Original Paper

The Effects of the Use of Patient-Accessible Electronic Health Record Portals on Cancer Survivors’ Health Outcomes: Cross-sectional Survey Study

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Abstract

Background: In the past decade, patient-accessible electronic health record (PAEHR) systems have emerged as an important tool for health management both at the hospital level and individual level. However, little is known about the effects of PAEHR portals on the survivorship of patients with chronic health conditions (eg, cancer).

Objective: This study aims to investigate the effects of the use of PAEHR portals on cancer survivors’ health outcomes and to examine the mediation pathways through patient-centered communication (PCC) and health self-efficacy.

Methods: Data for this study were derived from the Health Information National Trends Survey (HINTS 5, Cycle 4) collected from February 2020 to June 2020. This study only involved respondents who reported having been diagnosed with cancer (N=626). Descriptive analyses were performed, and the mediation models were tested using Model 6 from the SPSS macro PROCESS. Statistically significant relationships among PAEHR portal use, PCC, health self-efficacy, and physical and psychological health were examined using bootstrapping procedures. In this study, we referred to the regression coefficients generated by min-max normalization as percentage coefficients (b_p). The 95% bootstrapped CIs were used with 10,000 resamplings.

Results: No positive direct associations between PAEHR portal use and cancer survivors’ health outcomes were found. The results supported the indirect relationship between PAEHR portal use and cancer survivors’ psychological health via (1) PCC (b_p=0.029; β=.023, 95% CI .009-.054), and (2) PCC and health self-efficacy in sequence (b_p=0.006; β=.005, 95% CI .002-.014). Besides, the indirect association between PAEHR portal use and cancer survivors’ physical health (b_p=0.006; β=.004, 95% CI .002-.018) via sequential mediators of PCC and health self-efficacy was also statistically acknowledged.

Conclusions: This study offers empirical evidence about the significant role of PAEHR portals in delivering PCC, improving health self-efficacy, and ultimately contributing to cancer survivors’ physical and psychological health.

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KEYWORDS

electronic health record; patient-centered care; health self-efficacy; cancer survivors; physical health; psychological health

Introduction

Cancer is among the leading causes of death worldwide, accounting for about 10 million deaths in 2020 [1]. In 2021, 1.9 million new cancer cases were diagnosed and over 600,000 cancer deaths were estimated in the United States [2]. Due to the growing and aging population as well as increases in early diagnoses and advances in cancer treatments, the number of cancer survivors continues to increase [3]. According to the National Cancer Institute, “An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life” [4]. Cancer is viewed as a chronic illness, and cancer survivors face ongoing health challenges that call for unique and long-term survivorship care. This is because physical problems such as functional disability and impairment and psychological disorders due to illness and aggressive treatments might persist throughout cancer survivors' lifetime [3,5]. As such, delivering high-quality and long-term health care for cancer survivors becomes a major challenge facing public health.

The maintenance of long-term cancer treatment plans requires effective patient-provider communication and coordination of cancer survivorship care [6,7]. Health care information technology has brought about a massive change in cancer care. The transition to patient-accessible electronic health record (PAEHR) systems has changed the way patients and providers engage in health care by facilitating access to patient information (eg, test results) [8], allowing timely and efficient patient-provider communication [9], reducing medical errors [10], educating patients with accessible and affordable health materials [11], and enhancing the privacy and security of patient data [12]. Therefore, researchers generally agree that PAEHR portals have the potential to improve health through evidence-based medicine and effective care coordination [13]. For instance, Wani and Malhotra [14] provided empirical evidence supporting that the assimilation of PAEHRs at a hospital-wide level can help deliver quality care and services, which in turn improve patients' health outcomes. A systematic review conducted by Kruse et al [13] identified a variety of facilitators of PAEHRs that can improve population health, including the enhancement in productivity/efficiency, the increase in the quality of patient data, and more flexible data management. Nevertheless, the majority of existing studies have inevitably investigated the PAEHR system from perspectives on professionals' innovation adoption [15] or organizational management [16]. There remains a paucity in the literature on the use of PAEHR portals and health outcomes from patient perspectives. To address this literature gap, our study aims to investigate how PAEHR portal use influences cancer survivors' health outcomes.

The Chronic Care Model (CCM) provides a framework for understanding the mechanisms through which health care provided via PAEHR portals influences patients' health outcomes [17]. Six key interdependent components of CCM that are essential for care delivery have been identified: (1) health system support, (2) delivery system design, (3) clinical information systems, (4) community resources, (5) decision support, and (6) self-management support. Researchers suggest that the PAEHR portal may be a prominent tool that incorporates the key elements of CCM and determines the success of care delivery and health management [18]. CCM relies on the use of health information technology for both public and private health care systems to facilitate the provision of longitudinal and patient-centered care, improve patient engagement, and empower patients with self-care skills to manage chronic illness [18,19]. Gee et al [19] proposed a revised CCM—eHealth enhanced CCM (eCCM)—and explicated that the use of eHealth technologies can help improve chronic care (eg, through patient-centered communication [PCC], clinical decision support, information provision, health education). Consequently, experienced PAEHR users have higher health self-efficacy and can achieve improved health outcomes [19].

Proponents of the eCCM contend that eHealth adoption, referred to in this study as PAEHR portal use, is likely to impact health outcomes through indirect pathways, which comprise proximal outcomes (eg, effective patient-provider communication) of eHealth that then influence health or that contribute to intermediate outcomes (eg, health self-efficacy) that lead to improved distal health outcomes [19]. Rathert et al [20] provide tentative support for the serial mediation effect of PCC and health self-efficacy in the relationship between PAEHR portal use and health outcomes. PCC is about delivering health care that relies upon effective communication and empathy to meet individual patient preferences, needs, and values [21,22]. Health self-efficacy refers to people's beliefs regarding one's capabilities to execute the courses of action to improve health [23]. There is a general consensus that the PAEHR is more than a tool that serves for patient data collection and information exchange. It is a "third agent" during patient care encounters that essentially improves PCC [20,24]. For example, patients who used PAEHR portals prior to doctor visits reported that communication with their physicians improved considerably [25]. This is because the patient data in the PAEHR system enables providers to monitor patients' symptoms and medication adherence [26]. Physicians thus would spend much time and pay more attention to patients during clinical encounters [27]. Meanwhile, patients who used PAEHR portals perceived more PCC, as they felt empowered to ask questions or offer comments regarding their health problems [24,28]. By this token, PAEHR portal use and PCC can facilitate patients' management of their health and should eventually contribute to health improvement [20,21,29]. Street et al [29] proposed a pathway model of health communication and suggested that, in most cases, PCC affects patient health through a more indirect route via an intermediate outcome of communication, such as health self-efficacy. It is understandable that PCC can increase patients' health self-efficacy because providers' clear explanations and expressions of support could increase patient knowledge and shared understanding, motivate patients to follow through with treatment recommendations, and thus improve patients' confidence in self-care management.

Following this line, 2 mediators—PCC and health self-efficacy—were conceptualized as the proximal and intermediate outcomes of PAEHR portal use, respectively. Previous research that examined related variables has provided empirical support. For instance, Madhavan et al [30] found that due to the transportability and interoperability, effective use of PAEHR contributes to improved PCC, which plays a cardinal role in cancer survivors' health management. Guo et al [31] found that eHealth adoption (eg, seeking web-based health information and using health apps) was significantly associated with improved self-care skills, which further led to more positive self-rated health among Taiwanese patients with chronic diseases [31]. Liu and Yeo [22] conceptualized a framework, suggesting that web-based patient-provider communication via eHealth technologies may improve patients' quality of life through sequential mediators of patient-centered care and health management skills. Building on prior research, this study aims to examine the relationships among cancer survivors' PAEHR portal use, PCC, health self-efficacy, and health outcomes. Moreover, the mediation roles of PCC and health self-efficacy were tested. Thus, the following direct and indirect relationships between PAEHR portal use and cancer survivors' health outcomes (see Figure 1) were proposed:

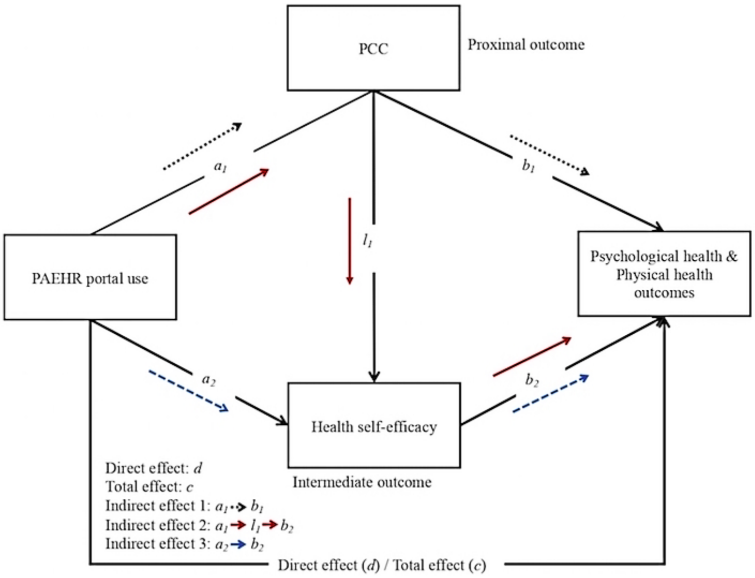
Hypothesis 1: PAEHR portal use is positively related to cancer survivors' health outcomes.

Hypothesis 2: PCC mediates the relationship between PAEHR portal use and cancer survivors' health outcomes.

Hypothesis 3: Health self-efficacy mediates the relationship between PAEHR portal use and cancer survivors' health outcomes.

Hypothesis 4: PCC and health self-efficacy sequentially mediate the relationship between PAEHR portal use and cancer survivors' health outcomes.

Figure 1. Pathways between patient-accessible electronic health record portal use and health outcomes. a_1, a_2, b_1, b_2, and l_1 indicate the pathways and the effects. PAEHR: patient-accessible electronic health record; PCC: patient-centered communication.



Methods

Study Design and Sample Population

Data for this study were derived from the Health Information National Trends Survey (HINTS 5, Cycle 4) collected from February 2020 to June 2020. HINTS is administered by the National Cancer Institute in the United States to collect nationally representative data about American adults' access to health-related information, health behaviors, and health outcomes. The survey design and sampling procedures for HINTS have been explicated extensively in previous research [32]. The final sample of HINTS 5, Cycle 4 consisted of 3865 respondents (response rate=36.7%) of the 10,531 participants. This study only involved respondents who reported having been diagnosed with cancer (N=626).

Ethical Considerations

This study used secondary data. The HINTS data meet strict ethical standards and have obtained ethics approval. Informed consent has been obtained from all participants, and all methods were carried out in accordance with relevant guidelines and regulations.

Measures

PAEHR portal use was measured by asking respondents whether they had accessed patient portals of PAEHR in the past year for certain eHealth activities [33]. Three items were included: "Look up test results," "securely message health care provider and staff," and "download health information to computer or mobile device." Responses were dichotomous (no=0, yes=1) and added up to represent PAEHR portal use (mean 1.726, SD 0.575).

PCC consisted of 7 statements that assessed patients' perceptions of communication with all doctors, nurses, or other health professionals in the past 12 months [21,34]. A 4-point Likert scale (1=always, 4=never) was used. Responses to the 7 statements were reversely coded and averaged to create the index of PCC, and higher values represent high levels of PCC (mean 3.414, SD 0.607; Cronbach α=.93).

Health self-efficacy was measured using 1 item to assess one's ability to take care of his/her health on a 5-point scale from 1 (completely confident) to 5 (not confident at all) [23]. Respondents' answers were reversely scored, and a higher score represented a higher level of health self-efficacy (mean 3.804, SD 0.812).

Physical health was measured by 4 items on comorbidities, drawn from prior research of similar measures [35]. Respondents were asked whether they had been told by a doctor or another health professional that they had medical conditions such as (1) diabetes or high blood sugar; (2) high blood pressure or hypertension; (3) a heart condition such as heart attack, angina, or congestive heart failure; and (4) chronic lung disease, asthma, emphysema, or chronic bronchitis. Responses to these items were dichotomous (no=0, yes=1). The answers were added up, and a higher value indicated better physical health (mean 2.748, SD 1.082).

Psychological health was measured by 4 items derived from previous research [36]. Sample items included "feeling down, depressed, or hopeless” and “feeling nervous, anxious, or on edge.” The 4 items were measured on a 4-point scale (1=nearly every day to 4=not at all) and averaged to form a composite score representing psychological health (mean 3.502, SD 0.706; Cronbach α=.88). A higher value suggests better psychological health. The descriptive details of the focal variables are shown in Tables 1-4.

The control variables included demographics such as age, gender (male=1, female=0), education (less than 8 years=1, postgraduate=7), annual household income (US $0-9999=1, US $200,000 or more=9), and race (non-Hispanic White=1, others=0).

Table 1. Descriptive statistics of the patient-accessible electronic health record portal use and physical health of the participants (N=626).

	Yes	No	Nonvalid
Patient-accessible electronic health record portal use, n (%)			
Look up test results	252 (40.3)	36 (5.8)	338 (53.9)
Securely message health care provider and staff	176 (28.1)	110 (17.6)	340 (54.3)
Download health information to computer or mobile device	68 (10.9)	218 (34.8)	340 (54.3)
Physical health, n (%)			
Diabetes or high blood sugar	176 (28.1)	440 (70.3)	10 (1.6)
High blood pressure or hypertension	374 (59.7)	244 (39)	8 (1.3)
A heart condition such as heart attack, angina, or congestive heart failure	91 (14.5)	527 (84.2)	8 (1.3)
Chronic lung disease, asthma, emphysema, or chronic bronchitis	132 (21.1)	486 (77.6)	8 (1.3)

Table 2. Descriptive statistics of patient-centered communication (N=626).

Patient-centered communication	Always, n (%)	Usually, n (%)	Sometimes, n (%)	Never, n (%)	Nonvalid, n (%)
Give you the chance to ask all the health-related questions you had	393 (62.8)	142 (22.7)	39 (6.2)	3 (0.5)	49 (7.8)
Give the attention you needed to your feelings and emotions	279 (44.6)	185 (29.6)	83 (13.3)	23 (3.7)	56 (8.9)
Involve you in decisions about your health care as much as you wanted	324 (51.8)	180 (28.8)	65 (10.4)	7 (1.1)	50 (7.9)
Make sure you understood the things you needed to do to take care of your health	362 (57.8)	169 (27)	43 (6.9)	3 (0.5)	49 (7.8)
Explain things in a way you could understand	366 (58.5)	164 (26.2)	43 (6.9)	3 (0.5)	50 (7.9)
Spend enough time with you	292 (46.6)	193 (30.8)	73 (11.7)	17 (2.7)	51 (8.2)
Help you deal with feelings of uncertainty about your health or health care	260 (41.5)	191 (30.5)	90 (14.4)	29 (4.6)	56 (9)

Table 3. Descriptive statistics of health self-efficacy (N=626).

