations	283				283				279				281			
Deviance (-2LogLik)	419.8				401.5				690.8				734.0			
AIC	433.8				415.5				704.8				748.0			
BIC	459.3				441.0				730.2				773.5			
Pseudo-R^2	0.13				0.12				0.23				0.14			

Bold indicates the significant value.
Confidence Intervals are based on 10,000 bootstrapped samples. Predictor variables are mean centered.

TABLE 6 Mixed models regressing repeated within-person measures of dependent variables on mediators and independent variables.

	Model 5: DV = Burnout exhaustion				Model 6: DV = Burnout disengagement			
	b	SE	95% CI		b	SE	95% CI	
Direct Effect			LL	UL			LL	UL
Fixed effects								
Intercept	2.53	0.03	2.46	2.60	2.08	0.03	2.01	2.15
Altruism	0.01	0.05	−0.08	0.12	−0.02	0.05	−0.12	0.07
Team identification	−0.05	0.02	−0.09	0.001	**−0.04**	**0.02**	**−0.09**	**−0.001**
Self-esteem	**−0.12**	**0.03**	**−0.19**	**−0.04**	**−0.11**	**0.03**	**−0.18**	**−0.04**
Time	0.05	0.41	−0.02	0.14	0.01	0.03	−0.04	0.10
Self-endangering cognitions	**0.19**	**0.03**	**0.12**	**0.26**	**0.15**	**0.03**	**0.08**	**0.22**
Self-endangering behavior tendency	**−0.08**	**0.03**	**−0.14**	**−0.01**	**−0.14**	**0.03**	**−0.21**	**−0.08**
Random effects								
Variance components								
Level 1 (Within-person)	0.14				0.14			
Level 2 (Between-person)	0.10				0.10			
Observations	283				279			
Deviance (-2LogLik)	419.8				369.1			
AIC	433.8				387.1			
BIC	459.3				419.8			
Pseudo-R^2	0.13				0.12			

Bold indicates the significant value. Confidence Intervals are based on 10,000 bootstrapped samples. Predictor variables are mean centered.

exhaustion, b = 0.005, 95% CI = [−0.022; 0.01], but a significant indirect effect from team identification over self-endangering behavior tendency to exhaustion, b = −0.008, 95% CI = [−0.02; 0.00].

TABLE 7 Unstandardized coefficients, confidence intervals and *p* values of mixed models for mediation effects.

Indirect effects				
Effect	Estimate	95% CI		*p*
		LL	*UL*	
Altruism → Self-endangering cognitions → Exhaustion	0.092	0.049	0.14	<.001***
Team Identification → Self-endangering cognitions → Exhaustion	−0.005	−0.022	0.01	.47
Self-esteem → Self-endangering cognitions → Exhaustion	−0.075	−0.113	−0.04	<.001***
Altruism → Self-endangering behavior tendency → Exhaustion	−0.044	−0.087	−0.01	.016*
Team Identification → Self-endangering behavior tendency → Exhaustion	−0.008	−0.020	0.00	.027*
Self-esteem → Self-endangering behavior tendency → Exhaustion	0.001	−0.009	0.01	.787
Altruism → Self-endangering cognitions → Disengagement	0.071	0.034	0.12	<.001***
Team Identification → Self-endangering cognitions → Disengagement	−0.004	−0.017	0.01	.479
Self-esteem → Self-endangering cognitions → Disengagement	−0.058	−0.092	−0.03	<.001***
Altruism → Self-endangering behavior tendency → Disengagement	−0.080	−0.125	−0.04	<.001***
Team Identification → Self-endangering behavior tendency → Disengagement	−0.015	−0.031	0.00	.009**
Self-esteem → Self-endangering behavior tendency → Disengagement	0.002	−0.014	0.02	.78

Confidence Intervals are based on 10,000 bootstrapped samples.
*Indicates $p < .05$.
**Indicates $p < .01$.
***Indicates $p < .001$.

Hypothesis tests using path analysis models

Cross-sectional data

The tested model showed that the model had been exactly identified ($df = 0$), which is why we could not determine the model fit. We found a significant positive association between altruism and self-endangering cognitions ($b = 0.43$, $p < .001$) and self-endangering behavior tendency: More altruism led to more self-endangering cognitions and behavior tendency. Hypothesis 1a and 1b were thus confirmed.

We found non-significant associations between team identification and self-endangering cognitions ($b = 0.002$, $p = .97$) and self-endangering behavior tendency ($b = 0.09$, $p = .06$). Hypotheses 2a and 2b were not confirmed.

Hypothesis 3a was confirmed, as we found a negative significant association between self-esteem and self-endangering cognitions ($b = -.43$, $p < .001$): Lower self-esteem led to more self-endangering cognitions. We found a non-significant association between self-esteem and self-endangering behavior tendency ($b = -.05$, $p = .43$). Hypothesis 3b had to be rejected.

Hypothesis 4a and 4b proposed that self-endangering cognitions and behavior tendency are positively related to emotional exhaustion. Hypothesis 4a was confirmed. We found a significant positive association between self-endangering cognitions and exhaustion, ($b = 0.20$, $p < .001$), but a significant negative association between self-endangering behavior tendency and exhaustion ($b = -.09$, $p = .01$). This means that more self-endangering cognitions led to more exhaustion and that less self-endangering behavior tendency led to more exhaustion.

Hypothesis 5a and 5b proposed that self-endangering cognitions and behavior tendency mediate the relationship between altruistic job values and burnout. The analysis revealed

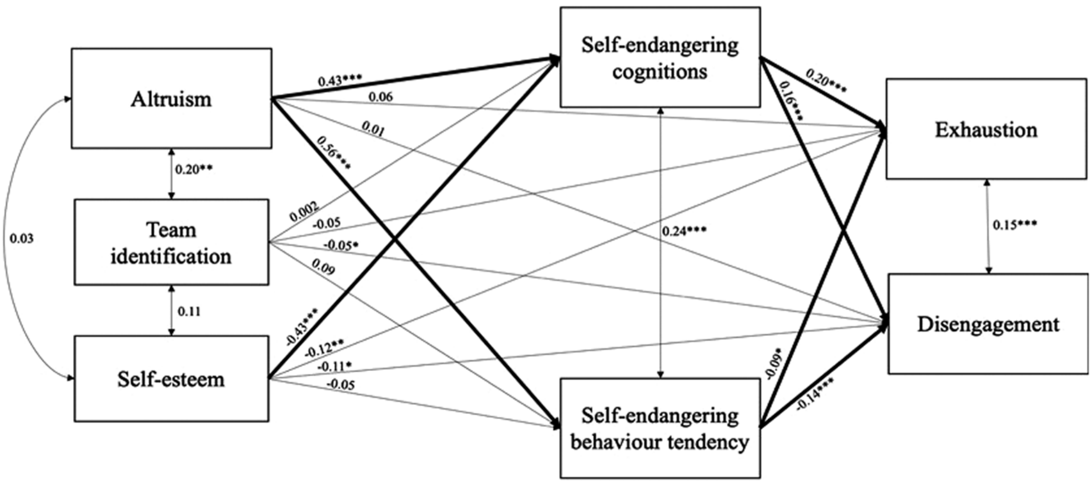

FIGURE 1
Cross sectional hypotheses testing using path analysis models ($N = 217$). Bootstrapped 10,000 times. * indicates $p < .05$. ** indicates $p < .01$. *** indicates $p < .001$.

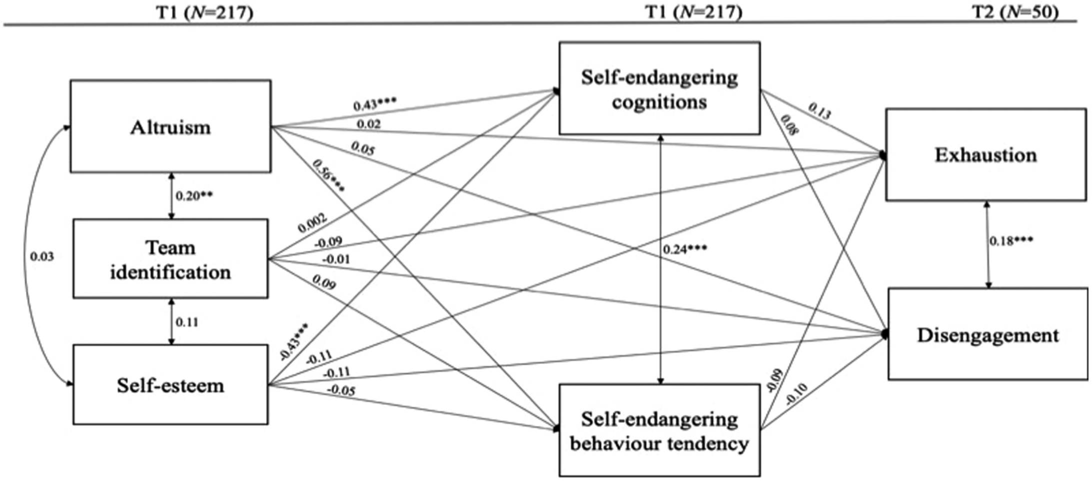

FIGURE 2
Longitudinal hypotheses testing using path analysis models. Bootstrapped 10,000 times. * indicates $p < .05$. ** indicates $p < .01$. *** indicates $p < .001$.

that the hypothesized positive indirect effect of altruism on exhaustion mediated by self-endangering cognitions was significant ($b = 0.09$, $p = .003$) and contrary to our hypothesis we found a negative indirect effect of altruism on exhaustion mediated by self-endangering behavior tendency was significant ($b = -.04$, $p = .04$).

Hypothesis 6a and 6b proposed that self-endangering cognitions and behavior tendency mediate the relationship between team identification and exhaustion. The analysis revealed that the hypothesized positive indirect effect of team identification on exhaustion mediated by self-endangering cognitions was not significant ($b = 0.00$, $p = .97$). Further, the analysis revealed that the hypothesized positive indirect effect of team identification on exhaustion mediated by self-endangering behavior tendency was not significant ($b = 0.01$, $p = .13$).

Additionally, we found a significant indirect effect of self-esteem on exhaustion mediated by self-endangering cognitions ($b = -.08$, $p = .001$) (**Figure 1**).

Longitudinal data

The tested model showed that the model had been exactly identified ($df = 0$), which is why we could not determine the model fit. The same as with the cross-sectional data, hypotheses 1a, 1b, and 3a were confirmed, and hypotheses 2a, 2b, 3b, and 4b were rejected. Again, hypotheses 4a was confirmed: Self-endangering cognitions were positively related to emotional exhaustion and behavior tendency negatively to emotional exhaustion. In contrast to the cross-sectional data, the mediation hypotheses were not confirmed in the longitudinal design (**Figure 2**).

Discussion

Our study investigated the effects of altruism, team identification, and self-esteem on exhaustion mediated by self-endangering cognitions and self-endangering behavior tendency in nurses working in elderly care in Germany. Our findings show that high altruism, regardless of the analysis method and the use of longitudinal or cross-sectional data, leads, in line with hypothesis 1a and 1b, to more self-endangering cognitions and to a higher self-endangering behavior tendency. Mixed model analysis and cross-sectional path analysis also confirmed the assumed mediation effects from altruism over self-endangering cognitions to exhaustion (hypothesis 5a). In contrast to a previous research finding that high intrinsic and altruistic work values reduced nurses' burnout (11), based on our findings there is a major health risk for nurses with high altruistic values and low ability to say no under the given circumstances in care. If the care system made it possible to care for the residents in line with nurses' own "helping values", we believe an intrinsic and altruistic motivation could improve the level of identification and meaningfulness in work. Given the terrible nursing staff situation in care, the development of a reliable plan for covering staff absences is currently unavoidable. A system has developed in which caregivers constantly experience moral imbalance and at the same time feel compelled not to leave their team and the residents in the lurch. In line with research on negative impacts of moral distress, e.g., moral distress increases burnout and dissatisfaction (58, 59), we assume there are heavy burdens on mental health, especially for this group of professionals, who show a high willingness to take on responsibility (60). We believe there is a great need to develop the skill of detached concern, defined as an emotion-regulating individual resource that leads to finding a balance between empathic concern and sufficient detachment (61). Detached concern could help nurses experience themselves as self-effective and the work as meaningful and above all increase their well-being (61). Contrary to assumptions (hypothesis 5b), longitudinal regression and cross-sectional path analysis and revealed an indirect negative effect of altruism on exhaustion mediated by self-endangering behavior tendency. We can imagine that as all analysis revealed negative relations for the subscale self-endangering behavior tendency one reason for the contradictory findings lies within the operationalization of the subscale. As we only could measure behavior tendency and not the actual behavior, e.g., frequency of actual substitution and actual overtime, we could not examine possible effects by, for example, reduced opportunities for recovery which then also increase exhaustion. Additionally, we can imagine, that, in particular, the cognitive facet of self-endangering has harmful effects, rather than the behavior or behavior tendencies, because since, for example, a bad conscience can arise even if nurses fill in, in case of absenteeism.

Considering hypothesis 2, we could only find some initial indications for positive effects from team identification to self-endangering behavior tendency: Stronger team-identification leads to a higher behavior tendency in our mixed model. Contrary to our hypothesis, self-endangering behavior tendency is negatively related to exhaustion, which means that a lower behavior tendency leads to higher exhaustion. This finding is contradictory, as we expected that a high moral commitment to the team would lead to a greater willingness to fill in for colleagues, but that this would also lead to more exhaustion. We suspect that one explanation lies in the operationalization of the construct of team-identification which only include one item. We can imagine that the wording of this item does not fit enough for the context of nursing. As analyzed in previous research (blinded for peer-review) nurses might feel high sense of duty towards their colleagues and are very sensitive to the extra work that is required for colleagues. However, nurses might not talk about "identifying" with their team or colleagues rather than feeling responsible.

Additionally, again the operationalization of the construct self-endangering behavior tendency might be difficult. Originally, we wanted to test this hypothesis using actual behavior, e.g., frequency of filling in for others, because it is obvious that people who fill in more often are working more, have less time for recovery, and are therefore more vulnerable to exhaustion. Further research should investigate this hypothesis using actual behavior frequency in a longitudinal study design. As we know that detached concern can lead to better health, nurses' identification with residents and patients should be investigated in future studies to identify possible associations with self-endangering. We could not find distinct results about the effect for the assumed mediation effect of self-endangering cognitions/behavior on the relation between team-identification and exhaustion (hypothesis 6a/b). First, considering our results it is still unclear how team-identification affects exhaustion, which is why further more complex analyses are less useful. Second, we can imagine that other team-based variables influence the effect of team identification on health, such as team commitment and psychological safety (62). Psychological safety climate promotes employees' wellbeing (63), so we assume that psychological safety also reduces self-endangering cognitions and behavior. Moreover, we can imagine that only identifying with colleagues might lead to self-endangering because identification alone might be not enough to feel secure in the team and therefore to be able to communicate one's boundaries. Future research should measure team identification and psychological safety and should investigate possible interaction effects.

Additionally, in line with our hypothesis 3, we found that low self-esteem leads to more self-endangering cognitions. Mixed model analysis and cross-sectional path analysis also showed a mediation effect from self-esteem over self-endangering cognitions to exhaustion: Low self-esteem promotes more self-endangering cognitions, and this leads to stronger feelings of exhaustion. Previous research found that nurses with high self-esteem have fewer psychological problems (64), cope more effectively in stressful situations (33, 65), and are more active and flexible (33). Taking these findings into account and bringing them together with our results, we consider that the mediation over self-endangering cognitions, e.g., nurses not feeling able to say no when asked to fill in for another nurse and having a guilty conscience when they do not fill in, could explain the psychological mechanism between self-esteem and exhaustion. We can also imagine that nurses with low self-esteem may identify themselves strongly with their work, e.g., their relationship with residents, the feeling of being needed, and the feelings they get from helping and guiding them, such that these experiences confirm them in their identity and self. This would result in nurses being "quasi-dependent" on their work for their self-esteem, making it difficult for them to say no, and when they do say no, feeling guilty about it.

Independent from the analysis method we found, that more self-endangering cognitions lead to more exhaustion (hypothesis 4a) and contrasting to our assumption (hypothesis 4b) that more self-endangering behavior tendency leads to less exhaustion. These results suggest that in particular self-endangering cognitions tend to have harmful effects and are exhausting over time. Recent research should investigate if those employees that tend to show self-endangering behavior tendency are also those employees that do fill in in case of absenteeism or if it is just a tendency that does not result in actual behavior which would mean that they do not have much overtime and therefore time for recovery and less risk for exhaustion.

Theoretical implications

In view of the contradictory findings in the research on the effect of altruism on the experience of exhaustion it seems necessary to examine whether there is an optimal level of altruistic motivation, e.g., an inverse u-shaped relation. We can also imagine that altruistic motivation, similarly to self-regulatory abilities, can be exhausted over time (66) and that nurses constantly experience a goal discrepancy with their altruistic motives, which promotes exhaustion.

Taking into account that self-esteem should be differentiated into self-liking and self-competence (67), especially the facet of self-liking might be interesting to examine in the context of self-endangering. Future research should investigate which facet explains more variance in self-endangering.

Servant leadership is related to meaning and work engagement (68) and organizational citizenship behavior and performance (69), so we assume that leadership behavior could have a similar influence on self-endangering, in that leaders who tend to ask the same employees for filling in may promote self-endangering in nursing.

As the data in subset A (used for exploratory and confirmatory data analysis) did not meet the criteria for normally distributed data, we consider that further research is needed to validate the self-endangering' items. We assume that due to the highly demanding working conditions nurses will always tend to show high rates of self-endangering, which is why normally distributed data is probably unlikely to find in this specific occupational group. Nevertheless, further research is needed to increase the significance of our self-endangering' items for the context of nursing.

Practical implications

Based on our results we believe that person-focused interventions could help to increase nurses' self-esteem and help them to develop a healthy and balanced altruistic job motivation. Additionally, leaders should be sensitized to notice if an employee tends to show too much self-endangering.

Further, fundamental changes in nurses' working conditions are needed, such that a reliable work schedule, using validated patient-to-nurse ratios, and a standardized absenteeism plan build the basis of the nursing work. From our point of view, this can be achieved by investing more money in nursing staff, so that that absences can be covered by external staff and the profession is made more attractive to young people. For example, more money could be provided to the care system, if a "care fund", similar to the old "solidarity tax" in Germany, were set up to cope with demographic change.

Limitations

To our knowledge this is the first quantitative study that focuses on individuals' self-endangering cognitions and behavior among nurses in the field of long-term care. Of course, our study is not without limitations, especially because our longitudinal evaluation was severely limited by the small sample size. Our sample decreased over the two waves from 416 to 50. We can image that in particular the worldwide COVID-19 pandemic causes this participant loss, as nurses suffered under high work strain (2, 4) and therefore the motivation for extra work, like participating in a survey without having any advantages, might decrease. In times of highly exhausted nurses (3) the willingness for extra tasks is certainly limited. Additionally, we assume that by participating in this survey, individuals might be confronted with their situation in the health care system, which might in particular worrying in times of a pandemic, where feelings of insecurity might be high. It should also be considered that the second measurement point, was around the time of the beginning of COVID-19 vaccinations which we can imagine lead to nurses' insecurity and anxiety and perhaps also to a reluctance to engage in scientific research.

First, our results are not generalizable and need to be examined in a large longitudinal design. It is also critical to note that we developed the items for self-endangerment ourselves, so future research should validate the items of self-endangering in a large sample.

Second, our sample is not representative and does not include data on nurses in acute care settings, e.g., hospitals, and due to the small sample size, we could not differentiate between outpatient and stationary care. In the future, group comparisons between different care settings should be examined. We can also imagine that having a child could influence the development of self-endangering; future research should investigate this aspect.

Third, as the data for EFA and CFA did not meet the criteria for normally distributed data the results cannot be generalized for other occupational groups and, therefore, further studies on larger samples and, in comparison, also on less strained samples are needed, especially for conclusions on other occupational groups. In large validation studies, the items should be tested for scale validity.

Nevertheless, we believe that our study offers new knowledge and approaches in the context of the health of workers in elderly care.