Health self-efficacy	Completely confident	Very confident	Somewhat confident	A little confident	Not confident at all	Nonvalid
How confident are you about your ability to take good care of your health, n (%)	111 (17.7)	318 (50.8)	159 (25.4)	28 (4.5)	6 (1)	4 (0.6)

Table 4. Descriptive statistics of psychological health (N=626).

Psychological health	Nearly every day, n (%)	More than half the day, n (%)	Several days, n (%)	Not at all, n (%)	Nonvalid, n (%)
Little interest or pleasure in doing things	31 (5)	53 (8.5)	123 (19.6)	404 (64.5)	15 (2.4)
Feeling down, depressed, or hopeless	18 (2.9)	31 (5)	122 (19.5)	436 (69.6)	19 (3)
Feeling nervous, anxious, or on edge	30 (4.8)	29 (4.6)	163 (26)	389 (62.1)	15 (2.5)
Not being able to stop or control worrying	29 (4.6)	44 (7)	112 (17.9)	424 (67.7)	17 (2.8)

Data Analysis

Data analysis was performed using SPSS version 26 (IBM Corp). First, the MEAN () function was used to compute the mean of multiple-item variables that at least one item has a valid value or single-item variables that have valid values. Otherwise, the cases were considered missing in the following analysis. Besides, as a complementary technique, min-max normalization [37] was introduced to compare the estimates of all the paths in the mediation model. Specifically, all research variables were converted into a common measurement scale of 0 to 1. For example, we can subtract 1 from a 5-point rating to adjust the scale to start at 0 and then divide it by 4 to compress the scale. In this study, we referred to the regression coefficients generated by min-max normalization as percentage coefficients (b_p) [38,39]. Second, the mean substitution was used for all missing cases. Third, descriptive statistics was analyzed. Fourth, the mediation models were tested using Model 6 from the SPSS macro PROCESS; statistically significant relationships among PAEHR portal use, PCC, health self-efficacy, and physical and psychological health were examined using bootstrapping procedures. The 95% bootstrapped CIs were used with 10,000 resamplings.

Results

The mean age of the cancer survivors was 67.46 (SD 13.19; range 19-104) years. There were more female respondents (370/626, 59.1%) than male respondents (256/626, 40.9%). The majority of the participants had received some college education (405/626, 64.7%), were non-Hispanic White (428/626, 68.4%), and had annual household income between US $35,000 and US $74,999 (259/626, 41.4%). The detailed demographic information is summarized in Table 5.

Table 5. Sample population characteristics (N=626).

Characteristic	Value
Age in years, mean (SD)	67.46 (13.19)
Gender, n (%)	
Male	256 (40.9)
Female	370 (59.1)
Education, n (%)	
Less than 8 years of education	14 (2.2)
8-11 years of education	29 (4.6)
12 years of education or completed high school	132 (21.1)
Post high school training other than college	46 (7.3)
Some college	143 (22.8)
College graduate	145 (23.2)
Postgraduate	117 (18.7)
Annual income (USD), n (%)	
0-9999	33 (5.3)
10,000-14,999	34 (5.4)
15,000-19,999	37 (5.9)
20,000-34,999	79 (12.6)
35,000-49,999	87 (13.9)
50,000-74,999	172 (27.5)
75,000-99,999	58 (9.3)
100,000-199,999	94 (15)
200,000 or more	32 (5.1)
Race, n (%)	
Non-Hispanic White	428 (68.4)
Others	198 (31.6)

Hypothesis 1 posited that PAEHR portal use is positively related to cancer survivors' health outcomes. Table 6 shows that there was no significant direct association between PAEHR portal use and cancer survivors' health outcomes, irrespective of the physical or psychological health. Thus, hypothesis 1 was not supported.

Hypothesis 2 predicted that PCC mediates the relationship between PAEHR portal use and cancer survivors' health outcomes. As depicted in Table 6, PAEHR portal use was significantly and positively associated with PCC (b_p=0.131; β=.125, 95% CI .048-.214; *P*=.002) in the 2 models. Meanwhile, PCC was positively associated with cancer survivors' psychological health (b_p=0.270; β=.269, 95% CI .258-.461; *P*<.001). No significant relationship between PCC and cancer survivors' physical health was acknowledged. The results indicated that PCC indeed mediated the relation between PAEHR portal use and cancer survivors' psychological health (b_p=0.029; β=.023, 95% CI .009-.054), whereas the counterpart effect failed to pass the statistical threshold (95% CI contained zero) for physical health. Hypothesis 2 was partially supported.

Hypothesis 3 predicted that PAEHR portal use might increase cancer survivors' health outcomes through the mediation of association with health self-efficacy. The mediation effects in the 2 models were statistically unacknowledged. Thus, hypothesis 3 was not supported.

Hypothesis 4 predicted that PAEHR portal use will be related to cancer survivors' health outcomes through the serial mediation of PCC and health self-efficacy. As shown in Table 6, the indirect relationship between PAEHR portal use and cancer survivors' physical health (b_p=0.006; β=.004, 95% CI .002-.018) and between PAEHR portal use and psychological health (b_p=0.006; β=.005, 95% CI .002-.014) via sequential mediators of PCC and health self-efficacy were statistically acknowledged, thereby supporting hypothesis 4.

Table 6. Mediation models[a].

	b_p[b]	β	SE	95% CI	*P* value[c]
Dependent variable: Psychological health (Model 1)					
PAEHR[d]→PCC[e] (a_1 path)	0.131	.125	.042	.048 to .214	.002
PAEHR→Health self-efficacy (a_2 path)	0.022	.021	.055	–.078 to .137	.59
PCC→Health self-efficacy (l_1 path)	0.270	.269	.052	.258 to .461	<.001
PCC→Psychological health (b_1 path)	0.217	.186	.046	.127 to .306	<.001
Health self-efficacy→Psychological health (b_2 path)	0.181	.156	.034	.068 to .202	<.001
PAEHR→Psychological health (direct effect, *d* path)	–0.016	–.013	.046	–.108 to .075	.73
PAEHR→Psychological health (total effect, *c* path)	0.023	.018	.048	–.072 to .117	.64
PAEHR→PCC→ Psychological health (indirect effect, a_1 b_1)	0.029	.023	.012	.009 to .054	N/A[f]
PAEHR→PCC→ Health self-efficacy→Psychological health (indirect effect, a_1 b_2 l_1)	0.006	.005	.003	.002 to .014	N/A
PAEHR→Health self-efficacy→Psychological health (indirect effect, a_2 b_2)	0.004	<.001	.008	–.012 to .020	N/A
Dependent variable: Physical health (Model 2)					
PAEHR→PCC (a_1 path)	0.131	.125	.042	.048 to .214	.002
PAEHR→Health self-efficacy (a_2 path)	0.022	.021	.055	–.078 to .137	.59
PCC→Health self-efficacy (l_1 path)	0.270	.269	.052	.258 to .461	<.001
PCC→Physical health (b_1 path)	0.013	.010	.070	–.120 to .154	.81
Health self-efficacy→Physical health (b_2 path)	0.168	.126	.052	.066 to .270	.001
PAEHR→Physical health (direct effect, *d* path)	–0.032	–.023	.071	–.183 to .096	.55
PAEHR→Physical health (total effect, *c* path)	–0.021	–.015	.071	–.168 to .112	.69
PAEHR→PCC→Physical health (indirect effect, a_1→b_1)	0.002	.001	.011	–.020 to .024	N/A
PAEHR→PCC→Health self-efficacy→Physical health (indirect effect, a_1 b_2→l_1)	0.006	.004	.004	.002 to .018	NA
PAEHR→Health self-efficacy→Physical health (indirect effect, a_2→b_2)	0.004	.003	.010	–.015 to .026	N/A

[a] a_1, a_2, b_1, b_2, and l_1 in this table indicate the pathways between patient-accessible electronic health record portal use and health outcomes and the effects.

[b] Regression coefficient generated by min-max normalization as percentage coefficient.

[c] *P* values are not computed for bootstrapped indirect effects.

[d] PAEHR: patient-accessible electronic health record.

[e] PCC: patient-centered communication.

[f] N/A: not applicable.

Discussion

Principal Findings

In light of the existing literature on the robust salutary effects of PAEHR portals on patient health, our study examined the effects of PAEHR portal use on cancer survivors' health outcomes as well as the mediating roles of PCC and health self-efficacy. The results of our study indicated that the significant effect of PAEHR portal use on cancer survivors' physical and psychological health was indirect through the mediated associations with PCC and health self-efficacy.

The direct association between PAEHR portal use and cancer survivors' health outcomes is not acknowledged in this study. The findings of our study emphasize the mediation mechanisms through which the PAEHR portal use exerts an influence on cancer survivors' physical and psychological health, which were in accordance with that reported in previous research that theorizes the process through which PAEHR may impact patient health [20]. Rathert et al's [20] and Street et al's [29] pathway models provide the needed theoretical foundation for this study, supporting that several steps must occur for health improvement to be influenced by cancer survivors' PAEHR portal use. First, PAEHR portals serve as a tool that facilitates patient-provider communication. Physicians should incorporate PAEHR systems to provide PCC that supports patients in making informed health care decisions that are consistent with their needs, values, and preferences. Unless PCC is improved, PAEHR portal use will not increase patients' health self-efficacy and improve their health outcomes. Although previous research has identified the association between PAEHR and patient health, we investigated the mediating mechanisms (the process) through which PAEHR impacts patient health.

PCC and health self-efficacy were identified as the intrinsic and extrinsic factors of PAEHR, respectively, that help explain how PAEHR portal use influences patients' health outcomes. The results of our study suggest that PCC can partially mediate the relationship between PAEHR portal use and cancer survivors' psychological health. The mediation results indicated that the more cancer survivors use the PAEHR portals to stay informed about their health and communicate with health care professionals, the more likely they are to perceive PCC, which in turn results in more positive psychological health. A plausible reason is that the increasing accessibility to health professionals and patient information facilitated by PAEHR systems may enhance patient involvement in their health care decision-making [40]. Through PAEHR portals, cancer survivors are likely to be informed about their health status, be well educated with adequate health information, and have convenient access to health care professionals for medical guidance [41]. As a result, patients feel more engaged in PCC, which helps better understand their health and motivate them to stay positive and improve their psychological health [42-44]. However, PCC has no mediation effect between PAEHR portal use and cancer survivors' physical health. This might be because the research sample of this study consisted of 626 cancer survivors with an average age >60 years, and they were likely to have inferior health status. PCC could not improve physical health unless patients were equipped with the necessary health skills. This assumption was supported by the sequential mediation effect of PCC and health self-efficacy between PAEHR portal use and cancer survivors' health outcomes.

The results of our study showed that PCC is positively associated with health self-efficacy, and higher levels of health self-efficacy can enhance cancer survivors' physical and psychological health. This finding was consistent with prior research, suggesting that PCC may empower patients, help increase their self-care skills, and provide the needed information and support to facilitate patients' health management [45,46]. Furthermore, improved health self-efficacy can help people take care of their physical and psychological health, and this finding was congruent with previous findings [47-49]. Our results provide empirical evidence of the indirect effect of PAEHR portal use on cancer survivors' health outcomes through PCC and health self-efficacy.

Comparison With Prior Work

Our study in comparison with previous work has heuristic value for public health research in several ways. First, the findings of our study offer empirical support for eCCM [19] and Rathert et al's [20] pathway model in understanding the process through which PAEHR impacts patient health. Second, this study extends the current literature by investigating the usability of eHealth technologies in delivering longitudinal survivorship care for patients with chronic diseases as well as examining the mediation roles of PCC and health self-efficacy. Our findings stressed PCC as the salient intrinsic factor of PAEHR that helps improve patients' health self-efficacy and prompts them into action to maintain their health. The mediation effects provide a more nuanced understanding of the mechanisms underlying the association between PAEHR portal use and patients' health outcomes. This model was established in several hypotheses by which the assumptions have been shown tenable. This study thus helps consolidate past research on the relationships between PAEHR portal use and patients' physical and psychological health.

This study also has important practical implications. First, given the important role of electronic means for health management, multifaceted strategies should be implemented to promote the assimilation of PAEHR at both institutional and individual levels. For example, through patient education and support, patients can gain knowledge about PAEHR and be encouraged to integrate PAEHR into their health care in everyday life. Besides, we should also encourage medical professionals to engage in PAEHR systems to provide customized health care services. For example, a medical professional can provide detailed explanations for certain clinical decisions through PAEHR portals, and patients can access and revisit the messages that can facilitate their self-care practices [50]. Second, considering the significant role of PAEHR portals, we should continue to develop information technology infrastructure to improve the accessibility of high-quality and long-term survivorship care. For example, patients who live remotely with low-speed internet and people who have poor internet skills may not benefit from the convenience and great efficiency brought by the internet for medical consultations [47]. Thus, information and communication technology companies should expand high-speed internet provisions to the other regions and deliver benefits to more people and communities. In addition, we should provide continuous support to help individuals overcome the barriers encountered in using PAEHR portals for health management [51]. Third, strict policies for web-based health service regulation should be implemented to protect patients' information and to ensure a safe PAEHR environment. In parallel with the governmental measures, it is equally important to educate patients about their rights to access health data and responsibilities for personal information security. Fourth, considering the effect of PCC, it is important to help patients more actively participate in health consultations as well as provide training to physicians in delivering empathetic, mindful, informative, and patient-centered care.

Limitations and Directions for Future Research

Several limitations of this study should be noted. First, owing to the cross-sectional design of HINTS, we know little about the causal inferences of relationships examined in this study. Further research should collect panel data or use experimental research designs to better understand the relationships among PAEHR portal use, PCC, health self-efficacy, and health outcomes. Second, according to CCM and eCCM, there are 6 key components of eHealth technologies for care delivery, such as health system support and delivery system design. However, PAEHR portal use in this study was measured using 3 items, that is, patients' past experience in PAEHR portal use for checking test results, patient-provider communication, and health information acquisition. We know little about the influence of other aspects of PAEHR portal use. To our knowledge, no study has examined the usability of PAEHR system design and how it impacts patient-provider communication and patients' health maintenance. Besides, PAEHR portal use was examined as an integrated concept, and we hardly know how different types of PAEHR portal usage may affect patient health differently. Based on this study, future research should take into account the different use dimensions of PAEHR systems or the different types of PAEHR portal usage and compare their different influences. Third, PCC and health self-efficacy were identified as the mediators in the relationship between PAEHR portal use and cancer survivors' health outcomes. Other potential interveners might be overlooked. Researchers should further extend the model and identify other mediators (eg, knowledge) or moderators (eg, health literacy, digital literacy) that significantly influence PAEHR portal users' health-related outcomes. Fourth, the research findings of our study might be impacted by sampling bias. For example, more than half of the respondents were aged between 60 years and 80 years (mean 67.46 years) and had at least completed some college education. It is recommended that a more representative sample be analyzed to better understand the full range of cancer survivors' PAEHR portal use. Moreover, our study focused on cancer survivors, and the results may not be generalizable to other populations. PAEHR portals can likely be helpful and useful for people with other chronic conditions such as diabetes and asthma. Thus, researchers should replicate this work in other populations to obtain more tentative evidence, thereby supporting the positive association between PAEHR portal use and health outcomes.