Conclusions

This quantitative study dealt with the question of self-endangering in nursing and possible antecedents and mediator effects. Our results show that a high altruistic job motivation and low self-esteem can lead to self-endangering and that this in turn can promote exhaustion in nurses working in elderly care. Future research needs to investigate whether data on nurses in hospitals confirm these assumptions. Our results underline the great need to change working conditions in nursing in a way that promotes stability in staffing.

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 human participants were part of a joint project "Healthy Ageing in Long-Term Geriatric Care" (gesaPflege) which was reviewed and approved by Ethikkommission TU Chemnitz. The patients/participants provided their written informed consent to participate in this study.

Author contributions

LE: Conceptualization; Data curation; Formal analysis; Investigation; Methodology; Project administration; Validation; Visualization; Roles/Writing—original draft BM: Funding acquisition; Formal analysis; Supervision; Writing—review & editing. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

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Supplementary material

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SUPPLEMENTARY DATA SHEET S1
Appendix 1: questionnaire

SUPPLEMENTARY DATA SHEET S2
Appendix 2: context Information

References

1. World Health Organization (WHO). WHO Calls on Governments to Invest in Nurses for a Healthy Europe. Available at: https://www.unbonn.org/news/who-calls-governments-invest-nurses-healthy-europe (Accessed 10 July, 2022).

2. International Council of Nurses. COVID-19 pandemic one year on: ICN warns of exodus of experienced nurses compounding current shortages. Available at: https://www.icn.ch/news/covid-19-pandemic-one-year-icn-warns-exodus-experienced-nurses-compounding-current-shortages (Accessed 10 July, 2022).

3. Woo T, Ho R, Tang A, Tam W. Global prevalence of burnout symptoms among nurses: a systematic review and meta-analysis. *J Psychiatr Res.* (2020) 123:9–20. doi: 10.1016/j.jpsychires.2019.12.015

4. International Council of Nurses. The COVID-19 Effect: World's nurses facing mass trauma, an immediate danger to the profession and future of our health systems. Available at: https://www.icn.ch/news/covid-19-effect-worlds-nurses-facing-mass-trauma-immediate-danger-profession-and-future-our (Accessed 10 July, 2022).

5. Köllner V. Psychisch krank in der Pflege—Psychische Belastungen durch den Beruf, Möglichkeiten zu Prävention und Rehabilitation [Mentally ill in nursing—mental stress caused by the profession, possibilities for prevention and rehabilitation] (Friedrich-Ebert-Stiftung, ed.). (2015).

6. Fuchs-Frohnhofen P, Altmann T, Döring S, Felscher A, Weihrich M. *Neue ansätze des arbeits- und gesundheitsschutzes im pflege-und dienstleistungssektor [new*

approaches to occupational health and safety in the care and service sector]. Weimar, Germany: Bertuch Verlag (2017).

7. Kocks A, Altmann T, Lux V, Roling D, Roth M. Pflege für pflegende: entwicklung und verankerung eines empathiebasierten entlastungskonzepts in der care-arbeit (empCARE). [care for caregivers: development and anchoring of an empathy-based relief concept in care work (empCARE)]. In: Fuchs- Frohnhofen P, Altmann T, Doering S, Felscher A, Weihrich M., ed. *Neue ansätze des arbeits- und gesundheitsschutzes im pflege- und dienstleistungssektor [new approaches to occupational health and safety in the care and service sector]*. Weimar, Germany: Bertuch Verlag (2017). p. 24–7.

8. Fuchs-Frohnhofen P, Scheen S, Metzen D, Bessin C, Hammann G, Bogert B. *Handlungsanregung „gesunde arbeitsbedingungen in pflegeeinrichtungen" [action plan "healthy working conditions in care facilities"]*. Würselen, Germany: Verlag der MA&T Sell & Partner GmbH (2019).

9. Techniker Krankenkasse. Gesundheitsreport 2019—Pflegefall Pflegebranche? So geht's Deutschlands Pflegekräften [Health report 2019—Care case care industry? This is how Germany's nurses are doing]. Available at: https://www.tk.de/resource/blob/2066542/2690efe8e801ae831e65fd251cc77223/gesundheitsreport-2019-data.pdf (Accessed 01 July, 2022).

10. Zhang XJ, Song Y, Jiang T, Ding N, Shi TY. Interventions to reduce burnout of physicians and nurses: an overview of systematic reviews and meta-analyses. *Medicine*. (2020) 99(26):e2099. doi: 10.1097/MD.0000000000020992

11. Saito Y, Igarashi A, Noguchi-Watanabe M, Takai Y, Yamamoto-Mitani N. Work values and their association with burnout/work engagement among nurses in long-term care hospitals. *J Nurs Manag*. (2018) 26(4):393–402. doi: 10.1111/jonm.12550

12. Steffens NK, Haslam SA, Schuh SC, Jetten J, van Dick R. A meta-analytic review of social identification and health in organizational contexts. *Pers Soc Psychol Rev*. (2017) 21(4):303–35. doi: 10.1177/1088868316656701

13. Eder LL, Meyer B. Self-endangering: a qualitative study on psychological mechanisms underlying nurses' burnout in long-term care. *Int J Nurs Scien*. (2022) 9(1):36–48. doi: 10.1016/j.ijnss.2021.12.001

14. Dettmers J, Deci N, Baeriswyl S, Berset M, Krause A. Self-endangering work behavior. In: Wiencke M, Cacace M, Fischer S, editor. *Healthy at work*. Basel: Springer International Publishing (2016). p. 37–51. doi: 10.1007/978-3-319-32331-2_4%2025

15. Baeriswyl S, Krause A, Kunz-Heim D. Job demands, self-compromising behavior and occupational health of teachers: an extension of the job demands-resources model. *Empirische Pädagogik*. (2014) 28:128–46.

16. Knecht M, Meier G, Krause A. Die eigene gesundheit gefährden, um die leistung zu steigern: soziale eigendynamik als folge indirekter steuerung. [endangering one's Own health in order to increase performance: social momentum as a consequence of indirect control]. *Gruppe. Interaktion. Organisation. Zeitschrift für Angewandte Organisationspsychologie* [group. Interaction. Organization]. *J Appl Organizational Psychol*. (2017) 48(3):193–201. doi: 10.1007/s11612-017-0377-3

17. Bakker AB, Demerouti E. Job demands-resources theory: taking stock and looking forward. *J Occup Health Psychol*. (2017) 22(3):273–85. doi: 10.1037/ocp0000056

18. Bakker AB, Demerouti E. The job demands-resources model: state of the art. *J Manag Psychol*. (2007) 22(3):309–28. doi: 10.1108/02683940710733115

19. McVicar A. Scoping the common antecedents of job stress and job satisfaction for nurses (2000-2013) using the job demands-resources model of stress. *J Nurs Manag*. (2016) 24(2):E112–36. doi: 10.1111/jonm.12326

20. Carver CS, Connor-Smith J. Personality and coping. *Annu Rev Psychol*. (2010) 61(1):679–704. doi: 10.1146/annurev.psych.093008.100352

21. Schmidt KH, Diestel S. Job demands and personal resources in their relations to indicators of job strain among nurses for older people. *J Adv Nurs*. (2013) 69 (10):2185–95. doi: 10.1111/jan.12082

22. Lazarus RS, Folkman S. *Stress, appraisal, and coping*. New York: Springer Publishing (1984). doi: 10.1007/978-1-4419-1005-9

23. Krause A, Dorsemagen C, Peters K. Interessierte selbstgefährdung: was ist das und wie geht man damit um. [Self-endangering: what is it and how to deal with it.]. *HR Today*. (2010) 4:2–4.

24. De Cooman R, De Gieter S, Pepermans R, Du Bois C, Caers R, Jegers M. Freshmen in nursing: job motives and work values of a new generation. *J Nurs Manag*. (2008) 16(1):56–64. doi: 10.1111/j.1365-2934.2007.00800.x

25. Mills AC, Blaesing SL. A lesson from the last nursing shortage: the influence of work values on career satisfaction with nursing. *J Nurs Adm*. (2000) 30(6):309–15. doi: 10.1097/00005110-200006000-00009

26. Thorpe K, Loo R. The values profile of nursing undergraduate students: implications for education and professional development. *J Nurs Educ*. (2003) 42 (2):83–90. doi: 10.3928/0148-4834-20030201-09

27. Höhmann U, Lautenschläger M, Schwarz L. *Belastungen im Pflegeberuf: Bedingungsfaktoren, Folgen und Desiderate Pflege [Stresses in the nursing profession: conditional factors, consequences and desiderata]. Pflege-Report*. (2016) 73–89.

28. Bräutigam C, Evans M, Hilbert J, Öz F. Arbeitsreport Krankenhaus [Work report hospital]. Hans Böckler Stiftung. Available at: http://www.boeckler.de/pdf/p_arbp_306.pdf (Accessed 05 May, 2022).

29. Kleinknecht-Dolf M, Spichiger E, Frei IA, Müller M, Martin JS, Spirig R. Monitoring von pflegekontextfaktoren: erste deskriptive studienresultate der schweizerischen DRG begleitforschung pflege [monitoring of nursing context factors: first descriptive study results of the Swiss DRG accompanying research nursing]. *Pflege [Care]*. (2015) 28:93–107. doi: 10.1024/1012-5302/a000411

30. van Dick R, Haslam SA. Stress and well-being in the workplace: support for key propositions from the social identity approach. In: Jetten J, Haslam C, Haslam SA, editors. *The social cure: Identity, health and well-being*. Hove, UK and New York, NY: Psychology Press (2012). p. 175–94.

31. Postmes T, Haslam SA, Jans L. A single-item measure of social identification: reliability, validity, and utility. *Br J Soc Psychol*. (2013) 52(4):597–617. doi: 10.1111/bjso.12006

32. Tajfel H, Turner JC. The social of identity theory of intergroup behaviour. In: Worchel S, Austin WG, editors. *Psychology of intergroup relations*. Chicago, IL: Nelson (1986). p. 7–24.

33. Kupcewicz E, Jóźwik M. Association of burnout syndrome and global self-esteem among Polish nurses. *Arch Med Sci*. (2020) 16(1):135–45. doi: 10.5114/aoms.2019.88626

34. Breinbauer M. *Arbeitsbedingungen und arbeitsbelastungen in der pflege [working conditions and workloads in nursing care]*. Wiesbaden: Springer Link (2020).

35. Wollesen B, Hagemann D, Pabst K, Schlüter R, Bischoff LL, Otto A-K, et al. Identifying individual stressors in geriatric nursing staff: a cross-sectional study. *Int J Environ Res Public Health*. (2019) 16(19):3587. doi: 10.3390/ijerph16193587

36. Galanis P, Vraka I, Fragkou D, Bilali A, Kaitelidou D. Nurses' burnout and associated risk factors during the COVID-19 pandemic: a systematic review and meta-analysis. *J Adv Nurs*. (2021) 77(8):3286–302. doi: 10.1111/jan.14839

37. Zander B, Busse R. Die aktuelle situation der stationären krankenpflege in deutschland. [the current situation of inpatient nursing in Germany]. In: Bechtel P, Smerdka-Arhelger I, Lipp K, editors. *Pflege im wandel gestalten—eine führungsaufgabe. [shaping nursing in change—a leadership task]*. Berlin: Springer (2017). p. 125–37. doi: 10.1007/978-3-662-54166-1_13

38. Simon M, Tackenberg P, Hasselhorn HM, Kümmerling A, Büscher A, Müller B H. *Auswertung der ersten befragung der NEXT-studie in deutschland [evaluation of the first survey of the NEXT study in Germany]*. Wuppertal: Universität Wuppertal (2005). Available at: http://www.next.uni-wuppertal.de (Accessed 05 May, 2022).

39. Demerouti E, Bakker AB. The oldenburg burnout inventory: a good alternative to measure burnout (and engagement). *Stress Burnout Health Care*. (2007) 8(6):65–78. http://www.psicopolis.com/burnout/bumesur.pdf

40. Vansteenkiste M, Neyrinck B, Niemiec CP, Soenens B, Witte H, Broeck A. On the relations among work value orientations, psychological need satisfaction and job outcomes: a self-determination theory approach. *J Occup Organ Psychol*. (2007) 80 (2):251–77. doi: 10.1348/096317906X111024

41. Van Den Heuvel M, Demerouti E, Schreurs BHJ, Bakker AB, Schaufeli WB. Does meaning-making help during organizational change? Development and validation of a new scale. *Career Dev Int*. (2009) 14(6):508–33. doi: 10.1108/13620430910997277

42. Burks DJ, Kobus AM. The legacy of altruism in health care: the promotion of empathy, prosociality and humanism: the legacy of altruism in health care. *Med Educ*. (2012) 46(3):317–25. doi: 10.1111/j.1365-2923.2011.04159.x

43. McMillan K, Perron A. Change fatigue in nurses: a qualitative study. *J Adv Nurs*. (2020) 76(10):2627–36. doi: 10.1111/jan.14454

44. Pask EJ. Self-sacrifice, self-transcendence and nurses' professional self. *Nurs Philos*. (2005) 6(4):247–54. doi: 10.1111/j.1466-769X.2005.00215.x

45. Coetsier P, Claes R. *Importance of life roles and values*. Oostende, Belgium: Infoservice (1990).

46. Robins RW, Hendin HM, Trzesniewski KH. Measuring global self-esteem: construct validation of a single-item measure and the Rosenberg self-esteem scale. *Pers Soc Psychol Bull*. (2001) 27(2):151–61. doi: 10.1177/0146167201272002

47. American Educational Research Association. *Standards for educational and psychological testing*. 3rd ed. Washington: American Educational Research Association (2014).

48. Goretzko D, Pham TTH, Bühner M. Exploratory factor analysis: current use, methodological developments and recommendations for good practice. *Curr Psychol*. (2021) 40(7):3510–21. doi: 10.1007/s12144-019-00300-2

49. Timmerman ME, Lorenzo-Seva U. Dimensionality assessment of ordered polytomous items with parallel analysis. *Psychol Methods*. (2011) 16(2):209–20. doi: 10.1037/a0023353

50. Ruscio J, Roche B. Determining the number of factors to retain in an exploratory factor analysis using comparison data of known factorial structure. *Psychol Assess*. (2012) 24(2):282–92. doi: 10.1037/a0025697

51. Brown JD. Choosing the right type of rotation in PCA and EFA. *JALT Test Eval SIG Newsl*. (2009) 3:20–5.

52. Cabrera-Nguyen P. Author guidelines for reporting scale development and validation results in the journal of the society for social work and research. *J Soc Social Work Res*. (2010) 1(2):99–103. doi: 10.5243/jsswr.2010.8

53. Steegen S, Tuerlinckx F, Gelman A, Vanpaemel W. Increasing transparency through a multiverse analysis. *Perspect Psychol Sci*. (2016) 11(5):702–12. doi: 10.1177/1745691616658637

54. RStudio Team. RStudio: Integrated Development Environment for R. RStudio, PBC, Boston, MA URL. Available at: http://www.rstudio.com/ (Accessed 05 June, 2022).

55. Bliese PD. Multilevel random coefficient modeling in organizational research: examples using SAS and S-PLUS. In: Drasgow F, Schmitt N, editors. *Measuring and analyzing behavior in organizations: advances in measurement and data analysis*. San Francisco, CA: Jossey-Bass (2022). p. 401–45.

56. Bliese PD. Multilevel modeling in R (2.6): a brief introduction to R, the multilevel package and the nlme package. Available at: https://cran.r-project.org/doc/contrib/Bliese_Multilevel.pdf (Accessed 05 June, 2022).

57. Shrout PE, Fleiss JL. Intraclass correlations: uses in assessing rater reliability. *Psychol Bull*. (1979) 86:420–8. doi: 10.1037/0033-2909.86.2.420

58. McCarthy J, Gastmans C. Moral distress: a review of the argument-based nursing ethics literature: a review of the argument-based nursing ethics literature. *Nurs Ethics*. (2015) 22(1):131–52. doi: 10.1177/0969733014557139

59. Pauly BM, Varcoe C, Storch J. Framing the issues: moral distress in health care. *HEC Forum*. (2012) 24(1):1–11. doi: 10.1007/s10730-012-9176-y

60. Monteverde S. Complexity, complicity and moral distress in nursing. *Ethik in Der Medizin [Ethics Med]*. (2019) 31(4):345–60. doi: 10.1007/s00481-019-00548-z

61. Lampert B, Hornung S, Glaser J. Detached concern and well-being: mediating roles of occupational self-efficacy and meaning in work as psychological resources. *Prävention und Gesundheitsförderung [Preven Health Promot]*. (2021) 16:179–87. doi: 10.1007/s11553-021-00864-7

62. Edmondson AC. Psychological safety and learning behavior in work teams author (s). In: Edmondson A, editors. *W. Administrative science quarterly*. C: Sage Publications, Inc. on behalf of the Johnson Graduate School of Management, Cornell University Stable (1999). p. 350–83. 44(2) URL : http://www.jstor.com/stable/2666999

63. Brunetto Y, Saheli N, Dick T, Nelson S. Psychosocial safety climate, psychological capital, healthcare SLBs' wellbeing and innovative behaviour during the COVID 19 pandemic. *Public Perform Manage Rev*. (2022) 45(4):751–72. doi: 10.1080/15309576.2021.1918189

64. Duran S, Önel Ç, Güloğlu P, Ümit S. The relationship between self-esteem and psychological distress in critical care nurses. *Nurs Crit Care*. (2021) 26(6):517–22. doi: 10.1111/NICC.12618

65. Yıldırım N, Karaca A, Cangur S, Acıkgoz F, Akkus D. The relationship between educational stress, stress coping, self-esteem, social support, and health status among nursing students in Turkey: a structural equation modeling approach. *Nurse Educ Today*. (2017) 48:33–9. doi: 10.1016/J.NEDT.2016.09.014

66. Rivkin W, Diestel S, Schmidt KH. Which daily experiences can foster well-being at work? A diary study on the interplay between flow experiences, affective commitment, and self-control demands. *J Occup Health Psychol*. (2018) 23(1):99–111. doi: 10.1037/ocp0000039

67. Tafarodi RW, Swann WB Jr. Two-dimensional self-esteem: theory and measurement. *Pers Individ Dif*. (2001) 31(5):653–73. doi: 10.1016/S0191-8869(00)00169-0

68. Khan MM, Mubarik MS, Ahmed SS, Islam T, Khan E, Rehman A, et al. My meaning is my engagement: exploring the mediating role of meaning between servant leadership and work engagement. *Leadersh Organ Dev J*. (2021) 42(6):926–41. doi: 10.1108/LODJ-08-2020-0320

69. Gui C, Zhang P, Zou R, Ouyang X. Servant leadership in hospitality: a meta-analytic review. *J Hosp Mark Manag*. (2021) 30(4):438–58. doi: 10.1080/19368623.2021.1852641

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A holistic approach to integrating patient, family, and lived experience voices in the development of the BrainHealth Databank: a digital learning health system to enable artificial intelligence in the clinic

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Artificial intelligence, machine learning, and digital health innovations have tremendous potential to advance patient-centred, data-driven mental healthcare. To enable the clinical application of such innovations, the Krembil Centre for Neuroinformatics at the Centre for Addiction and Mental Health, Canada's largest mental health hospital, embarked on a journey to co-create a digital learning health system called the BrainHealth Databank (BHDB). Working with clinicians, scientists, and administrators alongside patients, families, and persons with lived experience (PFLE), this hospital-wide team has adopted a systems approach that integrates clinical and research data and practices to improve care and accelerate research. PFLE engagement was intentional and initiated at the conception stage of the BHDB to help ensure the initiative would achieve its goal of understanding the community's needs while improving patient care and experience. The BHDB team implemented an evolving, dynamic strategy to support continuous and active PFLE engagement in all aspects of the BHDB that has and will continue to impact patients and families directly. We describe PFLE consultation, co-design, and partnership in various BHDB activities and projects. In all three examples, we discuss the factors contributing to successful PFLE engagement, share lessons learned, and highlight areas for growth and improvement. By sharing how the BHDB navigated and fostered PFLE engagement, we hope to motivate and inspire the health informatics community to collectively chart their paths in PFLE engagement to support advancements in digital health and artificial intelligence.

KEYWORDS

patient and family engagement, lived experience engagement, mental health, digital health technology, artificial intelligence, machine learning, learning health system

1. Introduction

Rapid advancements in digital health technologies and artificial intelligence/machine learning (AI/ML) have created tremendous potential for transformative change in healthcare. Applying AI/ML algorithms to large datasets generated by digital health technologies extends potential benefits beyond care provision, including healthcare planning, treatment, prevention, public health, and disease progression (1). In mental health, AI can improve diagnosis and predict risk, support remote monitoring, and enable access to more personalized and de-stigmatized treatment forms (2–5).

Despite the transformative potential, there have been varying degrees of success with implementing digital health and AI, as many initiatives faced barriers that hindered acceptance, uptake, and adoption. Barriers are commonly socio-technological, where socio-cultural factors affect individual perceptions, acceptance, use, and adoption of technology (6). Failed implementations of large-scale health data initiatives highlighted the importance of public perspectives on how data is used and managed (7). Given the complexity of AI initiatives, meaningful engagement is critical to improving the systems' fairness, accountability, and transparency (8). Furthermore, the limited evidence on the effectiveness of digital health and AI/ML for mental health makes public engagement increasingly important, as there are potential unintended privacy and health implications to any design decisions with its development. Dialogues on values, needs, and nuanced insights derived through lived experiences are critical to inform decisions about the governance, design and implementation of these data initiatives (9, 10). As such, sustained engagement from the initiative's outset would ensure meaningful contributions in shaping its development and governance in a trustworthy, ethical, and acceptable manner (11–15).

Engagement can come in many forms and range in degree of involvement (16, 17). The Carman Patient Engagement Framework (18) suggests the spectrum ranges from "consultation" to "involvement" to partnership (or shared leadership), where patients, families, and people with lived experience (PFLE) become increasingly involved, and their perspectives have a more significant impact on organizational decision-making. PFLE engagement guides and toolkits have commonly suggested the need for organizational readiness and commitment to engage; clear visions and opportunities for engagement; a common understanding amongst all stakeholders; accommodations that promote a safe, inclusive environment, evaluation of engagement, and mechanisms to report feedback (19). While these frameworks inform approaches, they may have limited transferability across contexts, requiring organizations or initiatives to adapt approaches to suit their context (20, 21). This perspective article shares our approach and reflection on achieving meaningful PFLE engagement in developing a complex, large-scale digital health care and research initiative called the BrainHealth Databank (BHDB). The BHDB is intended to serve as the foundation for AI/ML applications at the Centre for Addiction and Mental Health (CAMH).

1.1. BrainHealth Databank at the centre for addiction and mental health

The BHDB is a hospital-wide initiative that advances patient-centred, data-driven care at CAMH — Canada's largest mental health teaching hospital and a leading research institute (22). The BHDB is a repository of numerous data types from various sources (e.g., sleep and physical activity, blood samples and brain images, clinical assessments, etc.). As the foundation for a digital health learning system, the BHDB will leverage clinical data to inform research and research data to inform care. Its objective is to improve our understanding of the mental illness of individuals and broader populations to accelerate the ability to deliver personalized care. This transformative initiative is the first in the Canadian mental health context (23).

As a research Centre focused on developing clinical applications of AI/ML and computational modelling, CAMH's Krembil Centre for Neuroinformatics (KCNI) led the development of the BHDB by building upon CAMH's strategic investments in core infrastructure. This includes the Cerner Millennium Electronic Health Record (EHR) and CAMH Neuroinformatics Platform to support multimodal research studies (24, 25). To support care delivery, CAMH clinics have developed and implemented evidence-based integrated care pathways that utilize measurement-based care (MBC) to monitor patient progress and inform clinical decisions (26–28).

The BHDB was developed in collaboration with clinicians, scientists, data engineers, clinical application specialists, privacy officers, legal counsel, ethicists, hospital administrators, and PFLEs to leverage their expertise to inform the various aspects of development and implementation. The first phase of the BHDB enhanced digital technology infrastructure by adding new capabilities, including electronic self-assessment capture and patient trajectory visualization, which have already influenced care. Digital MBC allows patients to complete assessments on their own device or clinic tablet before appointments resulting in efficiencies and increased patient flow (29). It has enabled the generation of real-time visual displays of patient treatment journeys, allowing clinicians to assess patients' progress quickly.

To better understand patient trajectories, the BHDB is enriching EHR treatment trajectory data by integrating the collection of research samples and daily activity and sleep data from wearable devices. The accumulated rich, integrated real-world clinical and research data is ideal for future AI/ML applications. Study participants can consent to donate their data to the BHDB for secondary use by other researchers. A patient-facing version of this dashboard is in development.

2. Engaging patients, families, and people with lived experience

Given that the core BHDB goal is to improve patient-centred, data-driven mental health, there was a recognition that PFLE engagement is critical during the initial planning stages to ensure the foundation of the BHDB was patient-centred and based on community needs. CAMH and KCNI's commitment to meaningful PFLE engagement was intentional, established, and communicated from the onset of the initiative.

2.1. Establishing the BHDB PFLE engagement team

The BHDB steering committee tasked a working group to create a strategy for facilitating PLFE engagement throughout the initiative's life cycle. This task dovetailed with CAMH's clinical and research patient and family engagement strategy and the organizational PFLE engagement roadmap. The roadmap grounded and adapted the Carman patient engagement framework (18, 30). Moreover, four clinical and research family advisory committees were established, which included CAMH PFLE engagement facilitators and coordinators who were trained specialists in PFLE engagement.

Based on the recommendation of CAMH PFLE facilitators and coordinators, the BHDB team was invited to join various PFLE advisory committees to introduce the BHDB and recruit individuals to join the BHDB PFLE engagement team. While this opportunity attracted PFLE advisors interested in AI/ML and digital health technologies, there was no requirement to have prior knowledge or experience in these areas. As team members, the recruited three BHDB PFLE partners ensured PFLE engagement, representation, and participation in BHDB activities.

To kick off the BHDB PFLE engagement team, Terms of Reference were co-created to establish roles, goals, and a common understanding of contributions. Since BHDB partners were also members of their respective CAMH PFLE advisory committees, they were responsible for reporting BHDB developments to their respective committees and soliciting feedback when necessary. As engagement team members, the partners would provide leadership and expertise in planning and supporting the engagement strategies and activities; make recommendations on meaningful engagement and representation; join the working groups within and outside the governance structure; and participate in designing various projects. To ensure accountability, an activity-tracking tool was used to document all the projects, goals, and ideas stemming from the project while providing the team with the status of various project objectives. The following section highlights three major projects where the team identified and developed mechanisms for PFLE engagement.

2.2. Different types of PFLE engagement across BHDB projects

2.2.1. Project 1: consultation—research and care coordination

As a first step to developing a digital platform to support clinics with the coordination of research and care, the BHDB launched a series of five interactive virtual workshops to engage stakeholders across the hospital to gather user requirements. BHDB partners invited advisors from their respective advisory committees to participate. Advisors were encouraged to attend a pre-workshop orientation session where they were briefed with information about the context, background, technical terminology, workshop expectations and outcomes.

The PFLE advisors were invited to attend multiple workshops. Their participation accounted for 21.5% (31/144) of stakeholder engagement across all five workshops. At the virtual workshops, PFLE advisors participated in breakout sessions and discussions with clinicians, scientists, and hospital administrators. Participants provided their user requirements for the digital platform and collectively prioritized the modules identified through the workshop. The PFLE engagement was critical in advocating for a patient-facing interface, ranked in the top 5 of 12 priority areas. This finding initiated the development of a patient-facing portal to be included. The clinical and patient portals are currently under development and will be integrated into a CAMH-wide digital initiative.

2.2.2. Project 2: involvement — co-designing the patient trajectory dashboard

As the BHDB clinical treatment trajectory dashboard was integrated across various CAMH clinics to support clinician decision-making, there was a growing recognition that a patient-facing dashboard can also benefit patients and families. This initiated a project to co-design a patient journey dashboard and was brought to the BHDB PFLE engagement team to plan. A BHDB partner volunteered to be the project co-lead with a design student from a local university. As co-leads, they planned and conducted the human-centred design project. They contributed to developing questions for semi-structured interviews and interviewed seven PFLE advisors and three clinicians. The joint analysis of gathered information informed the creation of a wireframe prototype. A formal project report and presentation were co-developed and co-presented to participants and BHDB stakeholders. This project initiated the future integration of a digital patient journey tool in the next iteration of the CAMH patient portal.

2.2.3. Project 3: partnership—BHDB governance

The BHDB PFLE engagement team operated on a partnership model with a shared decision-making process for enacting PFLE engagement opportunities. This included early engagements with the BHDB steering committee and external scientific advisory committees. However, the engagement team understood that if the goal was for a meaningful engagement at all levels, it was a natural evolution for the team to advocate for its PLFE partners to be members of the BHDB steering committee. This would enable PFLE to directly influence decision-making through their interactions with senior leadership and administrators on the committee. As a result, two PFLE partners formally joined the BHDB steering committee. To ensure a smooth transition to this new responsibility, roles and expectations were communicated, and the opportunity to have additional briefing sessions before meetings. As SC members, PFLE partners raised agenda items on the team's behalf and provided updates on PFLE engagement activities during SC meetings. It has been a positive experience for the other steering committee members and PFLE partners, with positive anecdotal feedback from all parties involved.

Participation at all levels in this work has also increased the visibility of PFLE engagement, which has led to additional opportunities for PFLEs, such as co-presenting to the hospital board of directors. Moreover, this approach was lauded by the external scientific advisory committee.

3. Discussion—critical success factors and lessons learned

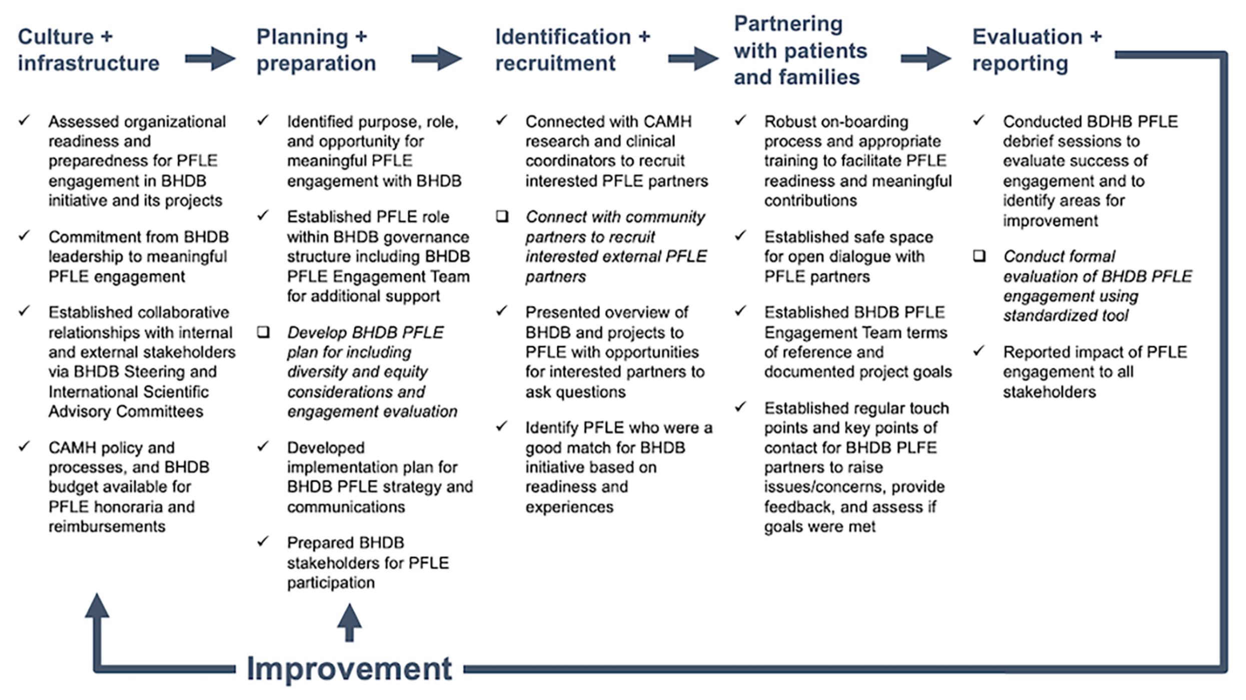
This perspective article is intended to contribute to our understanding of PFLE engagement in digital health and AI and this dynamic field of practice. While there is increasing recognition that PFLE engagement is crucial to the acceptability of AI in healthcare, engagement is predominantly overlooked in the development of AI or has a limited presence in academic literature (31–33). A recent scoping review on patient and public involvement in AI and digital health in mental health (33) found that only 5 of the 144 articles identified focused on PFLE, whereas most studies used and accessed patient and public perspectives to inform a project or co-design technologies. This paper provides some preliminary insights into other knowledge gaps in PFLE engagement in AI by reflecting on our longitudinal experiences in the context of mental health.

This article also documents a whole system approach to PFLE engagement (34), where engagement considers the individual, team, and organizational implementation factors. Based on feedback from BHDB internal and external stakeholders, PFLE partners and advisors, and use case outcomes described above, our dynamic approach to PFLE engagement has been successful overall. Guided by the PFLE process map (**Figure 1**) (19), we highlight the factors that contributed to our success and identify areas for improvement.

3.1. Culture and infrastructure

The commitment at the CAMH organization, BHDB leadership, and PLFE individual level led to active PFLE engagement in various degrees across the BHDB implementation. At the organizational level, CAMH's culture and PFLE engagement infrastructure immensely benefited the BHDB. At the BHDB leadership level, the genuine commitment and support to achieve meaningful PFLE engagement at all levels of the BHDB contributed to the achievements to date. These findings align with existing literature and frameworks on developing organizational capacity for PFLE engagement (35).

We were fortunate to be situated in an environment where mobilizing PFLE engagement across all CAMH activities was an organizational priority. The organizational commitment and infrastructure aligned with the BHDB's approach to building, developing, and growing partnerships with PFLEs (36). The established clinical and research patient and family advisory committees created a community of interested PFLE experts for the BHDB to draw upon with PFLE engagement to build engagement capacity by educating and training staff and PFLEs.



Culture + infrastructure

- ✓ Assessed organizational readiness and preparedness for PFLE engagement in BHDB initiative and its projects
- ✓ Commitment from BHDB leadership to meaningful PFLE engagement
- ✓ Established collaborative relationships with internal and external stakeholders via BHDB Steering and International Scientific Advisory Committees
- ✓ CAMH policy and processes, and BHDB budget available for PFLE honoraria and reimbursements

Planning + preparation

- ✓ Identified purpose, role, and opportunity for meaningful PFLE engagement with BHDB
- ✓ Established PFLE role within BHDB governance structure including BHDB PFLE Engagement Team for additional support
- ☐ *Develop BHDB PFLE plan for including diversity and equity considerations and engagement evaluation*
- ✓ Developed implementation plan for BHDB PFLE strategy and communications
- ✓ Prepared BHDB stakeholders for PFLE participation

Identification + recruitment

- ✓ Connected with CAMH research and clinical coordinators to recruit interested PFLE partners
- ☐ *Connect with community partners to recruit interested external PFLE partners*
- ✓ Presented overview of BHDB and projects to PFLE with opportunities for interested partners to ask questions
- ✓ Identify PFLE who were a good match for BHDB initiative based on readiness and experiences

Partnering with patients and families

- ✓ Robust on-boarding process and appropriate training to facilitate PFLE readiness and meaningful contributions
- ✓ Established safe space for open dialogue with PFLE partners
- ✓ Established BHDB PFLE Engagement Team terms of reference and documented project goals
- ✓ Established regular touch points and key points of contact for BHDB PLFE partners to raise issues/concerns, provide feedback, and assess if goals were met

Evaluation + reporting

- ✓ Conducted BDHB PFLE debrief sessions to evaluate success of engagement and to identify areas for improvement
- ☐ *Conduct formal evaluation of BHDB PFLE engagement using standardized tool*
- ✓ Reported impact of PFLE engagement to all stakeholders

FIGURE 1
BrainHealth Databank patient, family, and persons with lived experience (BHDB PFLE) engagement process map [adapted from Shen et al. (19)]. The process map was created to provide an overview of PFLE engagement processes throughout the BHDB lifecycle. Check marks (√) indicate practices that contributed to successful PFLE engagement while check boxes (☐) and italicized font indicate areas for improvement moving forward. BHDB, BrainHealth Databank; PFLE, patients, families, and persons with lived experiences.

Institutional policy and processes for providing honoraria for PLFE participation were formalized as a requirement, acknowledging time for PFLE expertise. This organizational readiness immensely benefited BHDB's PFLE engagement plans, particularly for facilitating recruitment.

3.2. Planning and preparation

Readiness across the system enabled PFLE engagement at a team level. Establishing the BHDB PLFE engagement team was critical to integrating engagement across the breadth of activities in developing and implementing the BHDB. First, it connects the various project teams, committees, and the PFLE engagement community. This connection enabled the wayfinding and identification of PFLE engagement opportunities, evaluation of feasibility, and development of plans to support the identified opportunities. Secondly, having a team of on-boarded PFLE partners, facilitators, and coordinators with diverse expertise meet monthly allows flexibility and responsiveness in planning and mobilizing for engagement activities. This was especially valuable given that opportunities were often attached to short timelines and required an understanding of the complexity and breadth of the BHDB initiative.

3.3. Identification and recruitment

The BHDB's scale and focus on cutting-edge digital health and AI technologies have attracted PLFE participation. Opportunities to engage at various levels and with varying roles allowed us to attract and recruit advisors with different experience levels and diverse backgrounds from the respective CAMH advisories. For example, those newer to the role of PFLE advisor were more comfortable in a consultation role, while those with experience were drawn to leadership roles. PFLE readiness influenced the degree to which advisors participated in this work.

PFLE recruitment has solely been from the CAMH clinical and research patient and family advisory committees. While this has allowed us to be agile in responding to engagement opportunities with tight timelines, as experienced in case study 1, this approach has shortcomings. Recruitment was from a community of advisors supporting mental health care and research at CAMH. Much of this work was during the pandemic when recruiting from the community and clinics was difficult. Recognizing the need for a greater diversity of perspectives, the team will explore additional avenues for engagement, including reaching beyond the walls of CAMH.

A robust onboarding process is necessary to achieve meaningful engagement and ensure PFLE readiness, which requires understanding project background, context, and PFLE role. There was no requirement to have prior knowledge of digital health or ML/AI to participate. The onboarding process and engagement sessions were virtual due to the COVID-19 pandemic. While this removed the need for travel and provided greater flexibility for participation, this also created the requirement for participants to have access to technology. An option to call in and receive materials via email was provided to support those without access to stable internet.

Orientation sessions involved a project overview presentation including expectations, time commitments and anticipated outcomes, followed by a question-and-answer period, were held for each case study. For use cases 1 and 2, PFLE partners helped to co-create practical and accessible project orientation and background information materials, such as a terminology cheat sheet.

3.4. Partnering with PFLEs

At the PFLE individual level, a sense of understanding and appreciation of their impact on the BHDB motivated participation. Establishing a safe environment and building trust with PFLE Partners is vital for supporting meaningful engagement. One way the BHDB accomplished this was by ensuring that there was always more than one PFLE team member present during activities. PFLE partners could also contact PFLE staff facilitators and coordinators to raise any issues and concerns. These avenues minimized the risk of power differentials impacting this work.

Fostering open dialogue in these meetings was a critical prerequisite for thoughtful and meaningful PFLE engagement. To create a safe space for open dialogue, monthly BHDB PFLE team meetings provided a comfortable space for the team to check-in, share BHDB updates, learn about related projects, put forward items and recommendations to the SC and external scientific advisory committee, and, most importantly, make decisions on matters about PFLE engagement. It also ensured a common understanding of projects and objectives and allowed the team to ask questions and work through knowledge gaps and challenges.

These regular monthly team meetings also provided a consistent cadence for sharing BHDB activity updates which were critical in enabling PFLE partners to identify engagement opportunities, fostering a sense of shared accountability for this work. While BHDB updates would frequently come from the project team, other key BDHB stakeholders were invited to present to this group. Given the enormous scope of the BHDB, sharing updates is challenging and an area to improve upon. These factors echo the experiences of other PFLE engagement initiatives (37) and the literature on meaningful engagement (34).