Conclusion

This study offers empirical evidence on the influence of PAEHR portal use on cancer survivors' physical and psychological health. Although electronic technologies have been widely applied in health care settings, the adoption rate of PAEHR among patients remains low. This study suggests that PAEHR portal use is vital in delivering longitudinal survivorship care for cancer survivors. In particular, the influence of PAEHR portal use on health outcomes may be indirect through the mediated associations with PCC care and health self-efficacy. Understanding these relationships can help increase the use of PAEHR portals, promote PCC, enhance patients' health self-efficacy, and eventually improve their physical and psychological health.

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Data Availability

The data sets generated and analyzed during this study are publicly available on [52]. All data and materials comply with field standards.

Conflicts of Interest

None declared.

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Abbreviations

CCM: Chronic Care Model
eCCM: eHealth enhanced Chronic Care Model
HINTS: Health Information National Trends Survey
PAEHR: patient-accessible electronic health record
PCC: patient-centered communication

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Original Paper

Fine-tuned Sentiment Analysis of COVID-19 Vaccine–Related Social Media Data: Comparative Study

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Abstract

Background: The emergence of the novel coronavirus (COVID-19) and the necessary separation of populations have led to an unprecedented number of new social media users seeking information related to the pandemic. Currently, with an estimated 4.5 billion users worldwide, social media data offer an opportunity for near real-time analysis of large bodies of text related to disease outbreaks and vaccination. These analyses can be used by officials to develop appropriate public health messaging, digital interventions, educational materials, and policies.

Objective: Our study investigated and compared public sentiment related to COVID-19 vaccines expressed on 2 popular social media platforms—Reddit and Twitter—harvested from January 1, 2020, to March 1, 2022.

Methods: To accomplish this task, we created a fine-tuned DistilRoBERTa model to predict the sentiments of approximately 9.5 million tweets and 70 thousand Reddit comments. To fine-tune our model, our team manually labeled the sentiment of 3600 tweets and then augmented our data set through back-translation. Text sentiment for each social media platform was then classified with our fine-tuned model using Python programming language and the Hugging Face sentiment analysis pipeline.

Results: Our results determined that the average sentiment expressed on Twitter was more negative (5,215,830/9,518,270, 54.8%) than positive, and the sentiment expressed on Reddit was more positive (42,316/67,962, 62.3%) than negative. Although the average sentiment was found to vary between these social media platforms, both platforms displayed similar behavior related to the sentiment shared at key vaccine-related developments during the pandemic.

Conclusions: Considering this similar trend in shared sentiment demonstrated across social media platforms, Twitter and Reddit continue to be valuable data sources that public health officials can use to strengthen vaccine confidence and combat misinformation. As the spread of misinformation poses a range of psychological and psychosocial risks (anxiety and fear, etc), there is an urgency in understanding the public perspective and attitude toward shared falsities. Comprehensive educational delivery systems tailored to a population's expressed sentiments that facilitate digital literacy, health information–seeking behavior, and precision health promotion could aid in clarifying such misinformation.

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KEYWORDS

sentiment analysis; DistilRoBERTa; natural language processing; social media; Twitter; Reddit; COVID-19; vaccination; vaccine; content analysis; public health; surveillance; misinformation; infodemiology; information quality

Introduction

Background

The novel coronavirus (COVID-19) has impacted and disrupted many aspects of everyday life worldwide. Following the implementation of rigid pandemic mitigation strategies in early 2020, social media use substantially increased with internet users turning to social media platforms to communicate and gather information regarding the dynamic and uncertain situation [1-4]. As the pandemic progressed and researchers worked to develop vaccines, many social media users turned their focus to gathering information regarding various topics related to COVID-19 vaccines, such as side effects, availability, and efficacy. As of May 19, 2022, approximately 6.27 million people across the world have died due to complications from COVID-19. Moreover, many experience long COVID syndrome, in which viral symptoms persist past the expected clinical recovery time [5]. Although COVID-19 vaccines are safe and effective at preventing life-threatening infections, hospitalizations, and deaths, vaccine hesitancy related to COVID-19 vaccines has led to further comorbidities and many preventable deaths [6-8].

With an estimated 4.5 billion users worldwide, social media offers an opportunity for near real-time analysis of large bodies of text data (500 million tweets/day) that could be useful to public health officials [3,9]. Using machine/deep learning, recent advancements in natural language processing methods (eg, Bidirectional Encoder Representations from Transformers [BERT], RoBERTa, GPT2, and XLNet) have substantially improved previous text classification models (greater than 90% accuracy) [4,10-14]. Moreover, pretrained models such as BERT or RoBERTa are available and free to researchers from platforms such as Hugging Face. These platforms are extremely helpful to the greater scientific community, considering that many of these models take several days on dozens of tensor processing units to learn [15,16]. Importantly, these models can be fine-tuned based on a particular use case (eg, text classification, text generation, and sentiment analysis). The enhanced functionality provides a researcher with techniques to investigate a wide variety of phenomena across many scientific domains [17-19]. Sentiment analysis (ie, classifying text as positive or negative) in particular is a powerful tool that can be used to correlate events to the public mood, surveil public health discussion, and even detect disease outbreaks [18]. Most importantly, these methods can be used by public health officials to develop precise messaging strategies and intervention campaigns to address the information crises and improve vaccination rates.

Our study sought to examine and explore sentiment regarding COVID-19 vaccines expressed on 2 popular social media platforms—Reddit and Twitter. We calculated positive and negative sentiment by creating a custom fine-tuned DistilRoBERTa model with data labeled by members of our team and then augmented by back-translation. We then offered a comparison of sentiment regarding COVID-19 vaccines across Reddit and Twitter. We hypothesized that we would observe somewhat similar trends in polarity between the 2 social media platforms with minor differences, because DistilRoBERTa has typically displayed accuracies greater than 90% [16]. However, we expected that our labeled data set would provide more nuanced insight into public sentiments in these 2 communities than previous sentiment analysis methods. Additionally, based on our previous work, we hypothesized that sentiment would remain more positive than negative [4]. Finally, we argued that identifying and following social media shared sentiment allows for the eventual development of comprehensive response strategies, which are better aimed at combatting misinformation and disinformation; improvement of vaccine delivery; and containment of disease transmission.

COVID-19–Related Social Media Analysis

Social media content analysis is not a brand new concept and has been used for data mining and sentiment analysis before COVID-19. However, the nature of the pandemic response and the necessary separation of populations for safety have led to an unprecedented number of new users [9]. This influx caused a surge in social networking posts, leaving researchers with mountains of content to sort through. One positive aspect of social media data mining is that the content is publicly available and easily obtainable, allowing for rapid collection. The rapid collection of data, especially those related to COVID-19, permits researchers to follow the pandemic's progression alongside sentiment on the web. For example, the ability to rapidly collect tweets from a specified time period allows for the parallel analysis of general public opinion during major events, such as the release of the Pfizer vaccine in late 2020 or the death of a celebrity post–COVID-19 infection [20]. This targeted approach provides tools for niche discovery and exploration of the sentiment behind health decision-making.

Researchers have used the recent increase in opinion sharing to measure overall sentiment and vaccine hesitancy or acceptance [4,20-24]. As social media usage has continued to grow throughout the pandemic era, more than 3.6 billion people are known to regularly log on to at least one networking platform. Twitter is considered one of the largest and most used social media platforms, with more than 400 million account owners [9]. The platform allows users to post short messages or tweets for "followers" to see and respond to, based on the underlying sentiment they evoke. Tweets are limited to brief messages, with a 280-character limit, but may contain attached images, videos, or highlighted popular keywords known as "hashtags." Additionally, tweets can include hyperlinks to news articles or scientific literature. If another user agrees with a posted tweet, they can "retweet" or share the message to their profiles in a show of rapport. Rather than joining topic-based communities, users typically follow other users.

The Reddit platform is similar in size, with approximately 430 million current users [9]. However, it is different in message format and delivery, in that users are allowed to create groupings based on a topic, called "subreddits." Subreddits often contain open dialogue alongside images, videos, and hyperlinks to news articles or literature. Similar to "retweeting," subreddit subscribers have the unique ability to "upvote" or "downvote" a post based on the user's opinion of its contents. Users are also able to join the discussion by leaving comments, which can also be upvoted or downvoted. If a subreddit becomes increasingly popular and receives a good share of upvotes, the post will appear first within a topic category. The more traffic a subreddit receives, even if it is sharing misinformation or disinformation, the higher the Reddit platform will promote it. Notably, subreddits generally have rules that community members must adhere to or risk the potential for the removal of a post or banning.

BERT Algorithm

Substantial advances in natural language processing have occurred since the development of BERT and the work built from its architecture. BERT is a powerful and versatile artificial intelligence–based natural language processing algorithm developed at Google AI Language that excels at text classification (ie, ontologies, categories, and sentiment, etc) of unstructured/semistructured text data that are characteristic of social media data [10]. The BERT algorithm was trained on the entirety of Wikipedia and the Brown Corpus over 4 days using 16 cloud-based tensor processing units. BERT is a transformer-based language model that uses multiple encoders to create word embeddings. These embeddings are then used in concert with masked language modeling and next sentence prediction to learn by predicting random masked words in a sentence and learning to predict sentences, respectively. These 2 steps teach BERT to understand context, a skill that older recurrent neural networks typically struggled with. A convenient aspect of BERT is that it has the capability to fine-tune the model with relevant data by replacing the output layer with weights from custom data. Researchers have been inspired by the original BERT architecture to create many variations (eg, RoBERTa, DistilRoBERTa, DistilBERT, and BART, etc) that have surpassed the benchmarks of previous models. Moreover, these models can be fine-tuned for specific domain-based tasks (ClinicalBERT and BioBERT) in multiple languages [11,12,25]. Furthermore, several studies have used other fine-tuned BERT models to investigate COVID-19–related content expressed on social media related to misinformation detection, sentiment classification, and continent analysis [13,26-29].

Methods

Study Overview

Our study compared COVID-19 vaccine–related postings from 2 popular social media platforms—Reddit and Twitter—from January 1, 2020, to March 1, 2022. These 2 platforms were chosen due to their worldwide usage, vibrant discussions, and high user count. The time frame included the earliest parts of the pandemic to trace the evolution of sentiments over time. Most importantly, these platforms were chosen because only a small number of comparative studies have focused on the typical user, especially studies related to COVID-19 vaccine sentiment or other vaccines. Our study used a binary (ie, positive or negative polarity) sentiment classification method for training our model and for sentiment analysis. A binary system was chosen for a few reasons. (1) Binary systems are more computationally efficient when processing large bodies of data. (2) Binary classifiers are typically more accurate than multiclass systems. (3) In the past, sentiment classifiers that incorporate a neutral class often rely on a low probability or confidence score. Since our model reported a confidence value, this information could be extrapolated.

Data Overview

Substantial effort was taken to identify and remove Twitter posts that were found to be directly from news agencies or bots. These posts were identified by their source having an overwhelmingly high post count during the 26-month period relative to the average number of posts of a “normal” user, as well as by visually inspecting tweets of users that appeared at an abnormal frequency. Both Twitter and Reddit data sets were limited to only include users who posted fewer than or equal to 200 times throughout our time frame. These steps were important due to the repetitive nature of many bot tweets, which had the potential to skew sentiment calculations and misalign the goal to compare the normal user base of both platforms. Although the methodologies in harvesting Reddit and Twitter data differ slightly, both data sets underwent similar cleaning steps. Both data sets were queried for the same relevant terms typically present in web-based discussions about COVID-19 vaccines. This step was important due to the tendency for some extended comment threads to meander off-topic. This occurrence was especially true with threads from some Reddit communities. The daily posting frequencies of the 2 platforms were relatively similar in the early months of the pandemic. The frequency increased dramatically for both platforms in late September to October 2020 as news of vaccine circulation became more widespread. Although each platform displayed 4 spikes in posting frequency at similar time periods (October 2020, March to April 2021, August to September 2021, and December 2021 to January 2022), they obtained a maximum in different time periods. Reddit reached its maximum posting from March to April 2021, whereas Twitter reached its maximum from September to October 2021.

Twitter

Approximately 13 million tweets were harvested using the *snscrape* and *Tweepy* API Python libraries based on the search term “COVID Vaccine.” After removing tweets by suspected bots, news media, or highly repetitive high-frequency users and duplicate tweets, our final Twitter data set consisted of 9,518,270 tweets authored by 3,006,075 Twitter users. The tweets contained approximately 16.32 million total likes, with a maximum of 430,758 likes and an average of 14.9 likes per tweet. Tweets cannot be downvoted, but approximately 4,794,865 tweets were attributed with 0 likes. Statistics on tweet sharing or retweets were not collected because this metric was not available for both platforms.

Reddit

We harvested 579,241 user-created posts from 67 subreddits with the Python Reddit API *Wrapper*. These subreddits were collected to gain a broad understanding of sentiments related to the COVID-19 vaccines as well as to avoid potential biases in data collection. These subreddits contained a total of 5,590,913 subscribers as of March 1, 2022. Our query removed a large portion of unrelated terms. After visually inspecting and confirming the results of the querying process, our final Reddit data set consisted of 67,962 comments composed by at least 9843 authors. These posts contained approximately 2.1 million total upvotes, with an average of 31 upvotes and a maximum of 18,253 upvotes per comment.

Data Labeling and Augmentation

Since time is of the essence in a global pandemic, combined with the fact that labeling data is time-consuming and costly, we created a custom training data set by labeling sentiment (positive or negative) for approximately 3600 tweets related to COVID-19 vaccines. We chose to label tweets exclusively for this study, because the 280-character limit of a tweet (ie, compared to a Reddit post limit of a maximum of 10,000 characters) would allow our small team to create a time-relevant training data set more quickly. We then augmented our data set through the process of back-translation with several language models on the Hugging Face model repository. Back-translation was chosen after testing a few other methods of text augmentation. Some techniques (eg, word masking) resulted in far more duplicated texts that would eventually need to be removed. Back-translation relies on subtle differences between language structure, word meaning, and syntax. In effect, the outputted text will vary slightly from the inputted text without losing semantic and contextual meaning [14]. In our case, the back-translation method translated our English-language text into another language (eg, French, Chinese, Greek, and Hebrew) and then back into English. After removing duplicates, our final augmented data set consisted of 48,691 tweets.