3.5. Evaluation and reporting

Debrief sessions were held by either BHDB or CAMH advisory committees post-PFLE engagement to assess meaningful engagement and gather feedback. Regular reporting on PFLE engagement activities to stakeholders occurred at every BHDB SC and external scientific advisory committee meeting. Any feedback received was discussed at subsequent BHDB PFLE team meetings, and an action plan was developed accordingly. The opportunity to request additional information on any topics or issues discussed during these meetings was also provided to improve understanding of the matters discussed.

In retrospect, formal evaluations of the engagement were overlooked, which is a limitation of our work to date. Moving forward, implementing standardized evaluation tools and frameworks will help systematically evaluate the impact of each engagement and inform future engagements (38, 39). Tools and frameworks such as the Public and Patient Engagement Evaluation Tool (PPEET) (40) and Guidance for Reporting Involvement of Patients and the Public (GRIPP2) (41) would allow for more consistent evaluations and reporting, thereby improving applicability across contexts. Sharing lessons learned will be critical in advancing the collective understanding on meaningfully engaging PFLE in implementing these large initiatives, documenting how we circumnavigate emerging challenges.

4. Future directions and conclusion

As the BHDB continues to grow, there is an imperative to keep improving our approach to PFLE engagement. In our future engagements, we aim to increase the diversity of PFLE perspectives in our engagements and team. Moving forward, we will explore additional areas for engagement—for example, building capacity for PFLE engagement in research through the BHDB. With the eventual integration of BHDB AI use cases, PFLE engagement becomes increasingly critical to ensure the development of responsible and ethical products that meet the community's needs, especially concerning AI's appropriateness, equity and fairness, privacy, governance, and transparency. Formal evaluations of those engagements should be a foundational activity to ensure it is increasingly meaningful and impactful for the individuals, teams, and organization. By sharing how the BHDB navigated and fostered PFLE engagement, we hope this will motivate and inspire the digital health, AI, and mental health community to continue to collectively chart this path to both support advancements and implementation of novel cutting-edge digital health and ML/AI products that will improve brain health.

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

JY and NS: wrote the first draft of the manuscript. SC, BL, and RM: are BHDB patient, family, and lived experience research partners. All authors contributed to the article and approved the submitted version.

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Conflict of interest

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

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References

1. Kruse CS, Goswamy R, Raval YJ, Marawi S. Challenges and opportunities of big data in health care: a systematic review. *JMIR Med Inform*. (2016) 4(4):e5359. doi: 10.2196/medinform.5359

2. D'Alfonso S, Santesteban-Echarri O, Rice S, Wadley G, Lederman R, Miles C, et al. Artificial intelligence-assisted online social therapy for youth mental health. *Front Psychol*. (2017) 8:796. doi: 10.3389/fpsyg.2017.00796

3. Graham S, Depp C, Lee EE, Nebeker C, Tu X, Kim HC, et al. Artificial intelligence for mental health and mental illnesses: an overview. *Curr Psychiatry Rep*. (2019) 21(11):116. doi: 10.1007/s11920-019-1094-0

4. Lee EE, Torous J, De Choudhury M, Depp CA, Graham SA, Kim HC, et al. Artificial intelligence for mental health care: clinical applications, barriers, facilitators, and artificial wisdom. *Biol Psychiatry Cogn Neurosci Neuroimaging*. (2021) 6(9):856–64. doi: 10.1016/j.bpsc.2021.02.001

5. Lovejoy CA. Technology and mental health: the role of artificial intelligence. *Eur Psychiatry*. (2019) 55:1–3. doi: 10.1016/j.eurpsy.2018.08.004

6. Greenhalgh T, Wherton J, Papoutsi C, Lynch J, Hughes G, A'Court C, et al. Beyond adoption: a new framework for theorizing and evaluating nonadoption, abandonment, and challenges to the scale-up, spread, and sustainability of health and care technologies. *J Med Internet Res*. (2017) 19(11):e367. doi: 10.2196/jmir.8775

7. Wachter RM, Cassel CK. Sharing health care data with digital giants: overcoming obstacles and reaping benefits while protecting patients. *JAMA*. (2020) 323(6):507. doi: 10.1001/jama.2019.21215

8. Nebeker C, Torous J, Bartlett Ellis RJ. Building the case for actionable ethics in digital health research supported by artificial intelligence. *BMC Med*. (2019) 17 (1):1–7. doi: 10.1186/s12916-019-1377-7

9. Bao L, Krause NM, Calice MN, Scheufele DA, Wirz CD, Brossard D, et al. Whose AI? How different publics think about AI and its social impacts. *Comput Hum Behav*. (2022) 130:107182. doi: 10.1016/j.chb.2022.107182

10. Carr S. 'AI gone mental': engagement and ethics in data-driven technology for mental health. *J Ment Health*. (2020) 29(2):125–30. doi: 10.1080/09638237.2020.1714011

11. Armstrong N, Herbert G, Aveling E, Dixon-Woods M, Martin G. Optimizing patient involvement in quality improvement. *Health Expect*. (2013) 16(3):e36–47. doi: 10.1111/hex.12039

12. Leung K, Lu-McLean D, Kuziemsky C, Booth RG, Rossetti SC, Borycki E, et al. Using patient and family engagement strategies to improve outcomes of health information technology initiatives: scoping review. *J Med Internet Res*. (2019) 21 (10):e14683. doi: 10.2196/14683

13. Muller SHA, Kalkman S, van Thiel GJMW, Mostert M, van Delden JJM. The social licence for data-intensive health research: towards co-creation, public value and trust. *BMC Med Ethics*. (2021) 22(1):110. doi: 10.1186/s12910-021-00677-5

14. Carter P, Laurie GT, Dixon-Woods M. The social licence for research: why care.data ran into trouble. *J Med Ethics*. (2015) 41(5):404–9. doi: 10.1136/medethics-2014-102374

15. van Staa TP, Goldacre B, Buchan I, Smeeth L. Big health data: the need to earn public trust. *Br Med J*. (2016) 354:i3636. doi: 10.1136/bmj.i3636

16. Majid U, Gagliardi A. Conceptual frameworks and degrees of patient engagement in the planning and designing of health services: a scoping review of qualitative studies. *Patient Exp J*. (2019) 6(3):82–90. doi: 10.35680/2372-0247.1356

17. Smits DW, van Meeteren K, Klem M, Alsem M, Ketelaar M. Designing a tool to support patient and public involvement in research projects: the involvement matrix. *Res Involv Engag*. (2020) 6:30. doi: 10.1186/s40900-020-00188-4

18. Carman KL, Dardess P, Maurer M, Sofaer S, Adams K, Bechtel C, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. *Health Aff*. (2013) 32(2):223–31. doi: 10.1377/hlthaff.2012.1133

19. Shen N, Jankowicz D, Strudwick G. Patient and family engagement approaches for digital health initiatives: protocol for a case study. *JMIR Res Protoc*. (2021) 10(7): e24274. doi: 10.2196/24274

20. Greenhalgh T, Hinton L, Finlay T, Macfarlane A, Fahy N, Clyde B, et al. Frameworks for supporting patient and public involvement in research: systematic review and co-design pilot. *Health Expect*. (2019) 22(4):785–801. doi: 10.1111/hex.12888

21. Bombard Y, Baker GR, Orlando E, Fancott C, Bhatia P, Casalino S, et al. Engaging patients to improve quality of care: a systematic review. *Implement Sci*. (2018) 13(1):98. doi: 10.1186/s13012-018-0784-z

22. O'Malley S. The CAMH BrainHealth Databank. (2021). Available at: https://www.camh.ca/en/camh-news-and-stories/the-camh-brainhealth-databank (cited 2023 Jan 1).

23. Centre for Addiction and Mental Health. CAMH. BrainHealth Databank. Available at: https://www.camh.ca/en/science-and-research/discovery-fund/brainhealth-databank (cited 2023 Feb 8).

24. Sulkers H, Tajirian T, Paterson J, Mucuceanu D, MacArthur T, Strauss J, et al. Improving inpatient mental health medication safety through the process of obtaining HIMSS stage 7: a case report. *JAMIA Open*. (2018) 2(1):35–9. doi: 10.1093/jamiaopen/ooy044

25. Rotenberg DJ, Chang Q, Potapova N, Wang A, Hon M, Sanches M, et al. The CAMH neuroinformatics platform: a hospital-focused brain-CODE implementation. *Front Neuroinform*. (2018) 12:77. doi: 10.3389/fninf.2018.00077

26. Campbell H, Hotchkiss R, Bradshaw N, Porteous M. Integrated care pathways. *Br Med J*. (1998) 316(7125):133–7. doi: 10.1136/bmj.316.7125.133

27. Chen S, Awan S, Rajji T, Abdool P, George TP, Collins A, et al. Integrated care pathways for schizophrenia: a scoping review. *Adm Policy Ment Health*. (2016) 43 (5):760–7. doi: 10.1007/s10488-015-0696-z

28. Settipani CA, Cleverley K, Hawke LD, Rice M, Henderson JL. Essential components of integrated care for youth with mental health and addiction needs: protocol for a scoping review. *BMJ Open*. (2017) 7(4):e015454. doi: 10.1136/bmjopen-2016-015454

29. Hawley S, Yu J, Bogetic N, Potapova N, Wakefield C, Thompson M, et al. Digitization of measurement-based care pathways in mental health through REDCap and electronic health record integration: development and usability study. *J Med Internet Res*. (2021) 23(5):e25656. doi: 10.2196/25656

30. Research AI for. A Roadmap for Patient+Family Engagement in Healthcare Practice and Research: Practical strategies for advancing engagement in healthcare—starting today. Available at: https://www.air.org/sites/default/files/Roadmap-Patient-Family-Engagement.pdf (cited 2023 Mar 31).

31. Adus S, Macklin J, Pinto A. Exploring patient perspectives on how they can and should be engaged in the development of artificial intelligence (AI) applications in health care. In Review. (2023). Available at: https://www.researchsquare.com/article/rs-2972402/v1 (cited 2023 Jul 4).

32. Camaradou JCL, Hogg HDJ. Commentary: patient perspectives on artificial intelligence; what have we learned and how should we move forward? *Adv Ther*. (2023) 40(6):2563–72. doi: 10.1007/s12325-023-02511-3

33. Zidaru T, Morrow EM, Stockley R. Ensuring patient and public involvement in the transition to AI-assisted mental health care: a systematic scoping review and agenda for design justice. *Health Expect*. (2021) 24(4):1072–124. doi: 10.1111/hex.13299

34. Ocloo J, Garfield S, Franklin BD, Dawson S. Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews. *Health Res Policy Syst*. (2021) 19(1):8. doi: 10.1186/s12961-020-00644-3

35. Anderson NN, Baker GR, Moody L, Scane K, Urquhart R, Wodchis WP, et al. Organizational capacity for patient and family engagement in hospital planning and improvement: interviews with patient/family advisors, managers and clinicians. *Int J Qual Health Care*. (2021) 33(4):mzab147. doi: 10.1093/intqhc/mzab147

36. Centre for Addiction and Mental Health. ONE CAMH—CAMH Strategic Plan 2020–2023. Available at: https://www.camh.ca/en/driving-change/about-camh/one-camh-strategic-plan-2020-2023/-/media/images/all-other-images/onecamh/one_camh-strategic_plan_2020-2023-06-23-2020.pdf (cited 2023 Feb 8).

37. Huwe M, Woolf B, David J, Seid M, Saeed S, Margolis P, et al. Conceptualizing and redefining successful patient engagement in patient advisory councils in learning health networks. *Learn Health Syst*. (2023) e10377. doi: 10.1002/lrh2.10377

38. Abelson J, Tripp L, MacNeil M, Lang A, Fancott C, Ganann R, et al. Development of the engage with impact toolkit: a comprehensive resource to support the evaluation of patient, family and caregiver engagement in health systems. *Health Expect*. (2023) 26(3):1255–65. doi: 10.1111/hex.13742

39. L'Esperance A, O'Brien N, Gregoire A, Abelson J, Canfield C, Del Grande C, et al. Developing a Canadian evaluation framework for patient and public engagement in research: study protocol. *Res Involv Engag*. (2021) 7(1):10. doi: 10.1186/s40900-021-00255-4

40. Abelson J, Tripp L, Kandasamy S, Burrows K. Supporting the evaluation of public and patient engagement in health system organizations: results from an implementation research study. *Health Expect Int J Public Particip Health Care Health Policy*. (2019) 22(5):1132–43. doi: 10.1111/hex.12949

41. Staniszewska S, Brett J, Simera I, Seers K, Mockford C, Goodlad S, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Br Med J*. (2017) 358:j3453. doi: 10.1136/bmj.j3453

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Virtual collaborative creative engagement in a pandemic world: creative connection for older adults with lived experience of dementia

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Introduction: Older adults were disproportionately affected by COVID-19, and isolation and loneliness became key risk factors for mental illness and decreased quality of life. Older adults with lived experience of dementia and their care partners experienced isolation, loneliness, anxiety and depression, already heightened due to social stigma. Reduced access to resources was a notable problem.
Objective: This Canadian qualitative study investigates the *Raising the Curtain on the Lived Experience of Dementia* (RTC) Project's virtual turn in program delivery during the pandemic, asking "How did virtual collaborative creative engagement (CCE) impact well-being for people living with dementia and their care partners?"; and "What are key elements of RTC's unique virtual CCE approach?"
Methods: The study employs reflexive thematic analysis to analyse interviews and focus groups with the project's artist facilitators, researchers, peer collaborators living with dementia, and their care partners. Findings: Themes describe key elements of RTC's unique approach to virtual CCE and include: "Adjusting Expectations and Adapting to Technology"; "Re-imagining Creative Engagement in Virtual Space"; "Sustaining Reciprocal Caring, Learning, and Support"; "Disrupting Stigma and Welcoming a Wider Audience"; and "Supporting Well-being through Empowerment, Community, and Creativity."
Discussion: Findings offer new perspectives on how virtual CCE not only has the potential to decrease loneliness and isolation and associated mental health risks for older adults living with dementia and their care partners, but also can work to disrupt stigmatizing representations of dementia, promote inclusion, and enhance citizenship.

KEYWORDS

older adults, dementia, well-being, collaborative creative engagement, virtual, online, technology, community-based participatory research

1. Introduction

The COVID-19 pandemic provoked a mental health crisis for people of all ages worldwide. For older adults, who were disproportionately affected by COVID-19, and in some locations had self-distancing restrictions greater than other age groups, isolation and loneliness became key risk factors for mental illness. While some studies found older adults were at less risk of pandemic-related emotional distress than younger people (1), such findings are highly culture and context dependent. Many studies revealed that older adults were at increased risk of pandemic-related loneliness, which was associated with decreased mental health and quality of life (2, 3). Older adults also were shown to experience pandemic-related financial challenges associated with worse mental health and well-being (4). For people with lived experience of dementia and their care partners, the pandemic increased their risk of isolation and loneliness, and increased rates of anxiety and depression, which were already heightened due to social stigma. According to Chong et al. "Older adults living with dementia in the COVID-19 world have experienced reduced access to support and activities. These changes have caused distress and exacerbated behavioural and psychological symptoms of dementia" (5).

In the early days of the pandemic, many organizations providing services to people living with dementia believed that it would not be possible to offer services online, thinking that a diagnosis of dementia would disrupt people's ability to meaningfully participate, and also adopting the ageist belief that older people (including spousal care partners) would be incapable of handling technology. However, the community-based, art-engaged 5-year research project, *Raising the Curtain on the Lived Experience of Dementia* (RTC) located on the Sunshine Coast in British Columbia, Canada, pivoted almost immediately to continue its creative engagements with people living with dementia in a virtual context. This study uses reflexive thematic analysis (6, 7) to analyse interviews and focus groups with the project's researchers, artist facilitators, individuals with the lived experience of dementia (called peer collaborators within RTC), and their care partners. Themes describe key elements of RTC's unique approach to virtual collaborative creative engagement (CCE) with people with lived experience of dementia and their care partners which was developed in response to the pandemic.

1.1. Literature review of related works

The COVID-19 pandemic had disproportionately negative consequences for older adults broadly. In addition to "excess mortality," (8) these included,

> the presence of psychological symptoms, exacerbation of ageism, and physical deterioration … decreased social life and fewer in-person social interactions … occasionally associated with reduced quality of life and increased depression. Difficulties accessing services, sleep disturbances, and a reduction of physical activity (9)

For people with lived experience of dementia and their care partners, these negative consequences were often exaggerated. Dementia is an umbrella term that refers to a set of symptoms including memory loss, changes in mood, and difficulties with thinking, problem solving, and language (10). In Canada, the location of the study, over 597,300 people are currently living with a dementia diagnosis. This number, prior to the pandemic, was expected to increase to nearly 1 million by 2030, and more than 1.7 million by 2050 (11). While dementia is typically associated with various neurodegenerative conditions (12), rather than named as a mental health diagnosis, its impacts on mental health and well-being have been well documented. People living with dementia commonly experience stigma and discrimination (13–15), disempowerment (15), depression (16), and "struggles with self-identity, independence, control and status, participation in meaningful activities, and how to view the future" (15).

The COVID-19 pandemic presented global health, social, economic, and environmental challenges that put both people with lived experience of dementia and their care partners (also called caregivers or carers in various studies) at increased risk for physical and mental health challenges. Based on large-scale international clinical data, Numbers and Brodaty suggest that "As well as being at increased risk of contracting COVID-19, older adults with dementia are also more likely to have more severe disease consequences than those without dementia" (17) A range of studies considering data from Europe and Australia found that the experiences of social restrictions and isolation have been associated with worsening cognitive decline for people living with dementia (18), worsened neuropsychiatric symptoms such as depression (19), apathy (19, 20), delusions (19), anxiety (19–21), irritability (19, 20), agitation (19), and loss of self-worth and purpose stemming from inability to participate in meaningful activities" (21). In British Columbia, Canada, Tam, Dosso and Robillard found that both people with dementia and their care partners reported increased levels of stress and feelings of isolation resulted from COVID-19 (22). Amongst care partners increased stress and reduced social networks were associated with uncertainty about the future and loneliness in Australia, Germany, Spain and the Netherlands (19), and, in the Italian context, increased levels of depression were associated with increased caregiver burden during lockdown (23). In a large sample of family care partners in the UK, 43.7%, of them reported moderate loneliness and 17.7% reported severe (24). Survey data from a Canadian study by Faieta et al. showed that 87% of dementia care partners who were separated from their loved one during COVID-19 social isolation experienced negative mental health consequences beyond typical contexts, and over 70% of care partners were concerned with the care their loved one received (25).

The stigma of dementia has long been considered responsible for many of the negative experiences of people living with dementia and their care partners (26). Dementia stereotypes, that construct dementia as a tragedy (27, 28), pathology, moral failing (28), death of self, and social terror (29), have been widely associated with loss of identity, personhood, and citizenship (27, 30–32). In response, in recent years, human rights-based approaches that create opportunities for citizenship are favoured in Dementia Studies (27, 32, 33). Participatory arts-based practices have grown in popularity because many readily complement and integrate a citizenship orientation. Engagement in participatory arts is reported to positively impact health, well-being, social connectedness, and quality of life of older adults, including older adults living with dementia (34–38) While many participatory arts programs have focused on the beneficial role of the arts in enhancing health, wellbeing, or quality of life, increasing attention is being given to their role in supporting citizenship for people with lived experience of dementia. Canadian researchers Dupuis et al. demonstrated that, for people living with dementia, engagement in the embodied practice of participatory arts alongside family members, visual and performance artists, and researchers, profoundly challenged the tragedy discourse of dementia and fostered narrative and relational citizenship (27). Phinney et al. illustrated how participation in a community gathering and co-created performance at the American/Canadian Peace Arch (which included social gathering, a shared meal, exhibition of artworks by people with dementia, live music and participatory dance, tai chi instruction, and the creation of a community quilt) extended social citizenship by "challenging discourses and practices that maintain boundaries between 'us and them'" (39). Through critically examining elder clown practices for artistically engaging with people living with dementia in care home settings, Kontos, Miller and Kontos proposed a model of relational citizenship that "extends the concept of social citizenship by presuming that support of the central tenets of relationship-centred care …and embodied selfhood theory are necessary to more inclusively grant citizenship entitlements to persons living with dementia in long-term residential care" (32). To the authors' knowledge no studies to date link *virtual* participatory arts to concepts of citizenship.

Beyond considerations of citizenship, new research on participatory arts has begun to focus more specifically on the unique benefits of collaborative programs that "engage the innate creativity of people with a dementia" (40). Dementia scholar and playwright Anne Basting has been seminal in developing and implementing participatory arts approaches that integrate inclusive and collaborative ways of working together and highlight the creativity of people living with dementia (34, 35, 41–43). Basting's many community-engaged projects employ what she names "creative care" (34)—an approach grounded in the belief that creativity is universal, exists in everyday moments, and emerges through relationships. The concept of co-creativity, used by the UK project *Created Out of Mind* (44) is similar to Basting's creative care approach. Zeilig, West & van der Byl Williams describe co-creativity as a nascent term that refers to collaborative approaches to creative engagement that are: innately democratic and non-hierarchical, interactive and relational, dialogic and empathetic, recognize diverse capacities of all those involved and weave them into the creative process, and rely on and create openness, receptivity, and imaginative space (40). Kontos, Grigorovich & Colobong address the theoretical underpinnings of collaborative, creative practices for working with people living with dementia, arguing that "creativity is not an individual cognitive trait but rather emerges from the complex intersection of enabling environments and the embodied intentionality of all involved" (45). They critique the notion of creativity as a form of genius that is uniquely the domain of artists, and [similar to Basting (34) and Zeilig, West & van der Byl Williams (40)] advocate for a broader view of creativity that "account[s] for the everyday and ordinary creativity of 'regular' citizens, including persons living with dementia" (45). Kontos, Grigorovich & Colobong further call for scholars who are adopting embodied and relational approaches to creativity to more fully engage with theoretical and empirical scholarship, "either in terms of understanding how the body is a site for the inscription of discourse and the making of particular subjectivities, or in terms of how capacities, senses and experiences of bodies are central to the exercise of human agency and citizenship" (45).

The COVID-19 pandemic presented a profound challenge to arts-based, co-creative projects that worked with people with dementia and relied on collaboration, relational support, experimentation, extended time together, and embodied practices. Many such projects had to make a quick decision about whether to transition to virtual delivery, with little research to support its effectiveness, efficacy, or recommend best practices. As well, limited infrastructure, resources, and guidelines to support implementation were available. Since the "pandemic pivot", research has begun to emerge about online programs for older adults, including people living with dementia. Despite widespread prejudice around older adults that predicted their limited capacity with technology, older adults are reported to have used digital technology during COVID-19 to connect socially, access resources, and manage isolation (46, 47). A systematic review by Rai et al. of digital technologies specifically for people living with dementia, reported evidence that "technologies hold potential to improve quality of life and reduce isolation/loneliness for people with dementia" (48). Further, MacRitchie et al.'s scoping review of research on technology-assisted creative arts activities for older adults living with dementia, found technologies were mostly designed for music activities (listening, and music-making), storytelling and visual arts. Devices used included applications for tablet or computer, portable media players, video game systems, Virtual Reality (VR) and online software, thus demonstrating people with dementia were capable of engaging with a broad range of technologies. The majority of devices were reported to be custom-made and at the prototype phase (and not commercially available). Their recommendations for future research were to involve people living with dementia increasingly in co-design, to progress device development past prototyping, and to investigate comparisons across devices and across arts-based activities (49). Canadian researchers Faieta et al. (25) found that amongst care partners separated from their loved one with dementia during COVID-19, the majority perceived the need for smart mobile device (SMD) app use—a particular kind of digital technology—for example, video conferencing apps, messaging apps, browsers, etc. They found "more limited SMD app use was associated with poorer mental health outcomes" for care partners (p. 6). Further, a Texan qualitative study (51) of virtual memory cafés for individuals with Alzheimer's and related dementias and family care partners during COVID-19, found the virtual cafés offered important benefits including: "reprieve" (p. 4) from daily life and the stressors of the pandemic, a reminder of "what is still possible" (p. 5) despite living with dementia, a sense of "connectedness," "belonging," (p. 5) "community" (p. 6), and "inclusivity," as well as "cognitive stimulation," "education," and "resources." (p. 7) The researchers argue that virtual models may support social connectedness beyond the COVID-19 context, but that attention must be paid to the issues of access to technology and limitations of virtual engagement for those with late stage dementia (50). These studies point to the potential benefits of digital technology and virtual participation for people with lived experience of dementia and their care partners, and suggest the need for further research around access and implementation.

In terms of virtual *arts-based* programs, art workers in the UK reported that remote delivery of arts activities helped people with dementia gain a sense of community, find structure and purpose, combat physical isolation, and contribute and share, though they noted that setup and maintenance could be issues to access, and that some people with dementia could experience challenges interacting through technology (51). A Brazilian intergenerational virtual participatory arts program, Playful Living, designed to promote wellbeing and social connection among vulnerable older adults (mostly with aphasia and dementia), reported 83.7% adherence suggesting feasibility and acceptability, and noted that participants reported feelings of social connection and a sense of having learned together (52). Thompson et al. used interpretive phenomenological analysis and collaborative song writing to analyze participants' experiences with a virtual format in an Australian therapeutic community choir for people living with dementia. The experience reportedly "was acceptable, provided relief from the stress of COVID-19, and kept members connected" (53). However, technological limitations, such as accessing and learning new technology, and having the right equipment and someone to help them learn to use it were noted as challenges (p. 19). Research on virtual arts-based programs for people living with dementia and care partners remains quite limited, however, and most studies describe the experiences of participants, but not the "how to" aspects of the engagement. One exception is Kontos et al.'s qualitative study of participants with dementia who took part the Canadian Sharing Dance Seniors program, which involved remotely streamed dance sessions in long term care and community settings (54). The researchers provide details of how the program unfolded involving on-site facilitators and an emphasis on creative expression. They also identified and gave specific examples of how, in response to virtual instruction, persons living with dementia showed intrinsic capacities for creative self-expression, including playfulness and imaginative verbal and nonverbal engagement. According to the researchers, the participants "co-constructed and collaboratively animated the narrative of the dances," participating with playfulness and sociability (p. 714). However, while instruction was virtual, participants took part in face-to-face groups, so they were not collaborating with each other virtually. While much research on programs developed throughout COVID-19, no doubt, forthcoming, a recent Baring Foundation report, *Creative Aging in Lockdown and After* (which provides numerous case studies of online arts initiatives for older adults), highlights the need within the creative ageing sector "to innovate and adapt through researching, refining, documenting and disseminating new ways of working," with older adults through technology (55). This article represents a novel contribution to this important, emerging area of research.

2. Methods

2.1. Study context

Raising the Curtain on the Lived Experience of Dementia (RTC) was a 5-year (2017–2022) research collaboration between three partners: Douglas College in Coquitlam, B.C., Canada (education), Good Samaritan Society's Christensen Village, a long-term care home in Gibsons, B.C. (health care), and Deer Crossing the Art Farm in Gibsons, B.C. (participatory arts). The RTC team was comprised of researchers (academic researchers, a postdoctoral researcher, and research assistants), artist facilitators (or AFs, who were professional artists with experience in community engaged arts), individuals with the lived experience of dementia (called peer collaborators within RTC), and peer collaborators' care partners (who were their spouses or children). In RTC we sought to answer two research questions: "What is the lived experience of dementia?" and "How can participation in collaborative creative engagement (CCE) enhance the well-being of people living with dementia, their family and caregivers, and our society as a whole?"

RTC was guided by a community-based participatory research framework (CBPR). CBPR operates from a value base of sharing power and resources, and working for beneficial outcomes for all participants (56). It aims to foster equitable community engagement and active citizenship (57) through utilizing unique partnerships, methodological innovation, and community engagement in the co-creation and co-mobilization of knowledge to address issues of importance to community members (58–60). In CBPR, diverse perspectives (e.g., artistic and scientific) stimulate and inspire each other and enrich processes of collaboration (61).

All of RTC's project activities fostered the iterative interplay between CBPR and collaborative creative engagement (CCE). CCE is a "social and embodied experience of meaning making." (62) because it unites cognitive processes, creative probing and expression, and emotional experience (62). It is similar to the creative care (34) and co-creativity (40, 44) approaches described previously in the literature review. The interplay between CPBR and CCE was driven by and supported our commitment to create inclusive communities for individuals living with dementia, to build collaboration between all team members, to value different kinds of knowledge, and to create spaces for advocacy and social action.

RTC began by collecting data about peer collaborators' lived experience of dementia through a focus group. Themes derived from the focus group data were then used to structure the first "round" of CCE workshops. Data gathered from the first round of CCE workshops were used to further refine and develop the themes. The CCE workshops were collaboratively planned with input from peer collaborators. They were run by AFs using diverse media (for example, theatre, music, visual art, new media), but leadership was shared across the team, and researchers also attended. Over the 5 years, RTC's implementation of CCE varied between large and small groups and between in-person and online delivery. Between September 2017 and March 2020, RTC held 40 2-h in-person CCE workshops with peer collaborators that did not include care partners, and two face-to-face performances for invited audiences. For a more detailed description of these CCE workshops, see Reid, Landry & Henderson (63). In March 2020, pandemic public health orders suspended in-person CCE workshops. The team collaboratively made the decision to continue CCE remotely; from April 2020 to February 2022 all project activities were distanced, involving Zoom, and (for two peer collaborators and their care partners) several telephone sessions. Moving RTC online involved a significant amount of planning and an amendment to our ethics protocols. Moving the project to Zoom (primarily) enabled the continuation of CCE workshops, however it also involved greater exposure to the homes, family and friends of team members and research participants. We remained mindful of the blurring of these boundaries and careful in our documentation of the CCE sessions.

To mitigate concerns about peer collaborators and care partners navigating technology, becoming confused or fatigued online, and lacking necessary art supplies, the RTC team changed the structure of CCE. Now each AF was paired with one peer collaborator and their care partner, and a student research assistant (RA) supported as needed. AFs, peer collaborators, and care partners met in smaller groups, usually with two peer collaborators, their care partners, and their AFs. Workshops became more focused on individual interests, rather than the whole group doing the same activity as had been the case for in-person CCE. This phase of the project included over 120 1-h virtual CCE workshops, and two virtual performances where researchers also collaborated with AFs and peer collaborators (64, 65). The virtual CCE workshops were recorded on Zoom alongside the documentation of fieldnotes by the student RA in attendance. After each workshop the student RA reviewed the recording and added portions of the verbatim transcript into the fieldnotes that were relevant to the broader research question and that upheld our team's ethical commitments (Team members agreed that full verbatim transcripts were unnecessary but that excerpts that were relevant to the primary research questions added depth and accuracy). From March to June 2022 RTC re-introduced in-person engagements that adhered to the public health mandates, in conjunction with continued online sessions. In these last months of the project RTC held five in-person CCE workshops and hosted two days of live-streamed hybrid performances and presentations in which all team members participated (66, 67).

2.2. Research design and methodology

While the overall goals of RTC were broader, this article represents a more focused sub-study of the project's transition to virtual CCE. It was inspired as we coded data collected throughout project's virtual transition that suggested the relevance of this topic. This sub-study explored the research questions: What are key elements of RTC's unique virtual CCE approach?; and, how did virtual CCE impact the well-being of our peer collaborators living with dementia and their care partners? The sub-study used a qualitative design, informed by the principles of CBPR. In CBPR clear distinctions between researcher and research participant become untenable in the context of peer research where "researchers are known to participants and do not always leave 'the research field' when the project is over" (56). Because RTC was a lengthy, collaborative project in a small community, team members were embedded in and contributed to the data gathered. However, we remained consistently committed to our own training and reflexivity, both of which were deeply integrated in our ethical commitments, research processes, and bi-monthly team meetings. In this sub-study we used reflexive thematic analysis (6, 7) to develop trustworthy, rich descriptions that reflected participants' verbatim descriptions of the processes of virtual CCE and its influence on peer collaborators' and care partners' sense of well-being.

2.2.1. Data collection

This sub-study used qualitative data that had been collected in RTC for broader purposes, and analysed it to answer the specific research questions of the sub-study. The data set involved 5 semi-structured interviews (30–90-min in length) with 5 researchers, 23 interviews with 8 AFs, and one focus group with 5 AFs. While the data set for the broader project was larger and more equitably represented all voices within the project, this data set gave greater voice to AFs because of their central role in organizing CCE sessions, and because their experience as professional artists meant they could speak to the artistic processes and techniques beyond a lay understanding. The AFs participated in three sets of interviews: the first shortly after the pivot to online engagement (summer 2020); the next slightly later during virtual CCE activities (winter 2020 to spring 2021); the final near the end of the project (spring 2022). In order to represent the voices of peer collaborators and care partners, especially as related to their experiences of well-being, we used 11 interviews that were conducted with them by AFs during four livestream online performances for public audiences. We also used one care partner panel discussion, also from a livestream performance. These data were chosen over conducting additional interviews with peer collaborators and care partners because out-of-context interviews were difficult given peer collaborators' experiences of short-term memory loss, because the team had jointly chosen to concentrate energies on public sharing activities, and finally, because in the pandemic context, additional research interviews felt burdensome to peer collaborators and care partners. More details of the data set appear in **Table 1**.

AF and Researcher interviews and the AF focus group, used semi-structured interview guides, including open-ended questions such as the following: For you, how is the experience of working online/virtually? What changed because of COVID-19? How did changing the format from in-person CCE to virtual engagement change your creative process or practice? What was lost and what was gained? What is needed to maintain continuous and meaningful engagement? The online peer collaborator panel was also guided by semi-structured questions about experiences with

TABLE 1 Data set.

Data	Number	Conducted by	Date	Context
Interviews with researchers ($n = 5$)	5	RA	Winter 2020	Online
Interviews with AFs ($n = 8$)	23	RA (8)	Summer 2020	Online
		First author (7)	Winter 2020 to spring 2021	
		RTC researcher (8)	Spring 2022	
Focus group with AFs ($n = 5$)	1	First author	Summer 2022	In person
Panel discussion with care partners ($n = 6$)	1	2 RTC researchers and 1 AF	Spring 2022	Hybrid conducted during livestream public performances (58)
Interviews with peer collaborators & care partners ($n = 9$ PC & 9CP)	11	AFs	Spring 2020 (55, 56) and Spring 2022 (57, 58)	Conducted online (55, 56) and hybrid (57, 58) during livestream public performances

RTC and virtual CCE. Interviews with peer collaborators were more open-ended around a collaboratively pre-chosen topic (for example, discussing a particular artistic creation), and responsive to peer collaborators' in-the-moment interactions.

2.2.2. Demographics

Of the 31 participants in this sub-study, 24 team members lived in the local community, 6 lived in a larger city 45 min away, and one lived in another small distanced community. Twenty-three of the team members had been involved with RTC since its inception in 2017. Across 8 AFs, artistic expertise included: theatre, visual art, film making, podcasting, photography, web-design and new media. The 9 peer collaborators ranged in age from their 60's to 80's. They had diagnoses including Alzheimer's Disease, Vascular Dementia, and Lewy Body Dementia. While all peer collaborators had early-stage dementia when they began RTC, at the time of this sub-study the stage of their disease ranged in severity. Eight named English as their first language; one named German. Three care partners were children of peer collaborators, 6 were spouses (of these, two were same sex spouses). Eight peer collaborators lived in the community with their care partner(s), and one lived in long-term care where their care partner also lived. Two couples chose to do some of their CCE sessions by telephone. The others did sessions by Zoom and occasionally FaceTime. The devices used by peer collaborators and care partners were as follows: 5 pairs exclusively used iPads (of these one pair had the iPad connected to a larger monitor provided by RTC); one pair exclusively used a desktop computer; one pair used a combination of iPad and phone calls; one pair began with a combination of desktop computer and phone calls but due to technical difficulties transitioned to an iPad provided by RTC; one pair used an iPad for large group sessions and performances but chose not to participate in small group CCE sessions.

2.2.3. Data analysis

To remain consistent with our CBPR framework we used a collaborative approach to reflexive thematic data analysis (6, 7). All recordings were transcribed verbatim by research assistants or the first author. Pseudonyms were used to de-identify data in all Researcher and AF interviews and the AF focus group. Because the peer collaborator and care partner data came from transcripts of public livestream recordings, in which they chose to use their real names and consented to have permanently posted on YouTube, their real names have also been used in this article. Verbatim transcripts were analyzed using the software programs NVivo 11 and MS Word. The first author (a postdoctoral researcher on the project) was not able to access a computer with the NVivo 11 license due to social distancing, but having previously used NVivo, was able to replicate a similar style of coding using MS Word. Therefore, the coding style and processes for all researchers were aligned. Researchers immersed themselves in the data, reading and re-reading the transcripts, reviewing reflexive fieldnotes, and relistening to recordings when necessary. Initial "codes were descriptive and closely reflected the data. The researchers used constant comparison to compare and contrast codes, grouping and regrouping them into higher level codes. Initial coding of about half of the interviews was done by RAs with oversight by the article authors. Most of these RAs had participated in the CCE workshops and recorded the fieldnotes. After initial codes were collaboratively decided, a code book was created to guide the RAs and create consistency. The authors and an RTC researcher met regularly with the RAs to discuss and compare coding, and to adjust the code book to incorporate their insights. The other half of the interviews and the focus group transcripts were coded by the first author, who then compared and contrasted this data with the data coded by RAs to create conceptually higher-level codes and overarching themes. This allowed for the analysis to reflect the relationships between the codes and broader themes and achieve rich descriptions of participants" experiences (58). To establish trustworthiness, the first author engaged in member checks by email and the focus group with the AFs; this involved presenting coded data, asking for feedback, and making adjustments to make sure AFs felt it reflected their insights. Throughout the project coded data was also shared with peer collaborators (and later care partners) through creative engagements and refined based on their responses. Triangulation across participant groups was also used to enhance the credibility of the data, and the multiple perspectives of the RAs and the two authors also helped confirm the codes and themes reflected the data. The first author used a reflexive journal to record and reflect on assumptions and consider how they might influence the analysis process, and she also kept and reflexively analyzed detailed analytical memos. The second author followed the audit trail and reviewed coding to make sure decisions reflected the perspectives expressed by participants.

3. Results

Five themes were identified. The first four describe the processes of CCE. The fifth details the peer collaborators' and care partners' experiences of well-being related to CCE engagement. In these theme descriptions, the following acronyms are used to indicate roles of speakers: AF = artist facilitator; R = researcher; PC = peer collaborator; CP = care partner.

3.1. Adjusting expectations and adapting to technology

Quite early in the COVID-19 pandemic, when social distancing orders came into effect in British Columbia, RTC made the choice to shift its activities online. As Adam (AF) described it, "going virtual" meant that "we as a team and myself personally, had to adjust expectations and adjust the kind of engagement or exercises we would do." In some cases, shifting to virtual team meetings facilitated participation for team members at different locations. Charlotte Rae (R) noted,

> Because of COVID so much of the project was transitioned to being virtual that I was able to participate to a much greater degree so for me it was actually a big benefit as it meant that I could take part in the project in a more central way."

3.1.1. Including care partners

Working together from a distance brought challenges and revised expectations. One of the biggest changes to the project was the involvement of care partners. When RTC met in person prior to the pandemic the CCE workshops provided a space for peer collaborators to have independence from their care partners, and for care partners to have a break in their caring responsibilities. Now involving care partners was necessary to help peer collaborators manage the technology and scheduling. As Sonia (AF) noted, "after we went online, we became a bit reliant on care partners to act as co-facilitators, and especially in the tech and getting the person [peer collaborator] to be present, physically present." Esme (AF) elaborated on the new learning required for care partners: "A big part of it was dealing with the technology itself … I mean her daughter was the person who would set everything up for us but it was new for her as well." Despite the challenges and loss of time apart for peer collaborators and care partners, involving care partners in creative engagements had strong benefits, as DD (AF) described:

> there's probably lots of moments where the zooming really, really worked. It created a forum for us to bring the partners in … the caregivers. And I think that's a nice progression of this project. And I think it's supported the partners in ways and made them feel more a part of that, rather than, you know, they drop their partner off. They're engaged … and challenged.

Involving care partners and connecting via technology required adaptability, as it meant new demands on everyone.