RoBERTa and DistilRoBERTa

For our study, we chose to explore the capabilities of DistilRoBERTa. RoBERTa is a more robust model than BERT, and DistilRoBERTa is an optimized version of RoBERTa [15,16]. Developed at Facebook, RoBERTa was trained on 160 GB of text compared to the 16 GB of BERT. RoBERTa dropped the next sentence prediction feature of BERT and added dynamic token masking during training. These enhancements are estimated to have improved the original BERT's performance significantly (2% to 20%) [16]. Compared to RoBERTa, DistilRoBERTa was trained on approximately 40 GB of text data (OpenWebTextCorpus) and operates about twice as fast.

The University of Tennessee Health Science Center Vaccine Sentiment Labeling and DistilRoBERTa Fine-tuning

We fine-tuned the DistilRoBERTa base via the Hugging Face *Trainer* class, which provides the user with an API for training with *PyTorch*. Our data were then randomized and segregated into 40,000 training tweets, 4000 validation tweets, and 4691 tweets for testing. Training hyperparameters included a 2×10^{-5} learning rate, 32 training and evaluation batch size, a seed number of 42, and a linear scheduler with 500 warm-up steps. We used the *Adam* optimizer with betas of 0.9 and 0.999 and an epsilon of 1×10^{-8}. Lastly, our model was trained for 2 epochs. These hyperparameters achieved a training loss of 0.1284, a validation loss of 0.1167, a precision of 0.9561, an F_1-score of 0.9592, and an accuracy of 0.9592 (see Table 1).

Table 1. DistilRoBERTa fine-tuning training metrics. The model obtained optimal fine-tuning after 2 training epochs.

Step	Epoch	Training loss	Validation loss	Precision	Accuracy	F_1-score
500	0.4	0.5903	0.4695	0.7342	0.7728	0.7890
1000	0.8	0.3986	0.3469	0.8144	0.8596	0.8684
1500	1.2	0.2366	0.1939	0.9313	0.9260	0.9253
2000	1.6	0.1476	0.1560	0.9207	0.9452	0.9465
2500	2.0	0.1284	0.1167	0.9561	0.9592	0.9592

Analytical Methods

Following the fine-tuning of our model, we processed the Twitter and Reddit data through the Hugging Face *pipeline* for sentiment analysis. The model returned a label of either positive or negative for each tweet or Reddit comment. Along with the determined polarity, the model also returned a probabilistic confidence score ranging from 0 to 1. For clarity, tweets or comments classified as negative were multiplied by –1 to reflect the negative sentiment.

Ethical Considerations

No ethical approval was needed from our institution due to the public availability and nonidentifiable nature of the data used.

Results

DistilRoBERTa Fine-tuned to COVID-19 Vaccine

Twitter

The DistilRoBERTa fine-tuned polarity analysis determined that the 9,518,270 tweets were more negative (n=5,215,830, 54.8%) than positive (n=4,302,440, 45.2%) throughout our time frame (see Figure 1).

The maximum positive rating occurred in March 2021 (375,789/675,274 55.6%). However, the minimum positive rating occurred in January 2022 (191,159/526,582, 36.3%), displaying a steady decrease in polarity from the maximum. For the confidence score, the tweets classified as positive had a maximum score of 0.999, a minimum of approximately 0 (3.58×10^{-7}), and a mean of 0.868 (see Figure 2). The tweets classified as negative had a minimum score of –0.999, a maximum value of approximately zero (–1.78 × 10^{-6}), and a mean of –0.882 (see Figures 1 and 2).

Figure 1. Tweet polarity from the DistilRoBERTa model fine-tuned to COVID-19 vaccine. Polarity and the corresponding confidence probability are represented on the y-axis, and time is represented on the x-axis. Tweets are represented as light blue circles. Circle size indicates the number of likes per tweet—larger circles indicate more likes and smaller circles indicate fewer likes.

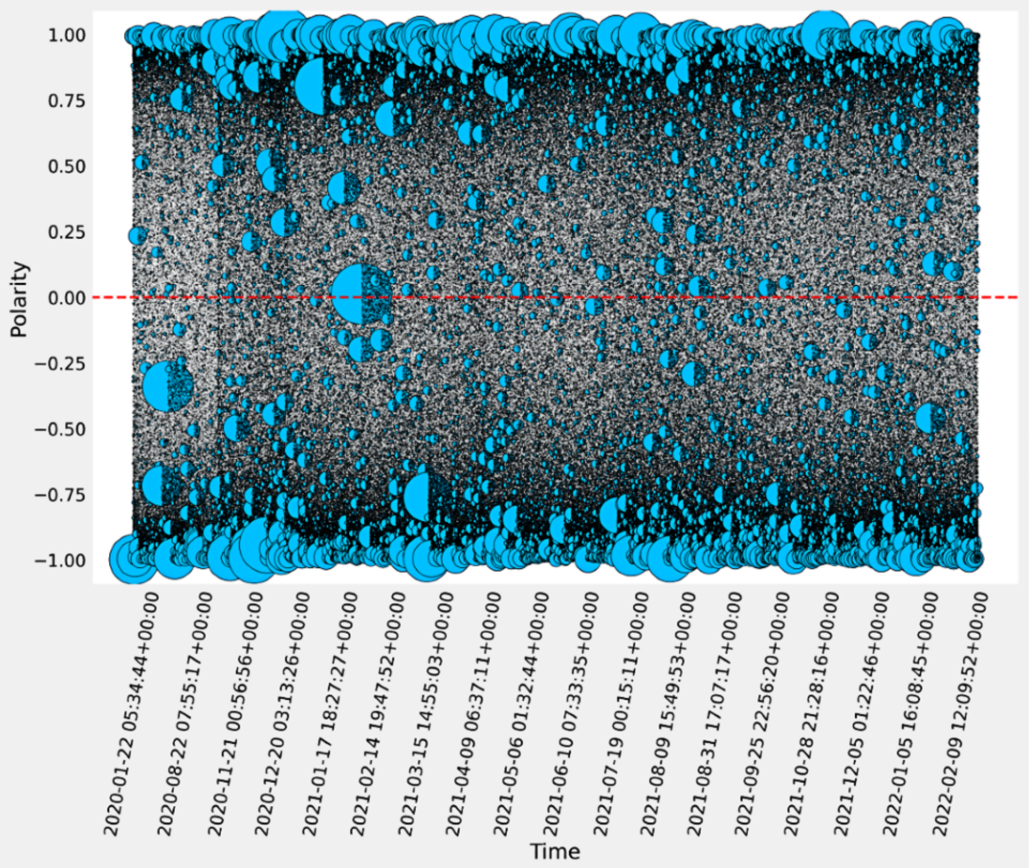
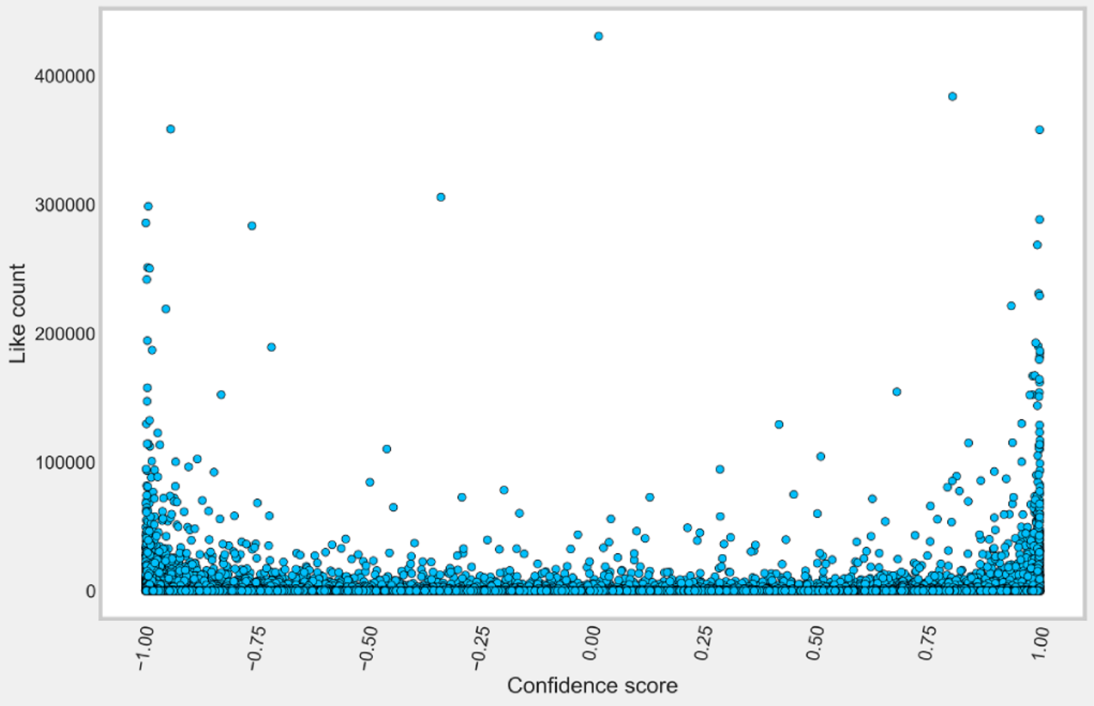


Figure 2. Confidence score versus like count for Twitter. The x-axis represents the confidence score and the y-axis represents the number of likes a tweet received. Data points below 0.00 on the x-axis represent a negative classification, and data points above 0.00 represent a positive classification. Data points are represented as light blue circles.



Reddit

The Reddit sentiment polarity analysis for the fine-tuned DistilRoBERTa model found that of the 67,962 posts, 37.7% (n=25,646) were classified as negative and 62.3% (n=42,316) were classified as positive. The highest polarity reported in our experiment and the maximum positive rating occurred in April 2021 (6611/9044, 73.1 %), and the minimum positive rating occurred in February 2020 (170/351, 48.4%). For the confidence scores, the comments classified as positive had a maximum score of 0.999, a minimum of approximately 0 (1.55 × 10^{-4}), and a mean of 0.870 (see Figure 3). The comments classified as negative had a minimum of –0.999, a maximum of approximately 0 (–4.74 x 10^{-5}), and a mean of –0.808 (see Figures 3 and 4).

Figure 3. Reddit comment polarity from the DistilRoBERTa model fine-tuned to COVID-19 vaccine. Polarity and corresponding confidence probability are represented on the y-axis, and time is represented on the x-axis. Data points are represented as orange-red circles. Circle size indicates the number of upvotes per comment—more upvotes are represented by larger circles and fewer upvotes are represented by smaller circles.

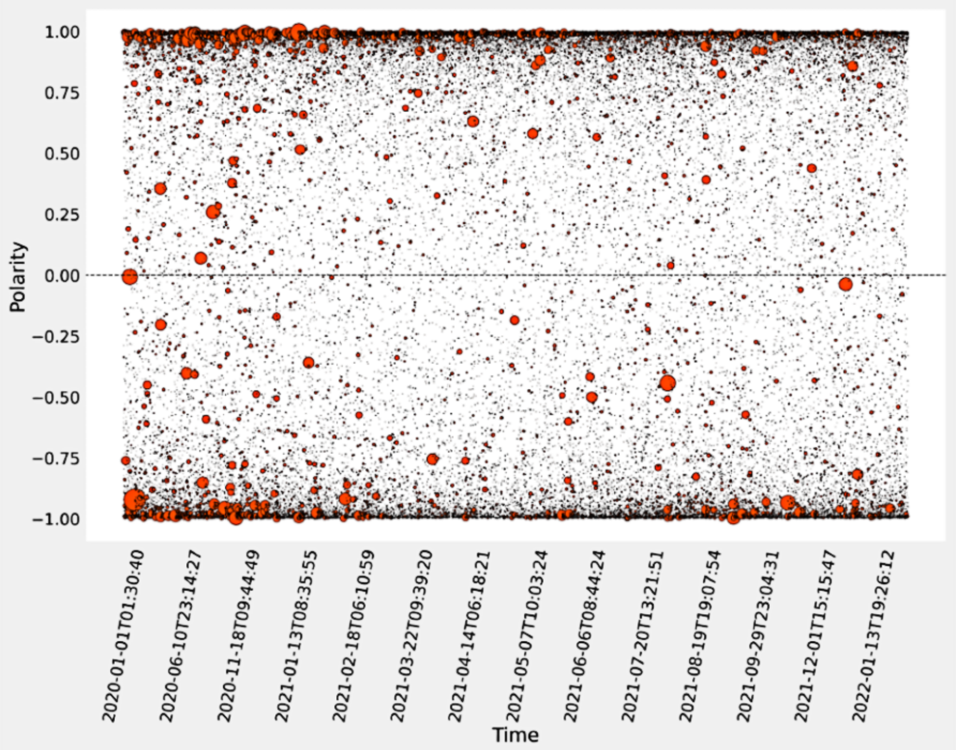
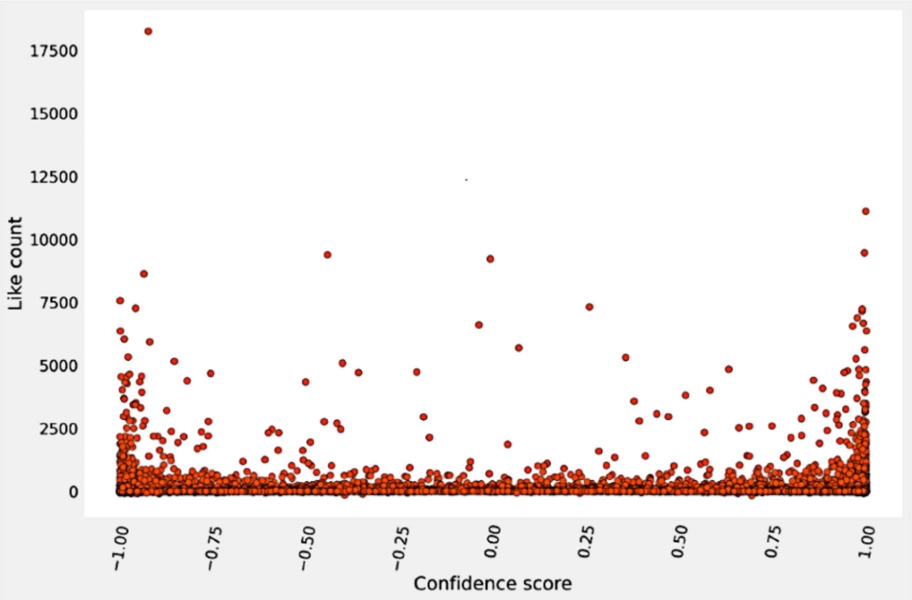