3.1.2. Developing caring and supportive virtual practices

The team also was compelled to develop caring and supportive approaches to virtual practice. As James (AF) put it "the team making that switch to … going online, it developed a whole new set of skills." The team had to spend more time and develop ways of providing technical support. Elizabeth (AF) described this, "I feel like we did a lot of back and forth to try and help get our participants online, like we cared a LOT." One of the researchers spent more time "touching base with people, reminding them, offering emotional support and encouragement regarding the technology" (Charlotte Rae, R). Jade (R) described the type of support that was needed, "support for the simplest things with technology, moving to a new device, how do you change your volume?" Elizabeth (AF) recounted driving to a peer collaborator's house (once social distancing orders allowed outdoor visitation) to help troubleshoot from outside,

> I went to his house…to try and troubleshoot his Wi-Fi and where it would reach and I think he had the wrong passcode… I got my other sheet of passwords… I think we did give him an iPad to support that and then tech support.

In some cases, the team provided peer collaborators with devices to use. Strong support was required, as Elizabeth (AF) put it, "for a lot of people [peer collaborators and care partners], the technology was a really scary thing to go into, it was really stressful for them." Thus, the team put much thought and effort into making the experience as approachable as possible.

For AFs, switching to online with little notice meant they were learning how to use virtual tools effectively at the same time as helping peer collaborators and care partners adapt to Zoom. As Esme (AF) expressed, this was a steep learning curve, "I had never done a Zoom conference much less FaceTime or anything like that. I don't have a huge facility or aptitude for technological things. So that's been a bit of an uphill challenge." Even for AFs who had more facility with technology, changes in how they prepared for CCE sessions were required. Ki (AF) described how virtual CCE required their workshop planning and preparation to be more methodical and purposeful:

> Having one of the participants that speaks the least, I would spend a large amount of time in between sessions trying new things, try[ing] to be more prepared. Look over my video from before, … how can I make this so that she feels comfortable? And she's not so alienated by this technology … that she doesn't get any benefit out of it.

Participating in long Zoom sessions was difficult for peer collaborators, Louise (AF) described, "This Zoom wears them out after like an hour tops, they're done." But Zoom fatigue was not unique to peer collaborators. Participating in Zoom sessions could be challenging for all team members,

> A Zoom call for anyone for two hours, I think can be hard on the brain and the psyche and everything. It's quite draining. So, I think making adjustments and keeping our timeframes short has been more successful in transitioning to an online space (Elizabeth, AF).

Thus, the team shortened the CCE sessions to 1-h, and used smaller groups. Sonia (R) noted "when we broke up into smaller groups … it really highlighted just how meaningful the work was to the individual [peer collaborators], because they were so willing to work with us" Adam (AF) further elaborated that Zooming with smaller groups was "probably the most exhausting, but also the most rewarding part, cause you were developing this really strong relationship." To accommodate fatigue, the team also adjusted the pace of CCE sessions. Adam (AF) explained: "It's certainly slowed it down even more because it had to be … more methodical and creating simple exercises that could translate to a virtual engagement."

With this came certain losses, particularly in casual interactions. Ki (AF) lamented that "it just wasn't the same as being in a whole room with chatty, interesting people who are excited to be with one another." But as Sonia (R) pointed out, virtual engagement also brought "a whole new level of intimacy with our participants, to be in their homes, to see their interactions with their partners, to be spending so much one-on-one time with them." DD (AF) also detailed how working in smaller groups meant that peer collaborators received more individual attention, "we are one-on-one… it became much more specific and catered to their strengths, or the world that we know they like to resonate in." AFs noted some benefits in terms of their own accessibility; "I can actually be more focused for an hour" (DD, AF). Virtual engagement also made participation more accessible for people who lacked transportation,

> The one thing we gained was that we didn't have to deal with the headache of transportation… it was just a challenge in a rural community like ours where there is not a ton of supportive transportation… so we gained in terms of reach and connection to people. (Adam, AF)

It also made it possible for family collaborations to develop. In the case of Traudi (PC), she and her husband (a poet) and daughter (an aerialist and dancer) created a piece together with the assistance of their AF, which became part of the project's Backstage Pass virtual performance shared with a public audience. Her daughter described the experience as "very emotionally nourish[ing] … very connecting and maybe a little cathartic." But not everyone was able to adapt. DD (AF) described how some peer collaborators and care partners stopped participating in creative engagements, "I believe two of our participants haven't participated in this last round, specifically because of the challenges with Zoom. Whether it's technological or the feeling of connection, they aren't playing with us right now."

3.2. Re-imagining creative engagement in virtual space

The shift to virtual CCE not only created the need to support technology use, but also called for the development of new approaches to facilitating, inspiring, and supporting collaborative creative work. This meant drawing on, adapting, and expanding some of the project's previous approaches. Adam (AF) described how this process was both challenging and rewarding,

> As we were trying to design activities collectively, … exercises and activities that would work online… I think it really stretched and tested my own ability to be adaptable… in some ways, I think that that was the gift of the Zoom era.

3.2.1. Fostering feeling in virtual space

The first adapted approach the team developed to support virtual CCE was "fostering feeling in virtual space." The project previously had a strong orientation toward drawing upon feeling as a way for participants to connect with each other, and as a gateway into creative exploration. Feeling each other's presence was key to group cohesion and creative exploration. Esme (AF) noted how she could feel "the joy … coming off the group when the group can come together." Focusing on affect when working with people living with dementia can be effective, described James (AF), because "people don't remember what you said, they remember how you made them feel." Sandra (CP) lauded this approach within RTC,

> the feeling of belonging and being amongst friends and the stimulation from the creative engagement lasts long after … having been in the moment and having been thinking and using your imagination and having fun,

Fostering feeling in virtual space, though, did not come as readily as it did in person. Adam (AF) explained,

> I come from a live performance or live art background so a lot of your time, energy, thought goes into creating a room, creating a feeling in a room, something in a physical space, so … how do you create that when people are in different spaces?

One technique the team continued to favour in online interactions was "being present" or "being in the moment." James (AF) explained that "it's not trying to draw on memory all the time, [it's] looking at the moment, and working with the person in the moment." Louise (AF) emphasized that being in the moment "remove[d] any shame," because "it wasn't about that [remembering or feeling a certain way], it's just being present." This adaptability enabled the peer collaborators to exercise more control or citizenship in those moments. Sandra (CP) described the value this has for her mother,

> sometimes my mom is concerned that she's going to do something wrong or she's not going to get it right. That doesn't happen here because …no matter what happens, a spontaneous break into song as she does routinely, everybody just joins in, it's applauded and you know people encourage that.

Encouraging this type of presence and adaptability was not only something AFs tried to inspire in peer collaborators and care partners to help them feel at ease, it was also an approach AFs and Researchers adopted themselves.

> It's really being in the moment with our participants and recognizing when something is making our participants uncomfortable and being willing to let go of the creative activity that we were hoping to achieve… really allowing the participants to turn the direction of the creative activity with their ideas and with their feelings at any time (Elizabeth, AF).

Attending to breathing was helpful to achieving this type of presence. Louise (AF) explained, "Allowing yourself to go into it with full relaxation and breath is so essential in allowing ourselves to play." As a result, RTC incorporated breath exercises into some of its online activities within team meetings and creative engagements. They were integrated into the project's collaborative song writing practice too.

One online-specific technique the team found supported being in the moment was avoiding the blurred backgrounds commonly used on Zoom. This allowed participants to see and respond to each other's actual social and physical contexts.

> I think on Zoom meetings … the past history of it was to pretend that your background reality doesn't exist, like some people will blur it out and try to have it with the plain background and it's just like, no, I'm here. I'm present… like kind of breaking that Zoom conference energy by integrating the space that everybody was occupying (Elizabeth, AF).

Avoiding blurred backgrounds allowed for the sharing of more intimate, personal space. As a result, the collaborative teams drew inspiration from home spaces to engender positive feelings. Ki (AF) explained that seeing her peer collaborator's home over Zoom was an "opportunity" to be influenced, in the moment, by the objects in her environment,

> I could also tell on the Zoom calls that there were like many examples of her artwork because she was a ceramicist, potter, and she made all manners of types of pottery, including visual art … that's framed and hanging on the walls … it's just really extraordinary the breadth of her artistic skill.

This inspired a shared activity, Ki (AF) explained, "their next photo assignment was to take photos of these [lamps she made], and then show me. And so we both did our thing and we came together. And then we made a photo collage of their lamps and my lamps."

Acknowledging and validating feelings was also important to encouraging emotional expression. Humour was used often as a means of connecting. Adam (AF) recalled the great sense of humour of one peer collaborator, "I remember he… would laugh every time… We just set him laughing. And it was like a bubble burst in the room. And then … it was just so freeing." However, fostering feeling was not only about encouraging fun, humour, and joy. It also involved acknowledging and validating peer collaborators and care partners' more difficult feelings, and accepting them "where they were at" (Ki, AF). DD (AF) expounded, "if they are grumpy, they are grumpy and if they're angry about their situation, they are angry." He noted that one of his mistakes in the beginning was to try to make everyone happy, saying "you don't have to do that and it's okay… eventually we just find our way out of it or we explore it." In virtual space, in the pandemic context, fostering feeling sometimes meant acknowledging that Zoom brought frustration, and that, as Adam (AF) put it, "Zoom fatigue, online time, added to our… stress in the sense of disconnection." Sometimes it meant acknowledging the feelings of isolation and loss people felt about not being able to meet in person. Esme (AF) described one peer collaborator, "She would also say she just missed hanging out with everybody," and "every week she would ask when are we going to be able to get together again in person." Sometimes fostering feeling meant accepting the confusion peer collaborators experienced about the pandemic and trying to offer comfort. DD (AF) described how one participant thought everyone was meeting without her,

> I would witness how the participant I was dealing with couldn't remember what's going on. She was often wondering how everybody is and assuming that everybody else is getting together in the room that we always get together but she wasn't. So, it was hard to witness her lack of comprehension and her desire for connection.

"Fostering feeling in virtual space" helped the team stay connected and helped sustain meaningful engagement despite the difficulties involved in collaborating online. Esme (AF) recognized how "feeling" allowed for authentic connections, "I think a true strength of our project was the bonds that people made with each other … in that they can witness each other going through a shared experience." Fostering feeling was also a technique used to connect with virtual audiences during the project's public live stream events.

3.2.2. Inspiring virtual play with intentionality

Building on techniques for fostering feeling, especially being in the moment, the next approach that was key to the project's effective CCE, was "developing virtual play." Similar to fostering feeling, play had always been a key element to RTC's creative engagement sessions. DD (AF) described the accessibility and effectiveness of engaging from a place of play,

> I didn't know anybody who ultimately wouldn't get into the play. Because again, it's play. And if we take out the stigma

> of "kids do that" … and just make it more about the fun. And there's a lot of things for them to choose, then they start getting into it.

Even peer collaborators and care partners who did not consider themselves "artistic" were able to meaningfully engage in play. Louise (AF) described the success of the team's play approach with one hesitant peer collaborator,

> She still is hesitant to be doing anything artistic… [saying] "I'm not an artist," because she was told she wasn't at a very young age… she came up with … just beautiful, beautiful, beautiful work of expression. And so there's so much in that … allowing them to explore allowing.

Play was often invigorating by way of its novelty, Elsie (R) noted:

> I think the … importance of play in RTC is that it makes you more alive when you play… it's like play offers a new experience that is very opposite to what often people might feel or might experience in their day-to-day lives, when they are living with dementia.

Sandra (CP) felt that RTC's playful orientation was central to the positive experiences her mother had with the project,

> It's not just the talking … I think that the collaboration and the fun and the encouragement to use your imagination and your intelligence … and the love, I think there needs to be more opportunity for that kind of thing.

However, like "fostering feeling," play was more challenging to evoke online. Esme (AF) noted that, "if we were meeting in a room, there'd probably be a bit more play." The team consciously adapted and developed playful approaches for a virtual context. Some of the session warmup activities became more "conversation, check ins" (Esme, AF). The team also found playful ways to adjust warmups, which began each CCE session, to work on Zoom. A favourite warmup was Energy Ball which involved imagining a ball of energy and miming holding it, describing and miming how it changed, and passing it on to another person. Esme (AF) recounted the playfulness and acceptance within the game:

> energy ball … if somebody is just like … throws it over their shoulder, we can all laugh at that and go, oh, that was their choice. Or if … somebody blows their nose on the imaginary thing and passes it on, the next person is like, oh, I'm not picking that up like that… if we are wishing them to engage in a performative way to honour the performance that they offer us in a very much of a sort of Theatresports-kind-of-rules way of accepting the offers that they put forth.

The team adapted this game to pass the ball across Zoom windows, finding playful ways to use the camera when simulating passing an object; it was even used in the project's hybrid capstone Encore Showcase (56). Louise (AF) described another warmup game that adapted well to Zoom, "One of the games we would play is 'What body part?' and this translated online… what part of your body is/wants to make a sound. And it was great." Physical warmups helped the group become energized and be present.

Starting gently was another approach to help all team members enter into play in the Zoom environment. Robby (AF) described how this removed pressure and helped build trust:

> Just kind of starting with some, you know, basic things like a little name game. And it was good to do gentle things like that, and gentle things that just let people contribute in a very, achievable manner and share something about themselves and that then kind of builds the trust. And once you have trust, then people are a little more available to be vulnerable, right?

It was important, "just to validate … the play impulse" (Esme, AF). Another technique used to achieve this, as well as help balance power relations (both in person and virtually), was for all team members to participate in CCE together. Esme (AF) described this approach,

> we're all just rolling up our sleeves and getting in there, side by side, which is valuable. Which is something that we have been able to do on Zoom. Like for instance when we do a creative activity … everybody [each team member] gets to go.

Working together in this way helped minimize power hierarchies and helped to engender empathy and understanding, "There's no escaping play, … you understand the feelings that they [peer collaborators and care partners] might be having, because you also have to do it" (Sonia, R).

Another technique the team used, now that they were virtually sharing more intimate, personal space, was to draw inspiration for play from peer collaborator's home spaces and circumstances. Ki (AF) described how she suggested an activity based on a peer collaborator's and care partner's routines,

> "One of our playful investigations was … they told me … they like to go for a walk outside their condo along the waterfront, …They took photos. And so it was like a photo adventure scavenger hunt. They took photos all along their walk. And then they brought it back to the Zoom call."

Adam (AF) agreed that seeing intimate spaces contributed to creativity, "I think the bonus of Zoom space was …seeing homes." Elizabeth (AF) added that seeing "garden spaces" became important to the project. In fact, the collaboratively composed "Protest Song" presented at the project's final Encore Panels (57) event used garden imagery (suggested by peer collaborators and care partners) in the lyrics of the song, and photos they took of their gardens in the accompanying video.

Not only did peer collaborators' spaces offer a window into their lives and contribute to playfulness, AFs' spaces were also visible and became part of the fabric of the interactions. Louise (AF) described how attending to her own surrounding space set the stage for playfulness and creativity,

> I need to be in my studio. And I do Zoom because I'm surrounded by things that stimulate me, constantly. So, I've got beads in front of me, I've got things that I could draw on. Things I can play with, because that helps me bring it back to the moment.

Animals became a natural part of the Zoom environment and often offered inspiration and sometimes humour. Louise (AF) described the central presence of her dog, "She was essential. Like, when we did it, she was always [there]. She just became part of the virtual reality… and that became a real conversation starter. And then they started looking forward to it."

While home spaces offered many advantages, peer collaborators and care partners lacked the wide range of art supplies that were available when the project met in person. Many team members missed working more extensively with tangible materials, as Louise (AF) expressed, "there's so much amazingness that can come from that [being online]. But for me, I'm always really grateful for something that I can do with my hands and without the glare of the screen." To compensate for this RTC turned to mailing packages to peer collaborators, and when public health orders allowed, AFs sometimes drove packages to peer collaborators' houses. Louise (AF) describes this playful experiment,

> the participants and our team are sending sort of creative care packages to each other, with art supplies in them… and, what's amazing is like, you can see what's been made so far, and then you're also left with, their kind of scraps… and you can add with your own materials that you have, and then send it on to somebody else.

Louise (AF) further explained that "it's not what you put in the package, it's the intention" and that the packages included "just like little things that would evoke, I don't know, play… like pieces of paper, different colours." Sometimes team members opened the packages together online during creative engagements. Louise (AF) described the response of one recipient, "she just lighted up." Being thoughtful about the content was important. The team learned that if the package contents were less intentional, "[peer collaborators and care partners] didn't have that same connection of what was going on in the bag. And so it didn't work for them" (Louise, AF).

3.2.3. Maintaining social rituals

Finally, an important aspect of re-imagining CCE in virtual space was the team's concerted attempt to "maintain social rituals." Prior to the pandemic, RTC recognized the importance of social rituals in providing social opportunities, creating a sense of connection, and helping with predictability. The project's most important social ritual was "tea and cookies." Elizabeth (AF) said, "We always felt crunched for time. And regardless, we took tea and cookie breaks with our participants … just having that social time of being together … was always something that we prioritized." James (AF) mentioned the particular social value that tea and cookies had for peer collaborators,

> For so many people with a lived experience of dementia, … their social networks get smaller… it was just this social banter and teasing and that social connection, and just knowing that you're surrounded by friends, right? Like, I mean, it was a really, really, really great friendship circle.

It was not surprising, then, when peer collaborators raised the need to maintain this social ritual in a virtual context. Ki (AF) noted how peer collaborator Betty exclaimed during a creative engagement session "we need food and drinks or cookies."

While the team found virtual CCE more effective and rewarding when done in smaller groups, RTC occasionally made a point of bringing the entire team together for tea or cookies or other celebratory events in order to maintain the social ritual of gathering as a community. During such sessions team members noticed how much peer collaborators enjoyed seeing each other for social time. Esme (AF) highlighted the sense of enthusiasm such virtual social rituals inspired, "our participants seemed to really enjoy group zooming … the twenty minutes of waving at each other and making jokes was so awesome." Team members also often dressed up and brought a mug to match the theme of the occasion (for example, Halloween or Christmas) which inspired playfulness and connection.

One event the team organized was a virtual wrap party that took place after the online two-day livestream event Backstage Pass (54, 55). James (AF) spoke to the meaningfulness of this social ritual for peer collaborators and care partners, "In the wrap-up party, … you could really feel that sense of joy and celebration and accomplishment. Fatigue, for sure, but people are just laughing, and they're raising a drink… like, what's next?" Part of the reason these events worked with a larger group (when CCE did not) was that they did not take place too often, they were short in duration (less than an hour), and participation was very open-ended. People could join in conversation or just watch and they could leave whenever they wanted.

3.3. Sustaining reciprocal caring, learning, and support

A central value for RTC was that caring, learning, and support were mutual and reciprocal, and this became important to translate to virtual engagement. Reciprocity was central to the team's approach to relationships, as Elsie (R) described,

> I think reciprocity … I don't know, like which one came first, reciprocity or like a sense of community, and a sense of belonging, but I think … attending to this principle helps us to establish a shared sense of community and sense of belonging.

Esme (AF) described how amongst AFs and researchers this meant sharing the lead during CCE, "care happens in the form of if you are in the lead or presenting/facilitating a certain workshop … your fellow artists, collaborators, researchers, whoever's in the room helping by supporting what you're doing." She also noted how it was important as a leader to receive help by "being open to each other's assistance and observations." This openness also extended to making space for peer collaborator's ideas and leadership, "It was completely essential to prioritise and to ask what the participants wanted to do … they have the creative power and initiative themselves to build what it is that they want to in the project" (Elizabeth, AF). It also meant recognizing peer collaborators' capacity to provide caring, support, and insights. James (AF) described how this is seldom recognized for people living with dementia,

> SOOO MUCH, if they've gone through the traditional way people react to them … they become a burden, right? … So how do you build enough of a relationship and caring and assisting, that it's not a burden–and it's not a burden when it's reciprocal. Because you've done something for them. They'll do something for you and that balance, I think that's important.

Being reflexive about power relations and interactions was essential. AFs, such as Louise, described how this orientation toward reciprocity and mutual support and learning was part of re-imagining more typical ways of engaging with individuals living with dementia**,** "[it involved] stepping outside the clinical model [or traditional medical model], really. Set it aside." DD (AF) further elaborated, "it's really in some ways dropping the role of client, it's interpersonal relationships, and a friendship. I never lost sight of my role, but it didn't define how I related with them [peer collaborators and care partners]." This meant that in Esme's role as an AF, she would "sometimes be a contributor and sometimes be a witness." She further explained, "these are my elders in a community and I want to learn from them as much as I can."