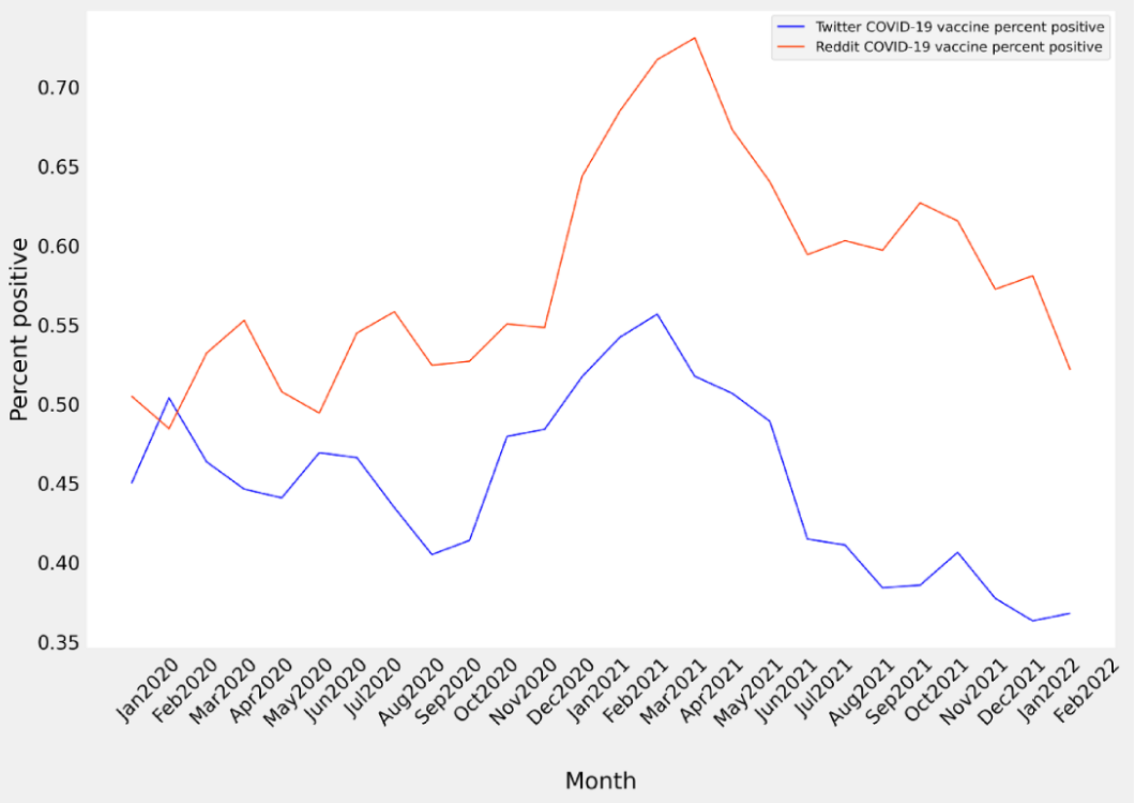
Figure 4. Confidence score versus like count for Reddit. The x-axis represents the confidence score and the y-axis represents the number of upvotes a comment received. Data points below 0.00 on the x-axis represent a negative classification, and data points above 0.00 represent a positive classification. Data points are represented as orange-red circles.



COVID-19 Vaccine Sentiment Expressed on Reddit and Twitter

Overall, the average sentiment for the 2 social media platforms was somewhat different (62.3% positive on Reddit vs 45.2% positive on Twitter). An interesting story begins to appear when looking closely at the month-to-month results in relation to each other. Although sentiment on both platforms oscillated in the early months of the pandemic, Reddit sentiment was higher (ranging from 48% to 55% positive) from January to August 2020. Twitter sentiment began similar to Reddit sentiment but gradually declined until becoming substantially more negative from September to October 2020, and then increasing to a maximum of 55% in March 2021. Reddit sentiment began a steep increase in polarity in December 2020 and continued to increase until reaching the maximum positive sentiment (approximately 73%) in April 2021. After sentiment on each platform achieved their maximum positive polarity, both began an oscillating and gradual decline in sentiment to near early pandemic levels. However, Twitter sentiment continued to fall until achieving a minimum of 36% (see Figure 5).

Figure 5. Monthly sentiment for Twitter and Reddit COVID-19 vaccine–related posts. The x-axis represents time and the y-axis represents the percentage of posts classified as positive. The blue line represents Twitter sentiment and the orange-red line represents Reddit sentiment. Note that since posting frequency was very low, sentiment for January 2020 is an average of all other months of corresponding data.



Discussion

Interpretation of Results

Ranging from January 1, 2020, to March 1, 2022, our results show that the average sentiment for the Reddit data set was more positive than the average sentiment expressed on Twitter. Interestingly, both platforms expressed similar sentiment changes during key moments of the pandemic (eg, vaccine efficacy announcements, vaccine distribution to all ages, new variants, and waning efficacy). This behavior is especially observable as vaccines became widely available to the public and the polarity diminished. Considering this similar behavior, we feel that both Twitter and Reddit continue to be valuable data sources that public health officials can use to develop vaccine education campaigns and digital interventions. Although Twitter is superior in the ability to access large numbers of tweets through an API, substantial steps need to be taken while cleaning Twitter data to remove bots, news media posts, commercial users, duplicates, and users who have extremely high posting frequencies. On the other hand, Reddit data are more plentiful in longer texts that could be more useful for topic modeling.

What drove sentiment changes related to COVID-19 vaccines on these 2 platforms? One possibility could be related to the character limit of tweets versus Reddit posts (ie, 280 vs 10,000 characters, respectively). The shortened character limit of tweets most likely contributes to the quick spread of information and can be reactionary in nature, driving negative sentiment. However, Reddit users typically take advantage of the longer character limit and share, at times, highly personal stories and experiences related to their health care. For this reason, Reddit could remain a highly valuable source when considering the development of public health messaging and education campaigns.

Correlating changes in sentiment with developments during the pandemic presents some interesting challenges and ideas alike. The most obvious steep increase in sentiment seems to be correlated with positive news regarding vaccine development and trials and news of high efficacy, distribution, and availability to those who patiently waited for the vaccine. It is challenging to correlate minimum sentiment scores because their decline was not uniform. It is highly likely that the gradual decline was related to a combination of unfortunate events related to the pandemic (eg, misinformation, pandemic fatigue, and falling vaccine efficacy). It is conceivable that challenges in vaccine rollout and distribution could negatively affect sentiment. However, previous topic modeling and semantic network analysis on portions of this data set did not find a meaningful occurrence of terms related to vaccine distribution. Therefore, more psychological, sociological, and cultural studies are desperately needed to understand what drives certain populations, news media, politicians, and entertainers to so readily accept and propagate misinformation and conspiracy theories rather than directly observable facts. Such studies would not only benefit future public health responses but also many other areas of life where misinformation and disinformation have taken hold. The success of digital interventions and education campaigns would likely be limited without a more thorough understanding of how to reach these populations.

Public Health Implications

The application of our findings could have momentous impacts on the public health sector in the fight against infectious diseases such as COVID-19. Further development of low–human effort surveillance systems optimized for the rapid collection of data would allow for the real-time analysis of public emotion in correlation with disease progression. Moreover, fine-tuning models to assess geographical and demographical differences in sentiment could provide insight into the attitudes of populations at the greatest risk of debilitating outcomes. In addition to geographically and demographically specific data mining, targeting public discourse during times of peak infection, vaccine releases, or the death of a celebrity, athlete, or political figure due to the disease could greatly bolster public health response [30,31]. The expansion of such disease projection and prediction models using sentiment mining techniques could also influence evidence-informed policy. Discerning the dynamic levels of population sentiment allows public health officials to design catered policy communication strategies. By providing the necessary tools to better understand public emotion related to disease prevention, control, and containment, policy makers would be better equipped to evaluate program successes and highlight any need for repositioning.

Furthermore, the analysis of sentiment shared via social media could prove to be a vital instrument in combatting rampant misinformation and disinformation shared on the web. As the spread of misinformation poses a range of psychological and psychosocial risks (anxiety and fear, etc), there is an urgency in understanding the public perspective and attitude toward shared falsities. Education delivery systems tailored to population-expressed sentiment could aid in clarifying such misinformation. Moreover, there is room for the expansion of artificially intelligent messaging systems, tasked with generating responses to waves of misinformation and disinformation shared via social media platforms. Overall, the proposed framework for the real-time analysis of sentiment could be useful in guiding governmental support of public health recovery efforts.

Limitations

As with most studies, ours has some limitations. Challenges occur when conducting sentiment analysis in social media texts due to some long-standing problems. Although BERT and newer models greatly mitigate many of these challenges, some models typically struggle with detecting sarcasm, humor, emotion, and complex inferences in texts unless specifically having been trained to do so. For example, many pro-vaccine social media users express extremely negative views and sentiments regarding the anti-vaccine community. How would BERT classify such an occurrence? Although their expressed sentiment is positive toward the vaccine, many natural language processing algorithms and data labelers would potentially struggle with this type of classification. Even though we took great care with this study to remove tweets by bots or tweets from highly repetitive users from Twitter and choose unbiased subreddits, it is possible that some could have still slipped through the data cleaning process. Moreover, augmented data can potentially cause problems with overfitting when fine-tuning models due to relatively similar semantic content. We limited our training epochs and closely monitored the relationship between training loss and validation loss to mitigate this potential problem. Future work could involve efforts to create a larger labeled data set that would include not only COVID-19 vaccine sentiments but those of other vaccines as well.

Conclusions

We conducted a sentiment analysis of approximately 70,000 Reddit comments and 9.5 million tweets with a fine-tuned DistilRoBERTa model. Our analysis found that both Reddit and Twitter users expressed similar changes in sentiment throughout the pandemic, even though Twitter was substantially more negative than Reddit. Although subtle differences in sentiment were observed monthly, both platforms demonstrated a substantial increase in positive sentiments as the COVID-19 vaccine became readily available to the general public. The results we present here are a portion of an ongoing study to investigate vaccine-related content on social media with a focus on identifying and combating misinformation in efforts to decrease vaccine hesitancy. Correlating strong sentiment with high infectivity rates could provide officials with forecasting for the public acceptance of migration strategies such as vaccine delivery and uptake. These integrated disease surveillance tools should not only be leveraged in the fight against COVID-19 but stand to play essential roles in the evolution of future health policy, decision-making, program implementation, and precision health promotion [32]. In the near future, our team plans to expand the methods demonstrated in this study into sentiment related to other types of vaccines (eg, human papillomavirus vaccines). We expect these results along with others to be used to develop tools to assist public health officials in monitoring public discourse regarding disease outbreaks, gaining a better understanding of vaccine hesitancy, and developing personalized digital interventions [33,34] and education campaigns.

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Data Availability

The data that support our findings are available upon reasonable request to the authors. Data are not available for commercial use.

Authors' Contributions

CAM conceptualized and supervised the study and drafted, reviewed, and edited the manuscript. BMW conceptualized the study and drafted, reviewed, and edited the manuscript. RLD reviewed and edited the manuscript. RAB reviewed and edited the manuscript. ASN drafted, reviewed, and edited the manuscript; supervised the study; and acquired funding.

Conflicts of Interest

None declared.

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Abbreviations

BERT: Bidirectional Encoder Representations from Transformers

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Original Paper

Tracking the Impact of COVID-19 and Lockdown Policies on Public Mental Health Using Social Media: Infoveillance Study

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Abstract

Background: The COVID-19 pandemic and its corresponding preventive and control measures have increased the mental burden on the public. Understanding and tracking changes in public mental status can facilitate optimizing public mental health intervention and control strategies.

Objective: This study aimed to build a social media–based pipeline that tracks public mental changes and use it to understand public mental health status regarding the pandemic.

Methods: This study used COVID-19–related tweets posted from February 2020 to April 2022. The tweets were downloaded using unique identifiers through the Twitter application programming interface. We created a lexicon of 4 mental health problems (depression, anxiety, insomnia, and addiction) to identify mental health–related tweets and developed a dictionary for identifying health care workers. We analyzed temporal and geographic distributions of public mental health status during the pandemic and further compared distributions among health care workers versus the general public, supplemented by topic modeling on their underlying foci. Finally, we used interrupted time series analysis to examine the statewide impact of a lockdown policy on public mental health in 12 states.

Results: We extracted 4,213,005 tweets related to mental health and COVID-19 from 2,316,817 users. Of these tweets, 2,161,357 (51.3%) were related to "depression," whereas 1,923,635 (45.66%), 225,205 (5.35%), and 150,006 (3.56%) were related to "anxiety," "insomnia," and "addiction," respectively. Compared to the general public, health care workers had higher risks of all 4 types of problems (all $P<.001$), and they were more concerned about clinical topics than everyday issues (eg, "students' pressure," "panic buying," and "fuel problems") than the general public. Finally, the lockdown policy had significant associations with public mental health in 4 out of the 12 states we studied, among which Pennsylvania showed a positive association, whereas Michigan, North Carolina, and Ohio showed the opposite (all $P<.05$).

Conclusions: The impact of COVID-19 and the corresponding control measures on the public's mental status is dynamic and shows variability among different cohorts regarding disease types, occupations, and regional groups. Health agencies and policy makers should primarily focus on depression (reported by 51.3% of the tweets) and insomnia (which has had an ever-increasing trend since the beginning of the pandemic), especially among health care workers. Our pipeline timely tracks and analyzes public mental health changes, especially when primary studies and large-scale surveys are difficult to conduct.

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KEYWORDS

COVID-19; mental health; social media; Twitter; topic model; health care workers

Introduction

The global COVID-19 pandemic has drastically changed people’s daily lives since the first confirmed case in December 2019 [1]. It has led to high hospitalization and fatality and negatively impacted public mental health [2,3]. Mental health problems cover a wide range of populations during the pandemic. The causes include but are not limited to the infection and death of relatives and friends, fear of illness, isolation brought by quarantine [4,5], and stress from unemployment [6]. At the same time, specific subpopulations such as children and adolescents [7,8], students [9,10], patients with COVID-19 [11], and health care workers [12,13] are particularly vulnerable to psychological disorders during the pandemic.

Studies have pointed out that health care workers in the United States experience psychological distress, facing high levels of anxiety, depression, and burnout during the pandemic [14]. The underlying reasons could be higher exposure risks to the virus and overwhelming workload [15,16]. Although there is literature on studying the mental health status of health care workers during the pandemic period, existing research primarily focuses on retrospective cross-sectional studies [13,14,16-19]. Therefore, it is necessary to study the dynamic characteristics of their mental status, identify general concerns, and provide timely support [20,21].

Due to their large scale, immediacy, and comprehensive coverage, social media platforms (such as Twitter, Facebook, and Weibo) have been vital data sources of research to analyze public perceptions timely when primary studies and large-scale surveys are difficult to be conducted. For example, Chew et al [22] used Twitter to study misinformation during the 2009 H1N1 pandemic, and Masri et al [23] found that new case trends can be predicted 1 week ahead based on related tweets for the 2015 Zika epidemic. Similarly, numerous studies have used social media to monitor public perceptions on topics such as enforced remote work [24], vaccines [25,26], drug use [27], mask wearing [28], and so on. Meanwhile, Berry et al [29] pointed out through a study with both quantitative and qualitative approaches that people are willing to discuss mental health problems on Twitter for varied reasons, including the sense of community and Twitter being a safe space for expression, coping, empowerment, etc. However, existing literature on public mental health during the pandemic using Twitter data [30-33] either has short study periods and small sample sizes or does not focus on subtypes of mental health problems and subgroup prevalence. More granular study designs and more comprehensive data are needed for such studies.