Part of what allowed this openness and reflexivity to continue to flourish in the shift to online engagement, was everyone's commitment to the project. Esme (AF) described the team's response to the virtual transition, "everyone involved in the project from like, team members, to peer collaborators, to care partners was very deeply committed." For Elizabeth (AF) peer collaborators' commitment was evidence of how much they cared, "I just was so impressed with the bravery and the adaptability of our participants who felt like no, we still want to see you, and hear you, even if it's online, even if it's on Zoom." She further elaborated on how support, understanding and adaptability went both ways in the shift to the Zoom world:

> The care through technology … it was mutual and reciprocal and we didn't make them feel like a burden, … we were being introduced to zoom around the same time, you know. So we could empathize with the struggles. We were muted sometimes when we didn't mean to be. It bonded us. In a way because we were learning together.

The strength of the team's relationships established prior to the pandemic undergirded the project's ability to maintain reciprocal caring, learning, and support online, "thankfully we had had two and a half years of team building, so those relationships had been strong and formed. I'm not sure how easily that could have been done [working virtually] if we were starting from scratch" (Adam, AF). Many team members described how RTC's continued orientation toward reciprocal caring, learning, and support was deeply valuable to them. Esme (AF) detailed how, for her, offerings of reciprocal care reminded her of her own vulnerability and humanity,

> I'm the facilitator, and I'm supposed to be caring for you … sometimes when you have the tension of needing to be there in a professional aspect, to be called into your human self [by a peer collaborator offering care and support] is really valuable, REALLY valuable.

The project's reciprocal orientation was highly valued by care partners too, as Tegan (CP) expressed,

> It's given my mom peers. People who she feels safe around and who she IS safe around because so many people don't know how to interact in an empowering way with people who have dementia … she's safe and in an environment within a community.

Finally, DD (AF) commented on the uniqueness of this approach, especially in a virtual environment, "it's a structure that is specifically focused on care and support and listening … it's a structure that is unfortunately rare."

3.4. Disrupting stigma and welcoming a wider audience

A strong focus of RTC was to disrupt the stigma of dementia. Elsie (R) explained,

> [An] intention in RTC … was to intentionally disrupt the stigma of dementia, disrupting the stereotypes of people living with dementia as those lacking capacity and lacking agency… in RTC, particularly people with dementia, were seen as creators, as mentors, as teachers, as performers.

Part of disrupting stigma involved creating safe spaces to talk openly about it. Ki (AF) articulated the significance of this, "[if] you have the lived experience of dementia … you can feel unsafe … if you don't feel like you fit in, or that you belong, or you've been made to feel othered or left out." She noted the effects this can have on people living with dementia, "either people treat them differently, or life is boring and repetitive, or there's actual harms that are happening to them." The stigma of dementia was explored in depth from peer collaborators' perspectives using interviews, discussions groups, and creative engagements in an earlier phase of RTC (see Reid, Landy and Henderson) (63).

The shift to online engagement brought the opportunity to further challenge the stigma of dementia, and also the stigma that older adults would have insurmountable difficulties with technology. Elizabeth (AF) noted "maybe one or two have not transitioned to working on Zoom. But for a large percentage of our participants to convert to using Zoom at their age range, it blows me away." The virtual transition provided peer collaborators and care partners with opportunities to learn new skills which were rarely offered to older adults prior to the pandemic. As James (AF) described, "it made people more comfortable with the technologies, … they wouldn't have learned those skills, … [RTC] gave that commitment, gave that focus … it set a framework."

One novel aspect of RTC was that, from the beginning, it punctuated its ongoing CCE activities by doing live performances for audiences, in which peer collaborators participated in central roles. Prior to the pandemic these in-person events were for small invited audiences. A significant advantage of the project shifting online was that it could now expand its audience by using livestreaming and publicly posting recordings of events online; "we were able to share that with a bigger audience really, or a more worldwide audience, in our performance of Backstage Pass" (Elizabeth, AF). This type of public performance required bravery,

> for our project, and our participants … to shift to a completely changed goal was incredible and surprising, and not surprising. I feel like our participants were so brave in the way that they shared their heart … [to] spend time on a live online event, … like how challenging that must have been for them (Elizabeth, AF).

The online performances went a long way in disrupting stigma. One audience member from Backstage Pass (55) wrote in the performance feedback,

> One of the most profound impacts this project has had on me is it has expanded my imagination about what the "lived" experience of dementia could be—and most importantly, has chipped away the corners of my fears of getting dementia myself.

James (AF) described how the reach of the online performances influenced the international dementia community.

> The team making that switch to Backstage Pass and going online … It inspired a whole other group of individuals like Gary Glazier and Susan McFadden in Milwaukee and the crew in the Timeslips organization, you know, for them to do their Memory Camp online because they saw this, it reached a much broader audience. That Dementia Lab, also, at Emily Carr tried to do it, so it opened up all these avenues.

For Joan (CP), challenging stigma publicly had great import, "I am just very, very grateful and I appreciate how Raising the Curtain is bringing this whole thing out into the larger community, larger world and the stigma is disappearing."

3.5. Supporting well-being through empowerment, community, and creativity

RTC peer collaborators and care partners talked about the value the project had for them in terms of their well-being. When asked during a Backstage Pass livestream performance (54). "Why are we doing this? [RTC engagement]," Marguerite (PC) responded,

> Well, there's a lot of people who have dementia, and often they're lost or abandoned, or whatever, as so having a program called Raising the Curtain with other people with dementia and people like you to facilitate it, we come to terms with our dementia in maybe more open ways, and we're with a group of people who also have dementia so you're not alone, and you don't have those stigmas and the things that society dumps on you. And so that's very useful. And you feel pretty good about what you do!

Care partners also expressed how RTC helped empower families by redressing the stigma of dementia. Tegan (CP) noted that because of RTC,

> Dementia was being talked about openly in our home and we were openly telling people that dementia is part of our lives. Whereas before there was a fear of telling people… having this community and doing the artistic engagement, I think, was very empowering

Leigh (CP) also expressed how RTC helped his spouse accept her diagnosis:

> She's 88, and when she grew up dementia was "crazy" … When we started this program, she was saying, oh, she didn't like the word dementia at all… during the course of this program, she's accepted it. And that, to me, is a major change.

Having a safe and accepting community helped people feel less isolated, as Cheri (CP) expressed, "to be with other people that have the lived experience of dementia and that, it's so critical to connect with other people. So that we're not so alone in the diagnosis." The sense of community was of great benefit to care partners as well as peer collaborators, "You don't just need community for your partner or a companionship for your partner, but there is a need for a community for both of you" (Joan, CP). Leigh (CP) conveyed the value that the accepting nature of the RTC community had for him,

> I love the program for the humour and the acceptance and everything else, and seeing that part. That the person that's

> still there, but we also have to recognize, sometimes we have to cry together because it's very sad. Sometimes [it's a] very sad journey.

Leigh (CP) also noted that RTC helped expand his community and base of support, "I find that my community has expanded in very unexpected ways and it's been a wonderful journey."

Care partners described how they felt that the creative engagement aspect of RTC was unique,

> It is really the only thing we've heard about in Canada… I've not heard quite something like [this] … there's actually performing things for people to join and be together with and it's very, very crucial for people with dementia to be in. (Joan, CP)

Similarly, Sandra (CP) found RTC's approach to be novel and especially valuable,

> I think that the creative engagement aspect of this is something that is very different to [other things] I take my mum to … [it] adds a whole other dimension to the stimulation.

Care partners highlighted the value of the caring nature of RTC's approach, "I'm totally blown away by [RTC] … how respectful it was" (Michael, CP). Tegan (CP) described how RTC created opportunities for advocacy and supported identity continuity for her mother, thus enhancing her well-being:

> My mom, she's somebody who's always … been an advocate for all kinds of things in her life and that is a huge part of her identity. And so, for her to feel as though she could advocate for people with dementia was huge, for her to still maintain a sense of her strong identity and validation as an advocate.

RTC's CCE workshops promoted lasting positive emotions for all peer collaborators; "That feeling … that [it] creates within her just lasts her through the whole of the rest of the day and into the evening. And it's incredible to see" (Sandra, CP). For care partners, positive feelings lasted long after too, "everybody who was involved, caregivers as well, whenever it occurred, whenever there was activity, it was a really wonderful thing because you carried that with you for quite a while, often days" (Michael, CP).

While the transition to virtual engagement was felt to lack some of the power of in-person engagement— "Zoom is great and I'm glad you have it but it just doesn't energize the same way" (Leigh, CP)— care partners and peer collaborators alike felt that it was effective and enhanced their feelings of connection and well-being. Sandra (CP) described the transition for her and her mom,

> I would say it did actually work remarkably well. In the initial attempt when we had a screen that had, I don't know, 15–20 people on it didn't work very well because it was a little bit too confusing. But once we went into smaller groups with two facilitators and two participants with their caregivers, that worked really well and my mum was still in, me too… the degree of stimulation obviously was not the same. But it worked and it kept the connection ongoing … once the people appeared on the screen, she engaged with them completely, so it was great that that was able to carry on.

When peer collaborators were asked how they felt about participating by Zoom, Margaret (PC) responded, "it feels great, it feels easy and yes, it feels okay, it feels good." Sadie (PC) expressed that for her it felt, "Just great! I enjoy people, meeting people and talking to people and listening to their lives. I just enjoy talking probably." Leo (PC) felt connecting online was valuable, "to me even going through a system like we're doing here today is a real goldmine in my thoughts." Traudi (PC) described the impact of collaborating online with her daughter and husband on a dance/song/poetry piece, "real life or real love, real everything, everything REAL is what I shared in."

Overall peer collaborators and their care partners expressed appreciation for the value and impact of RTC. When asked if the project played a role in improving quality of life for her mother and family, Tegan (PC), responded, "100%. Absolutely, absolutely." Marguerite (PC) offered her encouragement to the RTC team to continue its virtual engagement, "Good for you. That's what you do when there's a pandemic and there's technology to help … it's a good approach." Sandra (CP) summarised the valuable nature of the RTC project and online engagement,

> I fully believe that without this kind of engagement, my mum's dementia would be more advanced. She steps up a level when with other people and is involved in an activity that is centred around her abilities.

Peer collaborators and their care partners spoke unanimously about the positive impact of their online involvement in RTC on their well-being through the team's ongoing focus on co-creativity, empowerment, and community building.

4. Discussion

Like other studies on the use of digital technologies involving persons with dementia and their caregivers (47, 51, 50, 53), our findings suggest that, while virtual participation was not a perfect replacement for in-person collaborative activities, virtual CCE offered meaningful connection and stimulation to all team members during the COVID-19 pandemic. This was especially true for peer collaborators with lived experience of dementia and their care partners who were are at greater risk of more extreme isolation. Participants in this sub-study felt that virtual CCE sessions offered important social connections, and even more so, generated chances to collaboratively engage from a place of imagination, creativity, improvisation, and play. AFs, Rs, PCs, and CPs, all described how RTC drew on processes of relationality, reciprocity, shared-ownership and co-learning, that were aligned with CBPR principles (56–58, 60, 61). These processes are also consistent with the relational focus and non-restrictive, broadly inclusive understandings of creativity encompassed in both co-creativity (40) and creative care (34) approaches. Layering in CBPR principles brought an attention to method and rigor and heightened our focus on knowledge translation, especially for a broad public.

RTC's virtual context had both drawbacks and benefits in terms of relational citizenship. The relational model of citizenship, Kontos, Grigorovich, and Colobong argue, "broadens understanding of creativity by foregrounding how capacities and senses of the body are central to creativity in everyday life for persons living with dementia" (45). Relational citizenship "foregrounds the reciprocal nature of engagement and the centrality of capacities, senses, and experiences of bodies to the exercise of human agency and interconnectedness," according to Kontos, Miller and Kontos (32). The body, they contend, has a "pre-reflective capacity to inform and express distinctiveness and relationality" (p. 194), that persists in the face of cognitive losses such as occur with dementia. In RTC, on the one hand, all team members described a loss of collective group experiences and shared group feeling (or vibe) when not in person—the body's pre-reflective capacity to sense and respond to other bodies was challenged, to an extent, when bodies did not share physical space. However, RTC developed playful techniques to continue to draw on embodied know-how in a virtual context, such as adapted improvised movement, mime, breathwork, singing, and tactile activities, often finding ways to use the Zoom lens to enhance creative experimentation. The project also incorporated peer collaborators' previously-learned embodied expressions of creativity, for example, knitting, singing, drawing, and improvised chanting. These were featured in online public performances, along with in-depth conversations about the lived experience of dementia, creativity, and activism, and publicly demonstrated the "intrinsic capacities in persons living with dementia for creative self-expression" (54). Seeing peer collaborators and care partners in their home environments also allowed AFs to use details of their personal, physical space to inspire embodied expressions of creativity and relationality. For example, in one activity everyone found and shared treasured objects from around their home. RTC also did its best to compensate for the loss of in-person group connection by offering occasional group Zoom sessions for the purpose of sustaining social rituals like tea and cookies, post-performance celebrations, and holiday gatherings. Social rituals incorporated embodied and relational actions and responses (such as: toasting, eating and drinking, turn taking in conversation, mutual encouragement, joking and laughing) and were important to fostering relational citizenship in the virtual context.

In addition to challenges, AFs also described relational and creative benefits of the smaller CCE groups. They allowed for more intimate, deeper connections with peer collaborators and the inclusion of activities that catered to their specific interests, talents, and abilities. In addition, RTC's virtual shift expanded relational connections by including care partners, giving them a better understanding of their loved one's creativity, offering them emotional support, and deepening their own creative expression. Noteably, this decreased care partners' opportunities for respite, but care partners in our study found the supportive group experiences more valuable than time away from their loved one. Since RTC's virtual engagements largely took place during lockdown, they also expanded relationships in unexpected ways, involving family members and pets as a regular part of the social milieux. Future projects, then, might consider using a combination of in-person and virtual CCE activities as an optimal way to foster relational citizenship.

Play was central to RTC. Similarly, Zeilig et al. assert that the co-creative process can facilitate well-being through play. In "Dancing with Dementia", Kontos et al. also highlight the importance of playfulness, describing how participants living with dementia expressed themselves playfully and imaginatively through improvised movement connected to a narrative (54). Further, Swinnen and de Medeiros argue that for persons living with dementia, play is a way to explore potential for expression, meaning-making, and relationship-building and often leads to expressions of joy (68). In RTC, as opposed to these other projects, participants did not share physical space. This necessitated the development of techniques to inspire and support *virtual* play. Key to this was choosing playful approaches with *intentionality*. Sometimes warmup activities needed to start more gently in the smaller group context. Validating the play impulse for individuals became increasingly important. AFs used aspects of peer collaborators' home environments (as seen through the Zoom window) to inspire playful activities and responses (for example, two pairs took photos of their gardens and used them as inspiration to co-write a song). The project also used snail mail to send creative materials to peer collaborators, being careful to choose package contents with intention based on knowledge of the person. AFs, PCs, and CPs opened the packages together over Zoom and used the contents to engage in playful and creative expressions supportive of relational citizenship. The experience brought playful "moments of catharsis and release" that allowed for expressions of vulnerability and sharing similar to those described by Zeilig et al. in their With All study. Also similar to Zeilig et al., RTC, sought "an inclusive and equalizing approach" to supporting well-being and agency, and found 'fostering feeling in virtual space' to be and effective means of doing so. Fostering feeling involved acknowledging and validating all emotions, including frustrations around social isolation and technology use. CCE techniques were used to explore, validate, and, in some cases shift, negative feelings.

The importance of shared leadership and equally valuing each person's contributions was central to RTC, just like the co-creative process noted by Zeilig, West and van der byl Williams (40). This was reflected in RTC's theme 'sustaining reciprocal caring, learning, and support' in which leadership went beyond providing guidance, instruction, or input, to developing equitable processes that fostered care and support. It was important within RTC to create opportunities for peer collaborators to share in expressions of leadership (for example one PC taught her AF to knit), as they equalized power differentials and supported relational citizenship. Zeilig et al. further note that agency can include "apparent passivity, not actively leading". In RTC, this type of leadership (for all team members) was conceptualized as participating in quiet ways that contributed to group collaboration, coming and going from larger groups according to one's will, and sometimes acting as a witness and holding space.

The rapid development of video conferencing and virtual streaming platforms during COVID-19 allowed RTC to offer virtual live performances to an international audience, further expanding opportunities for peer collaborators to demonstrate and grow their relational citizenship. Dupuis et al. have argued that the arts can be used effectively to challenge dementia stigma by offering alternative narratives that "challenge dominate assumptions, foster critical reflection, and envision new possibilities for mutual support, caring, and relating" (27). In terms of theatrical performance more specifically, Zeilig and Burke note that, while the use of theatre and theatrical techniques to reshape perceptions of dementia have been explored by a number of scholars, they are "only recently being explored with people living with dementia as co-producers" (69). RTC, then, not only adds to the limited research on involving people with dementia in live performance, it also offers novel insights into how to do this virtually. Through involving peer collaborators and their care partners in live virtual performances [that involved high levels of creative expression, care, and education as Basting advocates (35)], RTC disrupted both dementia stigma and stigma around older adults and technology use, and inspired other creative dementia programs internationally to pursue virtual performance.

Navigating virtual engagement required sustained attentiveness to reflexivity (6, 56), especially given the power differential resulting from the fact that RTC researchers and AFs, on the whole, had more facility with, and access to, technology than its peer collaborators and care partners. Hebblethwaite et al. highlight the importance of attending to digital inequities such as internet access and ownership of digital devices, and the varied digital literacy of older adults (70). They note that desire to maintain social connection shifts when infrastructure is poor or initial experiences with digital technologies are unpleasant (p. 174). In RTC it was important, as a team, to thoughtfully and reflexively discover supportive approaches to technology and virtual engagement, such as those described in this article's themes, to creative positive experiences. An iPad was provided to a peer collaborator who did not have their own functioning technology, a large monitor was provided to another who needed it for accessibility, and phone calls were used for those who found on-screen time challenging. Ongoing coaching and support around technology was offered to care partners, AFs and Rs supported each other in learning the technology, and the entire team was committed to developing virtual CCE techniques that continued to support values of access and inclusion. Despite this, not all peer collaborators acclimatized to virtual CCE and several chose not to participate in the CCE workshops once the project shifted to virtual delivery.

Despite the large amount of rich qualitative data that informs this article, a primary limitation is the inequitable representation of team members' voices and experiences. This article represents a secondary analysis of data that were mostly gathered for other purposes. While it provides a rich and interesting view into the opportunities and challenges of CCE with individuals living with dementia, research participants are drawn upon unequally in the analysis. With the stresses of the COVID-19 pandemic and our awareness of the serious mental health risks of isolation and loneliness for the peer collaborators and their care partners, as a team, we prioritized sustaining CCE and the public performances and found ways to document these processes. Peer collaborators and their care partners discussed their general experiences with RTC in the public performances, however it is possible that they may have wanted to present a positive view to the public and might have been more hesitant to talk about negative aspects. An important consideration for future studies and programming is the need to explore condition-specific adaptations that can be made in virtual arts-based program delivery, particularly in attempting to work with diverse forms of dementia such as people living with non-memory-led dementias (for example, accommodating visuospatial challenges for people wanting to access online arts-based interventions who live with Posterior Cortical Atrophy, or behavioural challenges within Frontotemporal Dementia).

5. Conclusion

In the early days of the COVID-19 pandemic, there was the widespread belief that it was difficult, or even impossible, to engage virtually with people living with dementia because a dementia diagnosis was thought to limit meaningful participation, and older adults in general were prejudicially believed to have extreme difficulty managing technology. RTC pivoted almost immediately to continue its creative engagements online with people living with dementia, and in so doing offered novel and specific techniques for implementing CCE in virtual contexts. Project findings offer new perspectives on how virtual CCE not only has the potential to decrease loneliness and isolation and associated mental health risks for older adults living with dementia and their care partners, but also can promote well-being through the intentional use of reciprocal, supportive, and caring engagement processes. Indeed, the positive impact of RTC resulted from team members' commitment to reimagining virtual CCE with flexibility and adaptability. Our reimagining and sustainment of virtual CCE challenges stigmatizing representations of dementia and offers insights into the potential of virtual CCE to promote inclusion and enhance relational citizenship for individuals living with dementia and their care partners.