Finally, there is inconsistency in studying the effect of lockdown policies—one of the most highly debated topics related to mental health during the pandemic. Das et al [34] found that “state lockdown policies precede greater mental health symptoms.” In contrast, Adams-Prassl et al [35] found that “the lockdown measures lowered mental health by 0.083 standard deviations.”

To fill in these research gaps and potentially resolve the inconsistency, this study aimed to use related data from February 1, 2020—the beginning of the pandemic—to April 30, 2022, to analyze public mental status, problem types, their temporal and geographic distributions during COVID-19, as well as the effects of lockdown policies on public mental health across states (Figure S1 in Multimedia Appendix 1). In detail, we used this study to answer the 4 following research questions:

1. What types of mental health problems were the most frequent?
2. What mental health–related topics were the public the most concerned about, and how did relevant discussions change over time?
3. Are there differences in mental health concerns between the general population and health care workers?
4. How did lockdown policies impact public mental health?

To answer question 1, two mental health experts from our teams curated a mental health lexicon for Twitter that categorizes related tweets into 4 common mental health problems: anxiety, depression, insomnia, and addiction. Based on this lexicon, we extracted related tweets and visualized their distributions by week and state. To answer questions 2 and 3, we built a pipeline to identify potential health care workers, used a topic model to summarize related tweets into 16 topics, and compared the topic distributions among health care workers and the general population. To answer question 4, we identified tweets related to mental issues and compared their proportions before and after lockdown policies across different US states.

Methods

Data Collection

We collected and downloaded COVID-19–related tweets from February 1, 2020, to April 30, 2022, from Twitter’s application programming interface using the unique tweet ID provided by an open-source COVID-19 tweet database [36]. The downloaded data contained full tweet texts and the corresponding metadata, including created time, user information, tweet status, etc. We further filtered out non–English-language and retweeted tweets and kept 471,371,477 tweets. Our data collection process strictly followed Twitter’s privacy and data use management. This study followed the Strengthening the Reporting of Observational Studies in Epidemiology reporting guidelines.

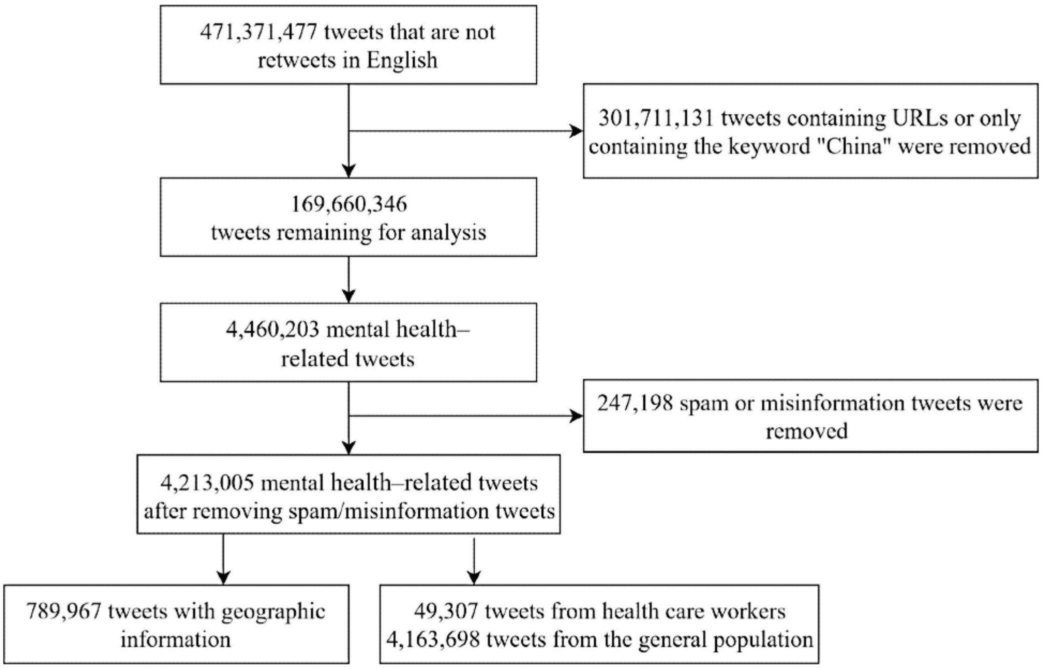
Ethics Approval

This study was conducted with approval by the Institutional Review Board of Zhejiang University (ZGL202201-2).

Data Preprocessing and Filtering

We removed tweets that contain URLs because such tweets often only included summaries or quotations of the original contents (169,660,346 tweets remained). A psychiatrist and a psychologist curated a mental health lexicon with 231 keywords. The keywords were categorized into 4 subgroups: anxiety, depression, insomnia, and addiction (Table S1 in Multimedia Appendix 1). We used this lexicon to extract mental health–related tweets through keyword matching against the preprocessed tweets and identified 4,460,203 tweets. To reduce the impact of spam and misinformation tweets, we removed data from users who posted more than 1000 mental health–related tweets during the study period. The final data set contained 4,213,005 tweets. Figure 1 shows an overview of the data preprocessing process.

Figure 1. Data collection and preprocessing.



Geographic Information Extraction

The geographic information of users was collected from 2 fields of the tweets: (1) the "place" field in tweet metadata and (2) the "location" variable nested in the "user" field of tweet metadata. The "place" information was chosen as the primary evidence of the users' geographic information, since it is generated from GPS data and is, therefore, more accurate than the information from the self-reported "location" field. We used a list of US state names to extract users' geographic information ("Methods" in Multimedia Appendix 1 [37-39]). Tweets from users associated with more than 1 state were removed in this step.

Topic Model Analysis

The Latent Dirichlet Allocation model [39] was used to conclude the main topics of mental health–related tweets. To create the corpora for topic modeling, we removed all stop words [40] as well as numbers and symbols. The topic model was implemented using the *LdaModel* function of the *Genism* package [40]. We selected the number of topics—a model hyperparameter—based on perplexity and topic coherence ("Methods" in Multimedia Appendix 1 [37-39]).

Health Care Worker Identification

To identify health care workers, we built a health care worker identification lexicon, whose keywords can be roughly divided into 3 groups: occupation, degree, and the title of the association ("Methods" in Multimedia Appendix 1 [37-39]). The dictionary contained 47 keywords, such as "doctor," "MD," "Doctor of Medicine," "FACP," etc (Table S2 in Multimedia Appendix 1). We used this lexicon to filter the user's description and extracted 49,307 tweets from health care workers.

Statistical Analysis

We applied standard descriptive statistics to summarize the 4 types of mental health–related tweets proportion, including median and IQRs. Wilcoxon matched-pairs signed-ranks test was used to compare differences between health care workers and the general population. Interrupted time series analysis [41] was applied to analyze the lockdown policy's effects on public mental health (see detailed information in "Methods" in Multimedia Appendix 1 [37-39]). We used Python software (version 3.8) to conduct the statistical analyses and chose a *P* value of .05 as the statistically significant threshold.

Results

Collected Data Set

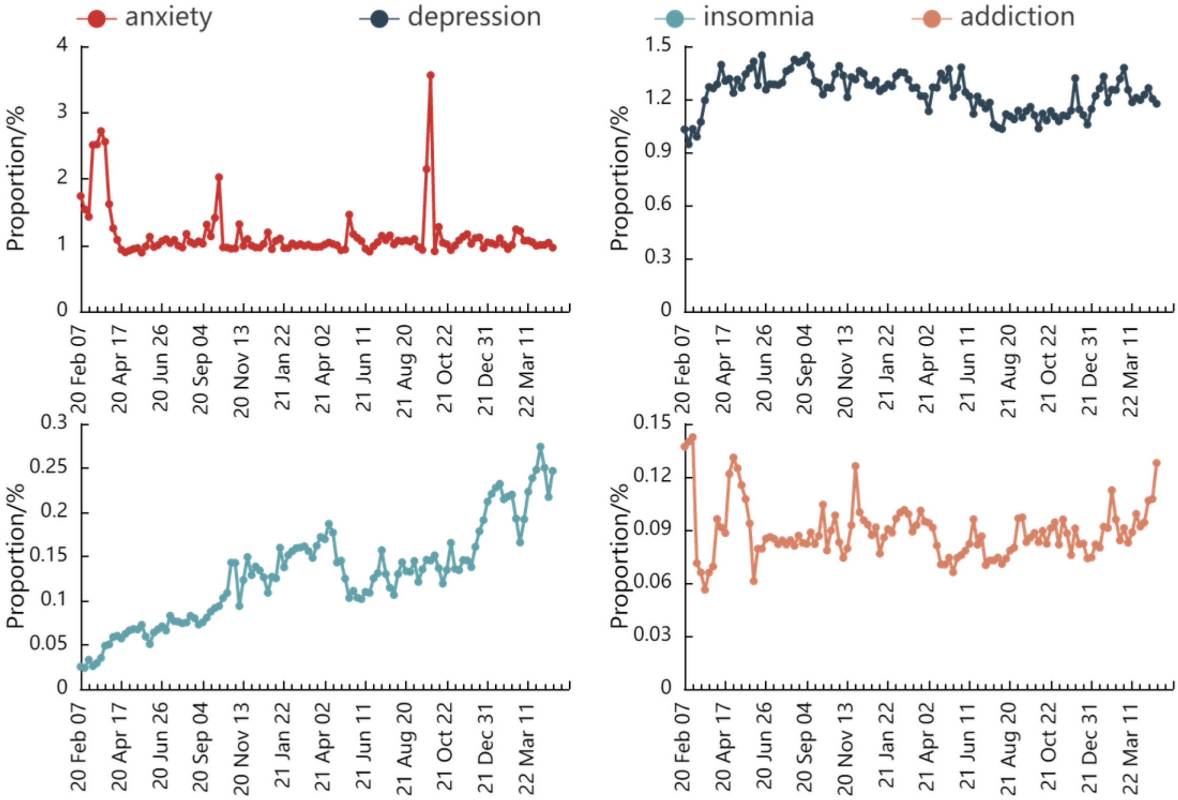
Data preprocessing selected 4,213,005 mental health–related tweets from 2,316,817 users (Figure 1). Among these tweets, 51.3% (2,161,357) were in the "depression" group, 45.66% (n=1,923,635) tweets were in the "anxiety" group, 5.35%

(n=225,205) tweets were in the “insomnia” group, and 3.56% (n=150,006) tweets were in the “addiction” group. The sum of the 4 proportions was larger than 100% because some tweets included multiple keywords that belong to different mental health subgroups. Additionally, 789,967 (18.75%) tweets were extracted with their geographic information, and health care workers posted 49,307 (1.17%) tweets (from 21,963 users).

Temporal Distribution of Mental Health–Related Tweets

The trends of the weekly numbers of COVID-19 new cases and mental health–related tweets in 4 subgroups are shown in Figure S2 in Multimedia Appendix 1. The number of tweets of mental health problems reached their first peak from February 29 to April 4, 2020. We calculated and visualized the proportions of mental health–related tweets among all COVID-19–related tweets in Figure 2. The proportion curve of anxiety-related tweets had 3 dominant peaks in March 2020, October 2020, and September 2021. The curve of insomnia-related tweets continually increased during the study period, whereas no specific trends were observed in the curves of depression and addiction.

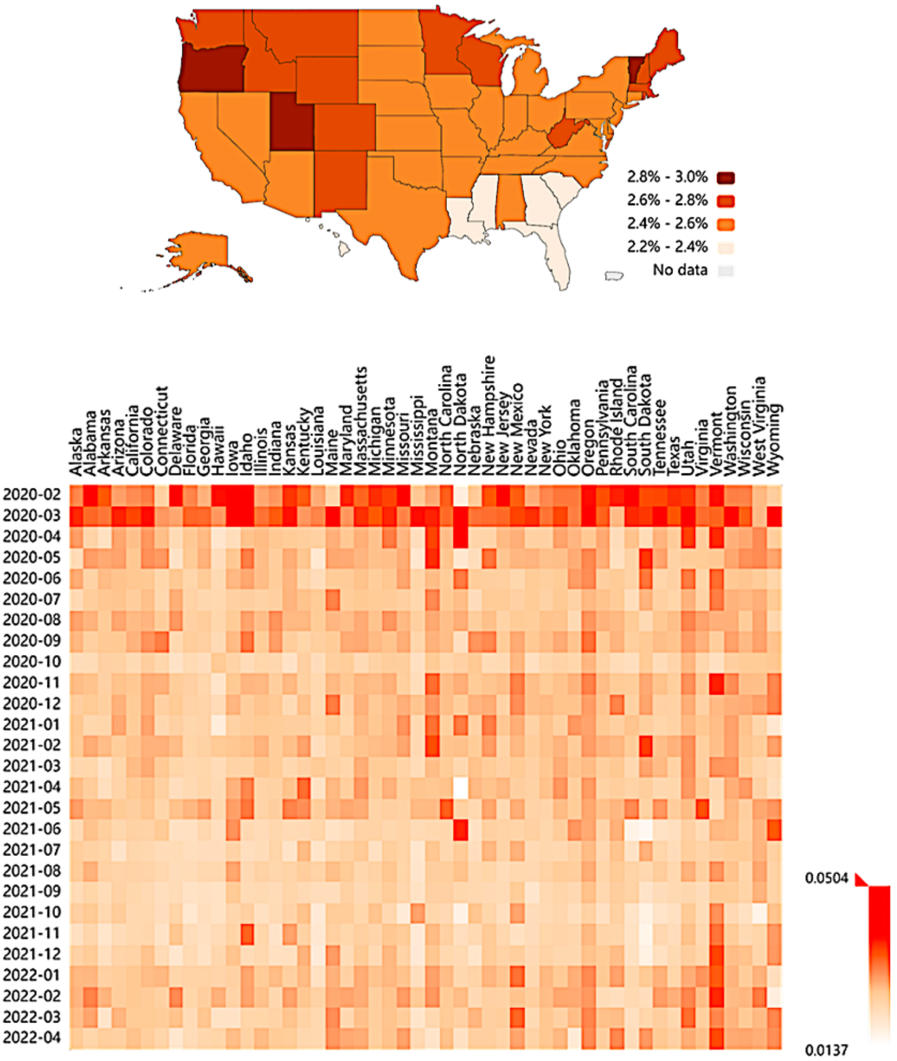
Figure 2. Trends of 4 types of mental health symptom–related tweets by the proportion of tweets.