Data availability statement

The datasets presented in this article are not readily available because ethical approval of this study did not include the release of interview and focus group data, and it would be difficult to de-identify this data enough to ensure confidentiality. Some data used in this study are from publicly available YouTube videos (to which participants consented and chose to use their real names). These videos are publicly available at the YouTube video links included in the reference list (64–67).

Ethics statement

This study involving humans was approved by Douglas College Research Ethics Board (no. OC19.29a-R) and Concordia University Human Research Ethics Committee (no. 30013541), and was conducted in accordance with the local legislation and institutional requirements. Written informed consent for participation was not required from participants' legal guardians/next of kin because participants living with dementia were considered capable of providing their own informed consent in this context; a process model of consent was used, as well as other measures, to ensure their ongoing informed consent. Their care partners (who were not considered vulnerable) participated together with them in the study and signed their own informed consents; care partners also provided implied consent for their loved ones with dementia to participate in virtual sessions by logging on to Zoom/FaceTime. All other team members were not considered vulnerable and signed their own informed consents. We also analyzed a number of YouTube videos of the project's public live-stream performances in order to include peer collaborator and care partner perspectives. Peer collaborators and care partners chose to participate in these public performances and consented to have them permanently posted on YouTube. The videos are therefore in the public domain and do not require further consent to use as data.

Author contributions

JH: conceived of article, participated in data collection, performed data analysis, drafted manuscript. CR: conceived of study, provided oversight of analysis, contributed to manuscript. Both authors approved the submitted version.

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Conflict of interest

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

Publisher's note

References

1. García-Fernández L, Romero-Ferreiro V, López-Roldán PD, Padilla S, Rodriguez-Jimenez R. Mental health in elderly spanish people in times of COVID-19 outbreak. *Am J Geriatr Psychiatry.* (2020) 28(10):1040–45. doi: 10.1016/j.jagp.2020.06.027

2. Bailey L, Ward M, Dicosimo A, Baunta S, Cunningham C, Romero-Ortuno R, et al. Physical and mental health of older people while cocooning during the COVID-19 pandemic. *QJM.* (2021) 114(9):648–53. doi: 10.1093/qjmed/hcab015

3. Greig F, Perera G, Tsamakis K, Stewart R, Velayudhan L, Mueller C. Loneliness in older adult mental health services during the COVID-19 pandemic and before: associations with disability, functioning and pharmacotherapy. *Int J Geriatr Psychiatry.* (2022) 37(1):1–8. doi: 10.1002/gps.5630

4. Samuel LJ, Dwivedi P, Hladek M, Cudjoe TKM, Drazich BF, Li Q, et al. The effect of COVID-19 pandemic-related financial challenges on mental health and well-being among US older adults. *J Am Geriatr Soc.* (2022) 70(6):1629–41. doi: 10.1111/jgs.17808

5. Chong TWH, Curran E, Ames D, Lautenschlager NT, Castle DJ. Mental health of older adults during the COVID-19 pandemic: lessons from history to guide our future. *Int Psychogeriatr.* (2020) 32(10):1249–50. doi: 10.1017/S1041610220001003

6. Braun V, Clarke V, Braun V, Clarke V. *Thematic analysis: A practical guide*. Los Angeles: Sage (2022).

7. Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods.* (2017) 16:1–13. doi: 10.1177/1609406917733847

8. Government of Canada. *COVID-19 and deaths in older Canadians: Excess mortality and the impacts of age and comorbidity*. Canada: Government of Canada (2021). Available at: https://www.canada.ca/en/public-health/services/diseases/coronavirus-disease-covid-19/epidemiological-economic-research-data/excess-mortality-impacts-age-comorbidity.html (Accessed November 30, 2023).

9. Lebrasseur A, Fortin-Bédard N, Lettre J, Raymond E, Bussières EL, Lapierre N, et al. Impact of the COVID-19 pandemic on older adults: rapid review. *JMIR Aging*. (2021) 4(2):e26474. doi: 10.2196/26474

10. Public Health Agency of Canada. *Dementia in Canada, including Alzheimer's disease: Highlights from the Canadian chronic disease surveillance system*. Canada: Government of Canada (2021). Available at: https://www *Canada.ca/en/public-health/services/publications/diseases-conditions/dementia- highlights-Canadian-chronic-disease-surveillance.html* (Accessed November 30, 2023).

11. Alzheimer Society of Canada. *Navigating the path forward for dementia in Canada*. Canada: Alzheimer Society of Canada (2023). Available at: https://alzheimer.ca/sites/default/files/documents/Landmark-Study-Report-1-Path_Alzheimer-Society-Canada_0.pdf (Accessed November 30, 2023).

12. National Institute on Aging. *What is dementia? symptoms, types & diagnosis*. USA: National Institute on Aging (2022). Available at: https://www.nia.nih.gov/health/what-is-dementia (Accessed November 30, 2023).

13. Evans SC. Ageism and dementia. In: Ayalon L, Tesch-Römer C, editors. *Contemporary perspectives on ageism. International perspectives on aging* (Vol. 19). Switzerland, Cham: Springer (2018). p. 263–75.

14. Kilduff A. Dementia and stigma: a review of the literature on the reality of living with dementia. *Ment Health Nurs.* (2014) 34(5):7–11. Available at: https://repository.derby.ac.uk/download/ce16bc8b6b455bf5eb2c3f2ccd7e56ec88523ed2b9149e43fba4e20d3c556976/140542/Kilduff_2014_Dementia_and_stigma_published.pdf (Accessed November 30, 2023).

15. Low LF, Swaffer K, McGrath M, Brodaty H. Do people with early stage dementia experience prescribed disengagement® ? A systematic review of qualitative studies. *Int Psychogeriatr*. (2018) 30(6):807–31. doi: 10.1017/S1041610217001545

16. Halse I, Bjørkløf GH, Engedal K, Selbæk G, Barca ML. Locus of control and its associations with depressive symptoms amongst people with dementia. *Dement Geriatr Cogn Disord*. (2021) 50(3):258–65. doi: 10.1159/000517936

17. Numbers K, Brodaty H. The effects of the COVID-19 pandemic on people with dementia. *Nat Rev Neurol*. (2021) 17(2):69–70. doi: 10.1038/s41582-020-00450-z

18. Tondo G, Sarasso B, Serra P, Tesser F, Comi C. The impact of the COVID-19 pandemic on the cognition of people with dementia. *Int J Environ Res Public Health*. (2021) 18(8):4285. doi: 10.3390/ijerph18084285

19. Wei G, Diehl-Schmid J, Matias-Guiu JA, Pijnenburg Y, Landin-Romero R, Bogaardt H, et al. The effects of the COVID-19 pandemic on neuropsychiatric symptoms in dementia and carer mental health: an international multicentre study. *Sci Rep*. (2022) 12:2418. doi: 10.1038/s41598-022-05687-w

20. Tuijt R, Frost R, Wilcock J, Robinson L, Manthorpe J, Rait G, et al. Life under lockdown and social restrictions—the experiences of people living with dementia and their carers during the COVID-19 pandemic in England. *BMC Geriatr*. (2021) 21:301. doi: 10.1186/s12877-021-02257-z

21. Talbot CV, Briggs P. 'Getting back to normality seems as big of a step as going into lockdown': the impact of the COVID-19 pandemic on people with early to middle stage dementia. *Age Ageing*. (2021) 50(3):657–63. doi: 10.1093/ageing/afab012

22. Tam MT, Dosso JA, Robillard JM. The impact of a global pandemic on people living with dementia and their care partners: analysis of 417 lived experiences reports. *J Alzheimers Dis*. (2021) 80(2):865–75. doi: 10.3233/JAD-201114

23. Altieri M, Santangelo G. The psychological impact of COVID-19 pandemic and lockdown on caregivers of people with dementia. *Am J Geriatr Psychiatry*. (2021) 29 (1):27–34. doi: 10.1016/j.jagp.2020.10.009

24. Victor CR, Rippon I, Quinn C, Nelis SM, Martyr A, Hart N, et al. The prevalence and predictors of loneliness in caregivers of people with dementia: findings from the IDEAL programme. *Aging Ment Health*. (2021) 25(7):1232–38. doi: 10.1080/13607863.2020.1753014

25. Faieta J, Faieta L, Leblond J, Routhier F, Best K. Can technology abate the experience of social isolation for those affected by dementia? *Front Aging Neurosci*. (2022) 13:779031. doi: 10.3389/fnagi.2021.779031

26. Nguyen T, Li X. Understanding public-stigma and self-stigma in the context of dementia: a systematic review of the global literature. *Dementia*. (2020) 19(2):148–81. doi: 10.1177/1471301218800122

27. Dupuis SL, Kontos P, Mitchell G, Jonas-Simpson C, Gray J. Re-claiming citizenship through the arts. *Dement*. (2016) 15(3):358–80. doi: 10.1177/1471301216637206

28. Goldman M. *Forgotten: Narratives of age-related dementia and Alzheimer's disease in Canada*. Montreal, QC & Kingston, oN: McGill Queen's UP (2017).

29. Henderson J. Dramaturgy of assistance: performing with dementia or age-related memory loss. *Res Drama Educ*. (2019) 24(1):72–89. doi: 10.1080/13569783.2018.1548272

30. Bartlett R, O'Connor D. From personhood to citizenship: broadening the lens for dementia practice and research. *J Aging Stud*. (2007) 21(2):107–18. doi: 10.1016/j.jaging.2006.09.002

31. Bartlett R, O'Connor D. *Broadening the dementia debate: Towards social citizenship*. Bristol, GB: Policy Press (2010).

32. Kontos P, Miller KL, Kontos AP. Relational citizenship: supporting embodied selfhood and relationality in dementia care. *Sociol Health Illn*. (2017) 39(2):182–98. doi: 10.1111/1467-9566.12453

33. Peoples H, Varming J, Kristensen HK. Social citizenship when living with dementia: a qualitative meta-study. *J OccupSci*. (2022) 30(3):453–71. doi: 10.1080/14427591.2022.2061040

34. Basting A. *Creative care: A revolutionary approach to dementia and elder care*. New York, NY: HarperCollins (2020).

35. Basting A. Building creative communities of care: arts, dementia, and hope in the United States. *Dementia*. (2018) 17(6):744–54. doi: 10.1177/1471301217740959

36. de Medeiros K, Basting A. Shall I compare thee to a dose of donepezil? Cultural arts interventions in dementia care research. *Gerontologist*. (2014) 54(3):344–53. doi: 10.1093/geront/gnt055

37. Groot B, de Kock L, Liu Y, Dedding C, Schrijve J, Teunissen T, et al. The value of active arts engagement on health and well-being of older adults: a nation-wide participatory study. *Int J Environ Res Public Health*. (2021) 18(15):8222. doi: 10.3390/ijerph18158222

38. Zeilig H, Killick J, Fox C. The participative arts for people living with a dementia: a critical review. *Int J Ageing Later Life*. (2014) 9(1):1–28. doi: 10.3384/ijal.1652-8670.14238

39. Phinney A, Becker M, Burnside L, Malcolm P, Puurveen G. Dementia without borders: building community connections to reduce stigma and foster inclusion. *Dementia*. (2023) 22(3):550–60. doi: 10.1177/14713012231151723

40. Zeilig H, West J, van der Byl Williams M. Co-creativity: possibilities for using the arts with people with a dementia. *Qual Ageing Older Adults*. (2018) 19 (2):135–45. doi: 10.1108/QAOA-02-2018-0008

41. Basting AD. *Forget memory: Creating better lives for people with dementia*. Baltimore, MD: Johns Hopkins University Press (2009).

42. Timeslips Creative Storytelling, Inc. *Timeslips*. [place unknown]: Timeslips Creative Storytelling, Inc. (2022). Available at: https://www.timeslips.org/ (Accessed November 30, 2023).

43. Basting A, Towey M, Rose E E. *The penelope project: An arts-based odyssey to change elder care*. Iowa City: University of Iowa Press (2016).

44. Brotherhood E, Ball P, Camic PM, Evans C, Fox N, Murphy C, et al. Preparatory planning framework for created out of mind: shaping perceptions of dementia through art and science. *Wellcome Open Res*. (2017) 2(108):1–18. doi: 10.12688/wellcomeopenres.12773.1

45. Kontos P, Grigorovich A, Colobong R. Towards a critical understanding of creativity and dementia: new directions for practice change. *Int Practice Dev J*. (2020) 10:1–13. doi: 10.19043/ipdj.10Suppl.003

46. Haase KR, Cosco T, Kervin L, Riadi I, O'Connell ME. Older adults' experiences with using technology for socialization during the COVID-19 pandemic: cross-sectional survey study. *JMIR Aging*. (2021) 4(2):e28010. doi: 10.2196/28010

47. Hicks B, Gridley K, Dixon J, Baxter K, Birks Y, Colclough C, et al. Using digital technologies to facilitate social inclusion during the COVID-19 pandemic: experiences of co-resident and non-co-resident family carers of people with dementia from DETERMIND-C19. *Int J Geriatr Psychiatry*. (2023) 38(2):e5886. doi: 10.1002/gps.5886

48. Rai HK, Kernaghan D, Schoonmade L, Egan KJ, Pot AM. Digital technologies to prevent social isolation and loneliness in dementia: a systematic review. *J Alzheimers Dis*. (2022) 90(2):513–28. doi: 10.3233/JAD-220438

49. MacRitchie J, Floridou GA, Christensen J, Timmers R, de Witte L. The use of technology for arts-based activities in older adults living with mild cognitive impairment or dementia: a scoping review. *Dement*. (2023) 22(1):252–80. doi: 10.1177/14713012221127359

50. Masoud SS, Meyer KN, Sweet LM, Prado PJ, White CL. "We don't feel so alone": a qualitative study of virtual memory cafés to support social connectedness among individuals living with dementia and care partners during COVID-19. *Front Public Health*. (2021) 9:660144. doi: 10.3389/fpubh.2021.660144

51. Christensen J, MacRitchie J, Timmers R. Accessible and meaningful engagement for people living with dementia when transitioning arts activities online. *Alzheimers Dement*. (2022) 18(S9):e063236. doi: 10.1002/alz.063236

52. Brandão L, Bauer MA, Haas AN, da Silveira RS, Alves CP, de Souza DN, et al. Playing remotely in times of crisis: a program to overcome social isolation. *Int J Geriatr Psychiatry*. (2022) 37(1):1–12. doi: 10.1002/gps.5638

53. Thompson Z, Baker FA, Clark IN, McLachlan G, Mountain S, Mountain D, et al. 'A light at the end of the tunnel': the experiences of members of a therapeutic community choir for people living with dementia and their care-partners who 'went online' during the COVID-19 pandemic—an arts-based phenomenological study. *Voices World Forum Music Ther*. (2023) 23(2). doi: 10.15845/voices.v23i2.3491

54. Kontos P, Grigorovich A, Kosurko A, Bar RJ, Herron RV, Menec VH, et al. Dancing with dementia: exploring the embodied dimensions of creativity and social engagement. *Gerontologist*. (2021) 61(5):714–23. doi: 10.1093/geront/gnaa129

55. Cutler D. *Key workers: Creative aging in lockdown and after*. London: The Baring Foundation. (2020). Available at: https://baringfoundation.org.uk/resource/key-workers-creative-ageing-in-lockdown-and-after/ (Accessed November 30, 2023).

56. Banks S, Armstrong A, Carter K, Graham H, Hayward P, Henry A, et al. Everyday ethics in community-based participatory research. *Contemp Soc Sci*. (2013) 8(3):263–77. doi: 10.1080/21582041.2013.769618

57. Ochocka J, Janzen R. Breathing life into theory: illustrations of community-based research hallmarks, functions, and phases. *Gateways*. (2014) 7(1):18–33. doi: 10.3316/informit.904331070805414

58. Reid C, Greaves L, Kirby S. *Experience, research, social change: Critical methods*. 3rd edn. Toronto, oN: University of Toronto Press (2017).

59. Taylor SM, Ochocka J. Advancing community-based research in Canada. *Int J Knowl-Based Dev*. (2014) 8(2):183–200. doi: 10.1504/IJKBD.2017.085151

60. Bocarro J, Stodolska M. Researcher and advocate: using research to promote social justice change: leisure research symposium. *J Leis Res*. (2013) 45(1):2–6. doi: 10.18666/jlr-2013-v45-i1-2939

61. Hughes JC, McCormick A. The art and practice of memory and forgetting. In: Hughes JC, editor. *How we think about dementia: Personhood, rights, ethics, the arts and what they mean for care*. London, UK: Jessica Kingsley Publishers (2014). p. 202–18.

62. Anderson RC. Creative engagement: embodied metaphor, the affective brain, and meaningful learning. *Mind Brain Educ*. (2018) 12(2):72–81. doi: 10.1111/mbe.12176

63. Reid C, Landy A, Henderson J. ‘Knocking at the door of humanity’: using co-creation and community-based participatory research to foster citizenship for individuals with lived experience of dementia. *Leisure/Loisir*. (2022) 47(2):257–80. doi: 10.1080/14927713.2022.2104347

64. The Imagination Network. *Backstage pass Thursday*. Canada: The Imagination Network (2020). Available from: Available at: https://www.youtube.com/watch?v=3O88cidjxYo (Accessed November 30, 2023).

65. The Imagination Network. *Backstage pass Friday*. Canada: The Imagination Network (2020). Available from: Available at: https://www.youtube.com/watch?v=tl6t8F0YOa8 (Accessed November 30, 2023).

66. The Imagination Network. *Encore showcase*. Canada: The Imagination Network (2020). Available from: https://www.youtube.com/watch?v=q2dSWU4mrwQ&t=4s (Accessed November 30, 2023).

67. The Imagination Network. *Encore panels*. Canada: The Imagination Network (2020). Available from: https://www.youtube.com/watch?v=MlhF2yyXbJk&t=3s (Accessed November 30, 2023).

68. Swinnen A, de Medeiros K. “Play” and people living with dementia: a humanities-based inquiry of TimeSlips and the Alzheimer’s poetry project. *Gerontologist*. (2018) 58(2):261–9. doi: 10.1093/geront/gnw196

69. Zeilig H, Burke L. Privileging the play: creating theatre with people living with dementia. In: Keady J, Hyden L, Johnson A, Swarbrick C, editors. *Social research methods in dementia studies*. London, GB: Taylor and Francis Group (2017). p. 205–21.

70. Hebblethwaite S, Young L, Martin Rubio T. Pandemic precarity: aging and social engagement. *Leisure Sci*. (2021) 43(1–2):170–6. doi: 10.1080/01490400.2020.1773998

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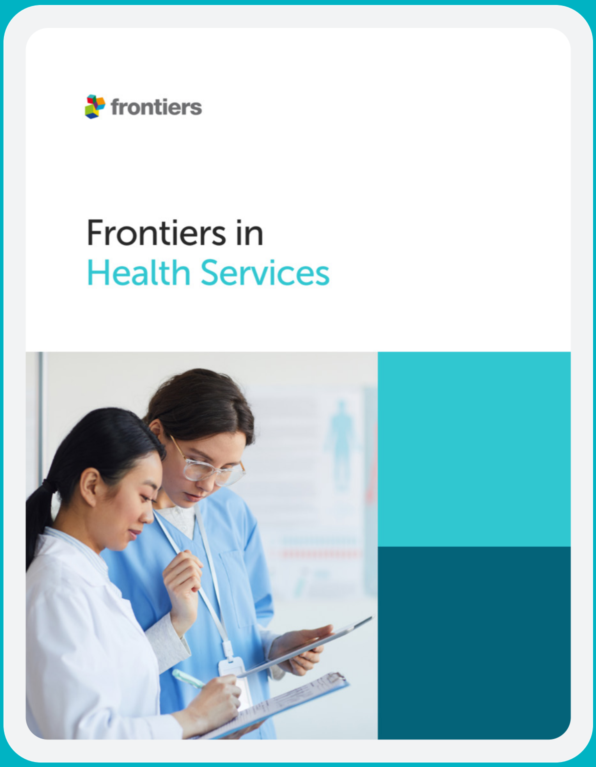

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