Geographic Distribution of Mental Health–Related Tweets in the United States

Figure 3 shows the proportion of mental health–related tweets among all COVID-19–related tweets in each US state from February 1, 2020, to April 30, 2022, and visualizes the monthly tweet proportion for all the 50 US states (concrete proportions and 95% CIs are listed in Multimedia Appendix 2). Vermont, Oregon, and Utah were the 3 states with the highest proportions of mental health–related tweets, whereas Mississippi, Hawaii, and Louisiana had the lowest proportions. The first 2 months had a more substantial proportion of mental health–related tweets than the following months across most states.

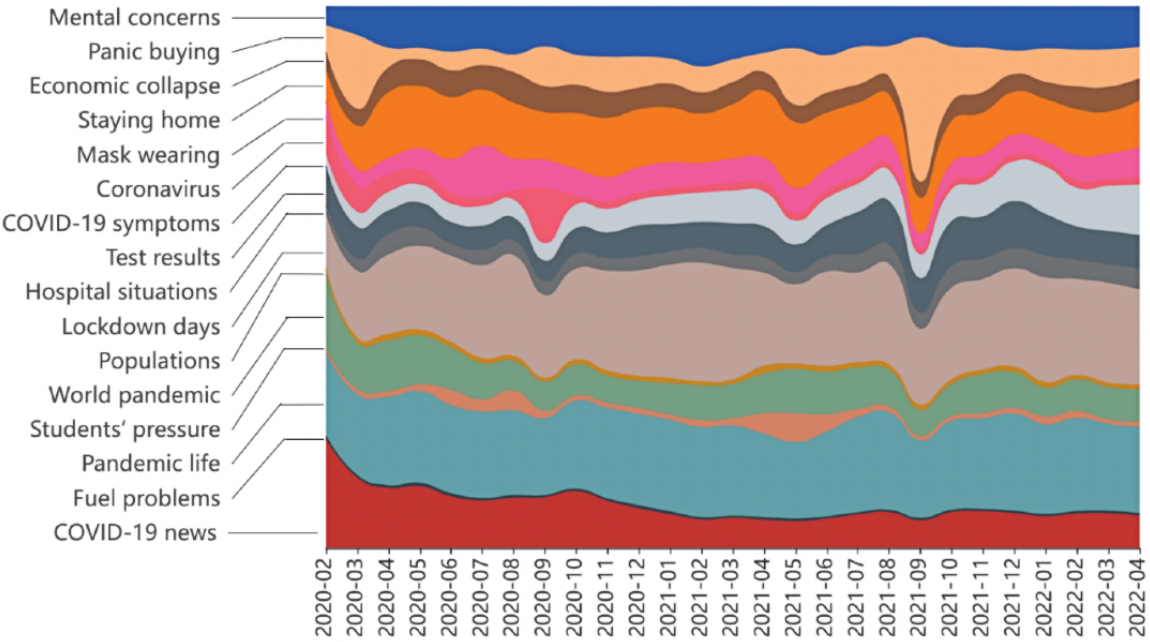
Figure 3. Proportion distribution of mental health–related tweets in the United States.



Topics of Mental Health–Related Tweets

The most frequent terms for mental health–related tweets were “people,” “worried,” “shame,” “panic,” “lockdown,” “anxiety,” “mask,” etc (Figure S3 in Multimedia Appendix 1). We chose 16 to be the number of topics based on the perplexity and coherence (“Methods” and Figure S4 in Multimedia Appendix 1 [37-39]). Topics and the corresponding top 20 most probable unigrams and bigrams are displayed in Table S3 in Multimedia Appendix 1. We assigned each topic with a topic name based on the keywords. For example, a topic having the keywords “college,” “student,” “stress,” and “exam” indicates that tweets on this topic was likely to have been focused on “students’ pressure.” Except for the issues related to COVID-19 itself, such as “COVID-19 news,” “test results,” and “mask wearing,” the public also showed particular interest in topics such as “economic collapse,” “panic buying,” and “fuel problems.” The 16 topics were then categorized into 6 topic groups: “COVID-19 pandemic,” “preventive measures,” “economic,” “people,” “education,” and “mental health.” Figure 4 shows the dynamic distributions of the investigated topics in relative tweet proportions. The topic “lockdown days” occupied a dominant position during the pandemic most of the time. “COVID-19 news” was frequently mentioned at the beginning of the pandemic but returned to an average level after June 2020. The topic of “panic buying” notably fluctuated in the research period and was relatively large from February to March 2020 and from August to October 2021.

Figure 4. Dynamic characteristics of topic proportions.



Mental Health of Health Care Workers

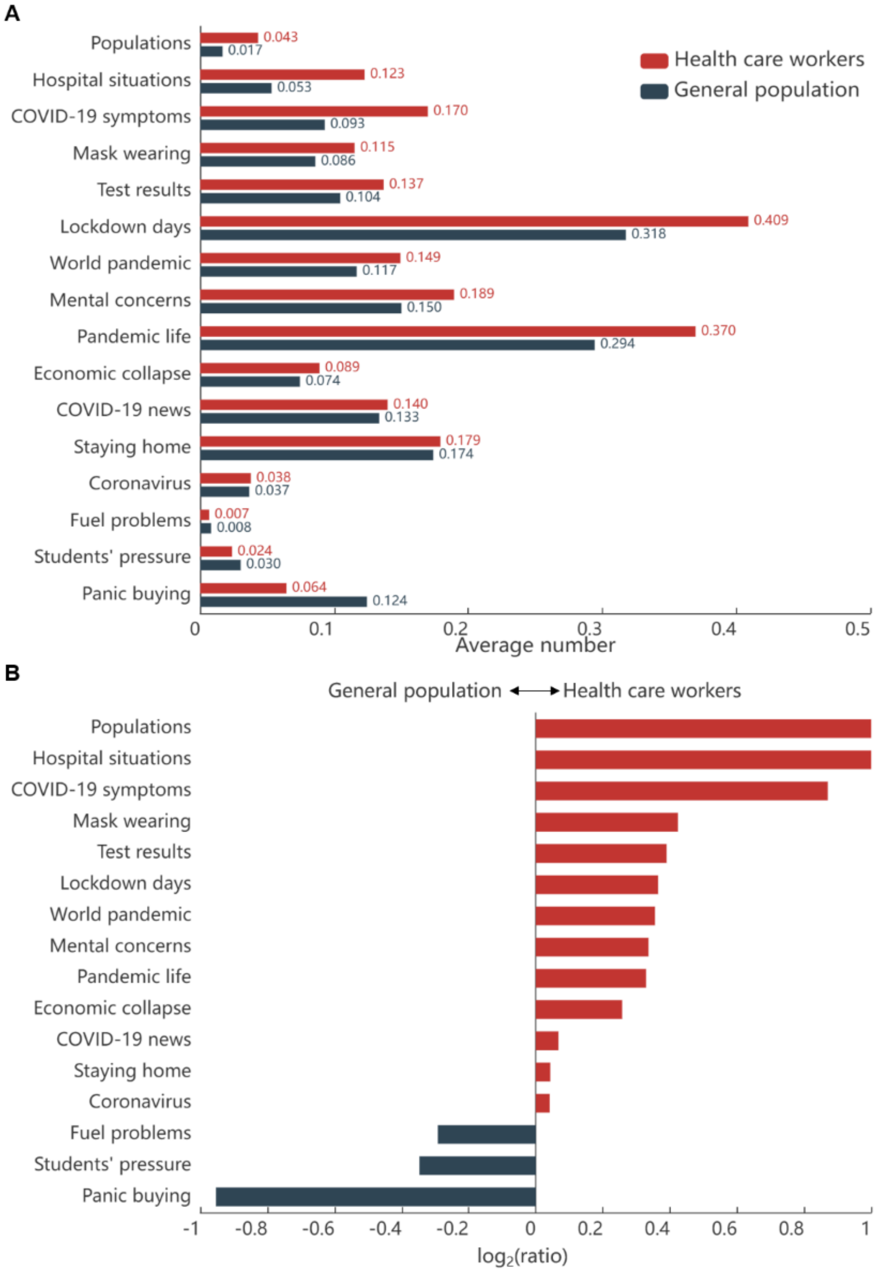
We assessed the differences in the proportions of 4 mental health symptom–related tweets between health care workers and the general population and showed the results in Table 1. Statistical results showed that the proportions of anxiety-, depression-, insomnia-, and addiction-related tweets were significantly higher in health care workers than in the general public (all *P*<.001). Figure 5A shows the average number of tweets per user on different topics. "Lockdown days" is the top topic discussed by both health care workers and the general population. To visualize the difference in topic distribution between health care workers and the general population, we visualized the ratios of the average number of tweets by topic for the 2 groups in Figure 5B. It demonstrates that health care workers discussed more on 13 topics, especially clinical-related topics such as "hospital situations," "COVID-19 symptoms," and "mask wearing." Conversely, the general population focused on topics such as "fuel problems," "students' pressure," and "panic buying."

Table 1. Comparison of proportions of mental health–related tweets between health care workers and the general population.

Mental health symptom	Health care workers (% tweets), median (IQR[a])	General population (% tweets), median (IQR[a])	W	*P* value
Anxiety	1.103 (1.02-1.187)	1.025 (0.956-1.094)	2120	<.001
Depression	1.519 (1.396-1.642)	1.255 (1.171-1.339)	26	<.001
Insomnia	0.251 (0.175-0.328)	0.131 (0.093-0.17)	7	<.001
Addiction	0.139 (0.114-0.164)	0.086 (0.079-0.094)	185	<.001

[a] IQR and Wilcoxon matched-pairs signed-ranks test were applied to compare the differences between the 2 groups.

Figure 5. The distribution of tweets in topics for health care workers and the general population. (A) Average number of tweets per user in each topic. (B) Logarithmic ratio of the average number of tweets between health care workers and the general population on each topic. The ratio equals the average number of tweets per user among health care workers divided by the average number of tweets among the general population.



Impacts of Lockdown Policies

We selected 12 states with more than 20,000 related tweets during the study period to explore the effect of lockdown policies on public mental status. We report the significant results found in Michigan, Pennsylvania, North Carolina, and Ohio (analysis results of the other 8 states are displayed in Figure S5 in Multimedia Appendix 1). Sensitivity analysis was applied to verify the stability of the results (Table S4 in Multimedia Appendix 1). Figure 6 shows the proportions of the 4 mental health–related tweets changed after the lockdown policy in Pennsylvania but not in the other 3 states. Table 2 lists the results of the interrupted time series analyses [41] of the lockdown policy on public mental health. The coefficient of "policy," meaning the change of intercept, was significant in the model of Pennsylvania (*P*=.007), and the coefficient of interaction term indicated that the change of slope was both significant in the models of Michigan (*P*=.03) and Pennsylvania (*P*=.04).

Figure 6. Daily proportion of mental health–related tweets before and after lockdown policies.

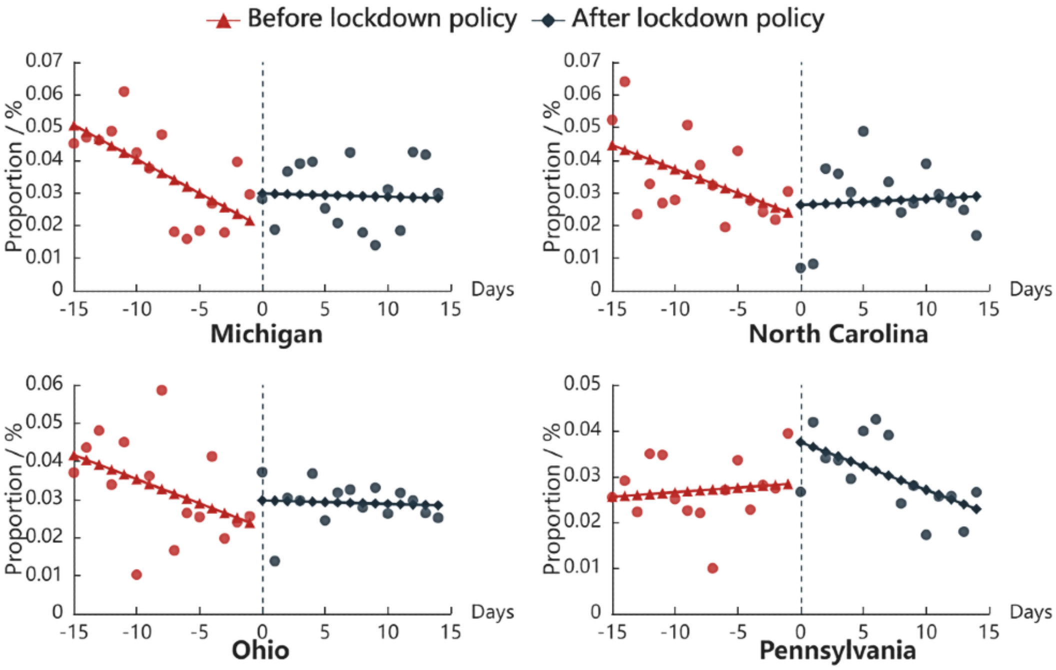


Table 2. The impact of lockdown policies on public mental health.

State	Date	Intercept	*P* value	Time[a]	*P* value	Policy[b]	*P* value	Time*policy[c]	*P* value	*F* statistic	*P* value
Michigan	March 24, 2020	0.0528	<.001	–0.0021	.003	–0.0214	.17	0.002	.03	4.669	.009
North Carolina	March 30, 2020	0.0461	<.001	–0.0015	.04	–0.0228	.16	0.0017	.08	2.509	.08
Ohio	March 23, 2020	0.0429	<.001	–0.0013	.03	–0.0117	.39	0.0012	.14	2.078	.13
Pennsylvania	April 1, 2020	0.0254	<.001	0.0002	.63	0.0288	.007	–0.0012	.04	3.033	.046

[a] Time: a continuous variable encoding the number of days in the research period (15 days before and after lockdown).

[b] Policy: a binary variable, encoded as 0 before the lockdown policy and 1 after the policy.

[c] Time*policy: the interaction term of time and policy.

Discussion

Principal Findings

We investigated public mental status for 2 and a half years since the beginning of the pandemic by analyzing topics of Twitter discussions, examining potential differences between health care workers and the general population, and studying the impacts of statewide lockdown policies. We found that anxiety and depression problems were frequently mentioned on Twitter during the study period, and the proportion of insomnia discussions increased continuously. The content analysis of mental health–related tweets revealed potential reasons: control measures, economic collapse, pressure from unemployment, and so on. Based on Twitter mentions, we found that all 4 mental health problems studied in this paper (addiction, anxiety, depression, and insomnia) were significantly more prevalent among health care workers than the general population. Finally, lockdown policies had different influences on public mental health status in different states. Among the 12 states studied, the negative effect of lockdown policies on public mental health was significant in Pennsylvania but not the other states.

Comparison to Prior Works

Consistent with research on similar topics, we found that COVID-19 has severely impacted public mental health and has dynamic influences on public mental health [30,42]. In addition, we found that the proportion of anxiety-related tweets increased to a substantial peak in March 2020 and remained low but stable for several months. A possible explanation is that the outbreak of COVID-19 caused various social problems, such as the shortage of necessities and unemployment, in the initial stage. These problems raised an intense but temporal public fear. As the pandemic continued, public concerns fell to normal as the early-stage issues were mitigated. Another possible explanation is that public emotional response diminishes as the pandemic intensifies, which is consistent with findings from Dyer and Kolic [43]. The remaining 2 peaks of anxiety-related tweets occurred during the presidential election (November 2020) and the fuel price surge (September 2021). The proportion of insomnia also increased during the study period. This observation is consistent with Shi et al [44], who reported an incremental prevalence of insomnia in the follow-up period (from July 8 to August 8, 2020) than the baseline period (from February 28 to March 11, 2020).

The topic analysis shows that the public was concerned about the pandemic, its prevention, and the economic and educational problems caused by COVID-19. Topics such as “social distancing,” “test results,” “world pandemic,” “COVID-19 news,” and “economic collapse” were both observed in our work and previous studies [32,45-49], which only analyzed tweets during the early stage of the pandemic (mainly from January to August 2020). Our study found 2 additional topics through a longer study period: “fuel problems” and “students’ pressure.” These topics correspond to the literature and observations: students (especially children and adolescents) are more vulnerable to psychological disorders [50], and fuel prices frequently fluctuated during COVID-19 [51].

Unlike previous studies that only compare the prevalence of mental health symptoms between health care workers and the general population [52], we also analyzed the topics they focused on. We confirmed that health care workers were more concerned by all the studied mental problems: anxiety, depression, insomnia, and addiction. Particularly, higher proportions of insomnia among health care workers have been extensively reported in the literature [53-57]. These increased problems may be attributed to higher risks of infection [15] and more intense environmental pressure (eg, increased workload, lack of medical supplies, etc) that they face. Health care professionals were more focused on discussing the virus and more interested in sharing news or experiences related to the pandemic, demonstrating a high level of concern about the pandemic, which may be associated with an increased rate of mental disorders.

Lockdown policies had various effects on mental health discussions across US states. In Pennsylvania, it showed a positive association with mental health discussions. However, an opposite association was observed in Michigan, North Carolina, and Ohio. The literature also suggests geographically different associations between local lockdown policies and public mental health. For example, Mittal et al [58] found that most Twitter users shared positive opinions toward lockdown policies in related tweets from March 22 to April 6, 2020, whereas another study focusing on Twitter users in Massachusetts found increased anxiety expression after the enforcement of the Massachusetts State of Emergency and US State of Emergency [59]. Notably, Wang et al [60] found that public sentiment toward lockdown policies was positive in most states (such as Michigan, North Carolina, and Pennsylvania) and negative in only a few states, including Ohio, which also demonstrates geographic variations of public reactions to lockdown policies.

Strengths and Limitations

Previous work on the same topic has either not focused on the subtypes of mental health problems or studied them over short periods. Our work fills these research gaps by focusing on more granular types of mental health problems over a more extended study period. We built a comprehensive pipeline, including temporal, geographic, and discussion topic analyses; comparisons of trends and topics of concern between groups; and the impact of lockdown policies. On top of the analyses, we released the code and contributed 2 lexicons that can be used to identify mental health issues and health care professionals from tweets.

We also acknowledge the following limitations. First, the evaluation of public mental health on social media is inevitably biased due to the underlying population distribution of social media users. For example, older adults and people with low socioeconomic status may have less access to social media. As a result, this study may not reflect accurate attributes of such subpopulations. However, given the sheer number of people on Twitter, the results of this study are helpful and valuable in tracking public mental health during the pandemic. Additionally, future work could consider sampling according to users’ age to avoid this problem. Second, professional psychologists must make precise diagnoses of mental health problems following official heuristics. Therefore, identifying patients using lexicons based on their tweets can introduce false cases. To validate the reliability of the lexicon, we had professional psychiatrists curate the lexicon based on sampled tweets. Third, tweets that contain keywords do not always reflect the user’s mental health status as they can instead be comments on the news or from other people. To reduce this noise, we removed tweets containing URLs in our preprocessing step, as these tweets were usually summarizations or quotes of different information sources.

Future Work

The proposed pipeline can be applied to study other public mental health problems, such as suicidal thoughts, posttraumatic stress disorder, paranoia, and so on. It can also be applied to studying characteristics of other cohorts, such as sex minority groups, college students, etc. Regarding the analyses, more data sources (eg, surveys and interviews) could be introduced to validate the conclusions of this research.

Conclusions

This study developed a comprehensive pipeline to use social media for tracking and analyzing public mental status during a pandemic. It also contributed 2 lexicons that could be used in future studies. We found that the impact of COVID-19 and the corresponding control measures on the public’s mental status is dynamic and shows variability among different cohorts regarding disease types, occupations, and regional groups. Health agencies and policy makers should primarily focus on depression (reported by 51.3% of the tweets) and insomnia (which has had an ever-increasing trend since the beginning of the pandemic), especially among health care workers. Our approach works efficiently, especially when primary studies and large-scale surveys are difficult to conduct. It can be extended to track the mental status of other cohorts (eg, sex minority groups and adolescents) or during different pandemic periods.

Acknowledgments

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Data Availability

The data and code supporting the study’s findings are available at https://github.com/zjumh/mental-health-during-COVID.

Authors' Contributions

ML and JY designed the study and drafted the manuscript. YH prepared the data, provided feedback on the study design, and helped draft and revise the manuscript. ML performed data and statistical analysis. YL and LW built the lexicon of mental health keywords. YL, LZ, and XL provided critical reviews. All authors reviewed the manuscript. ML takes responsibility for the integrity of the work.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary methods, pictures, and tables.
[DOCX File , 1138 KB-Multimedia Appendix 1]

Multimedia Appendix 2

The proportion and 95% CIs of mental health–related tweets in each state by month.
[XLSX File (Microsoft Excel File), 25 KB-Multimedia Appendix 2]

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Review

Conversational Agents in Health Care: Scoping Review of Their Behavior Change Techniques and Underpinning Theory

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Abstract

Background: Conversational agents (CAs) are increasingly used in health care to deliver behavior change interventions. Their evaluation often includes categorizing the behavior change techniques (BCTs) using a classification system of which the BCT Taxonomy v1 (BCTTv1) is one of the most common. Previous studies have presented descriptive summaries of behavior change interventions delivered by CAs, but no in-depth study reporting the use of BCTs in these interventions has been published to date.

Objective: This review aims to describe behavior change interventions delivered by CAs and to identify the BCTs and theories guiding their design.

Methods: We searched PubMed, Embase, Cochrane's Central Register of Controlled Trials, and the first 10 pages of Google and Google Scholar in April 2021. We included primary, experimental studies evaluating a behavior change intervention delivered by a CA. BCTs coding followed the BCTTv1. Two independent reviewers selected the studies and extracted the data. Descriptive analysis and frequent itemset mining to identify BCT clusters were performed.

Results: We included 47 studies reporting on mental health (n=19, 40%), chronic disorders (n=14, 30%), and lifestyle change (n=14, 30%) interventions. There were 20/47 embodied CAs (43%) and 27/47 CAs (57%) represented a female character. Most CAs were rule based (34/47, 72%). Experimental interventions included 63 BCTs, (mean 9 BCTs; range 2-21 BCTs), while comparisons included 32 BCTs (mean 2 BCTs; range 2-17 BCTs). Most interventions included BCTs 4.1 "Instruction on how to perform a behavior" (34/47, 72%), 3.3 "Social support" (emotional; 27/47, 57%), and 1.2 "Problem solving" (24/47, 51%). A total of 12/47 studies (26%) were informed by a behavior change theory, mainly the Transtheoretical Model and the Social Cognitive Theory. Studies using the same behavior change theory included different BCTs.

Conclusions: There is a need for the more explicit use of behavior change theories and improved reporting of BCTs in CA interventions to enhance the analysis of intervention effectiveness and improve the reproducibility of research.

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KEYWORDS

behavior change; behavior change techniques; conversational agent; chatbot; mHealth

Introduction

Conversational agents (CAs), or chatbots, are computer programs that simulate conversations with humans [1]. Although the first CAs were developed in the mid-1960s, it was not until the early 2000s that their availability and popularity markedly increased [2]. CAs can be used to automate a variety of tasks, such as the provision of news or weather forecasts and the facilitation of web-based shopping [3]. CAs may be deployed as stand-alone apps or websites, integrated into multifunctional apps, or included in messaging apps such as Telegram, Facebook Messenger, and Slack [2]. They may use text or voice-assisted interfaces or may include an embodied agent using virtual characters to simulate both verbal and nonverbal aspects of human communication [4]. CAs can be further classified as simple rule-based agents or smart, artificial intelligence (AI)–based agents using natural language processing or machine learning to generate the responses [2].

Following the trends in other industries, health care has seen increasing adoption of CAs in recent years [1]. Health care CAs are versatile tools able to cater to several health needs, such as providing timely information [5], supporting mental health disorder management [6,7], assisting with triage in clinical settings [8,9], supporting chronic disease self-management, or delivering lifestyle change interventions, such as physical activity [10] and dietary changes, that increasingly incorporate elements of behavior change in the intervention design. In general, health care CAs appear to be effective in improving individuals' outcomes [11,12] and are acceptable to users, who often describe them as friendly and trustworthy.

Increasingly, health care CAs are used to deliver behavior change interventions, defined as complex interventions, comprising an interplay of 1 or several heterogeneous behavior change techniques (BCTs) [13]. BCTs are "observable and replicable components designed to change behavior" [13]. BCTs are considered the smallest active ingredient in an intervention, and can be used alone or in combination with other BCTs [13]. Adequate categorization of the BCTs included in an intervention allows for more efficient coding, leading to easier replication when designing similar interventions [13]. Several methods to classify BCTs have been developed, of which the Behavior Change Technique Taxonomy version 1 (BCTTv1) [14] is the most established and commonly used.

Several reviews have synthesized the evidence about behavior change interventions delivered by digital health tools and CAs, such as a systematic review reporting on the use of BCTs in effective digital diabetes prevention interventions [15], a mapping review offering a description of the current uses of CAs for behavior change [16], and a scoping review describing the use of embodied CAs to support healthy lifestyle [17]. These reviews presented descriptive data, without an in-depth analysis of the type of BCTs used in the interventions, the use of behavior change theories to guide the interventions, the frequency with which each BCT was used, and potential associations between BCTs and intervention effectiveness. Therefore, this scoping review aims to analyze the use of BCTs in behavior change interventions delivered by CAs; specifically, it describes the health behaviors and disorders targeted by the intervention, describes the types of CAs used to deliver the behavior change interventions, identifies the theories or frameworks guiding the design of the behavior change interventions, identifies the most common type of BCTs used in CA-delivered interventions in health care, compares the BCTs employed in different types of CAs and for different health disorders, and compares the BCTs employed in the experimental and comparison interventions of studies evaluating CA-delivered behavior change interventions.

Methods

Overview

The scoping review was performed according to the Joanna Briggs Institute guidelines [18] and reported in alignment with the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) reporting guidelines (Multimedia Appendix 1) [19]. The protocol was registered in Open Science Framework Registries [20] in April 2021 and was published in a peer-reviewed journal in July 2021 [21].

Search Strategy

The search strategy was designed using a comprehensive list of words and phrases that define CAs (Multimedia Appendix 2). We searched PubMed, Embase (Ovid), and CENTRAL (Cochrane Central Register of Controlled Trials), from their inception, and the first 10 pages of Google and Google Scholar [22,23] on April 26, 2021.

Eligibility Criteria

This scoping review included primary, experimental studies in English evaluating the use of CAs to deliver health care interventions focusing on behavior change. Eligible study designs were randomized controlled trials (RCTs), quasi-RCTs, cluster-randomized trials, controlled before-and-after studies, uncontrolled before-and-after studies, interrupted time series, and pilot and feasibility studies. We excluded nonexperimental study designs, such as observational studies, qualitative studies, opinion pieces, editorials, conference abstracts, and secondary studies.

We included studies on text-based, voice-based, and embodied CAs, defined as conversational interfaces featuring a human-like avatar able to mimic the verbal and nonverbal components of a face-to-face conversation [24]. The eligible studies reported any health care intervention focused on behavior change to improve or promote a healthy lifestyle, or to support the management of physical or mental health conditions. Lastly, behavior change was an essential aspect of the eligible studies, with or without reference to an associated behavior change theory, in line with previous research in this area [25]. The BCTs were coded according to the BCTTv1 [14]. The taxonomy consists of 93 BCTs grouped into 16 distinct categories, aimed at providing a cross-domain template to facilitate research and intervention replication.

Screening, Data Extraction, and Analysis

Screening

Screening for eligibility was performed in 2 stages. First, 2 researchers (NYWL and WWTG) worked independently to screen the titles and abstracts of all retrieved studies using Covidence [26]. Studies were excluded if their focus or study design did not align with our predefined eligibility criteria. Studies included in the first round of screening were uploaded to EndNote X9 (Clarivate), and the full-text papers were retrieved and screened for eligibility by 3 researchers working independently (AIJ, NYWL, and WWTG). Discrepancies in any screening stage were resolved through discussions between the reviewers, or by engaging a fourth reviewer (LM). The search and screening processes were documented in a study selection flowchart [27].

Data Extraction

The data were extracted using a Microsoft Excel (Microsoft Corporation) form developed by the research team, based on a data extraction form used in a previous scoping review [2], and a section on behavior change was added. The form was piloted in 3 studies and amended according to team members' feedback before being used for data extraction. Reviewers worked in pairs (AIJ worked with LM and NYWL worked with WWTG) to extract data from 10 papers (20%) and individually for the remaining 42 papers (80%). Data extracted by all reviewers were subsequently reexamined by 2 researchers (LM and AIJ). Reviewers met regularly during this process to ensure a common understanding of the data extraction process and the concordance of the extracted data. The data extracted by each pair of reviewers were compared, and any disagreements were resolved through consensus or consultation with a third reviewer, acting as an arbiter.

The data extraction form contained the following items: first author, year of publication, title of the article, study design, target disorder, description of the behavior change intervention, CA name, delivery channel, dialog technique, input and output modalities, end goal of the intervention, use of behavior change theories or frameworks, and BCTs mapped according to the BCTTv1 [14].

Data Analysis

Data were analyzed using descriptive statistics and frequent itemset mining (FIM) to explore possible BCT clustering [28]. Data were presented in a diagrammatic or tabular form accompanied by a narrative summary.

Frequent Itemset Mining

The FIM analysis was performed by implementing the Apriori algorithm using the *arules* package version 1.7-1 [29] in R version 4.1.2 (R Foundation for Statistical Computing) [30]. FIM aims to find patterns or associations in a group of items (itemset) by sorting the items that frequently appear together in the data set. The analysis starts by calculating support (how frequently an item appears in the data set) and confidence (number of times individual items "x" and "y" appear together in the data set) thresholds and discarding any itemset with support or confidence values below the predetermined minimum threshold.

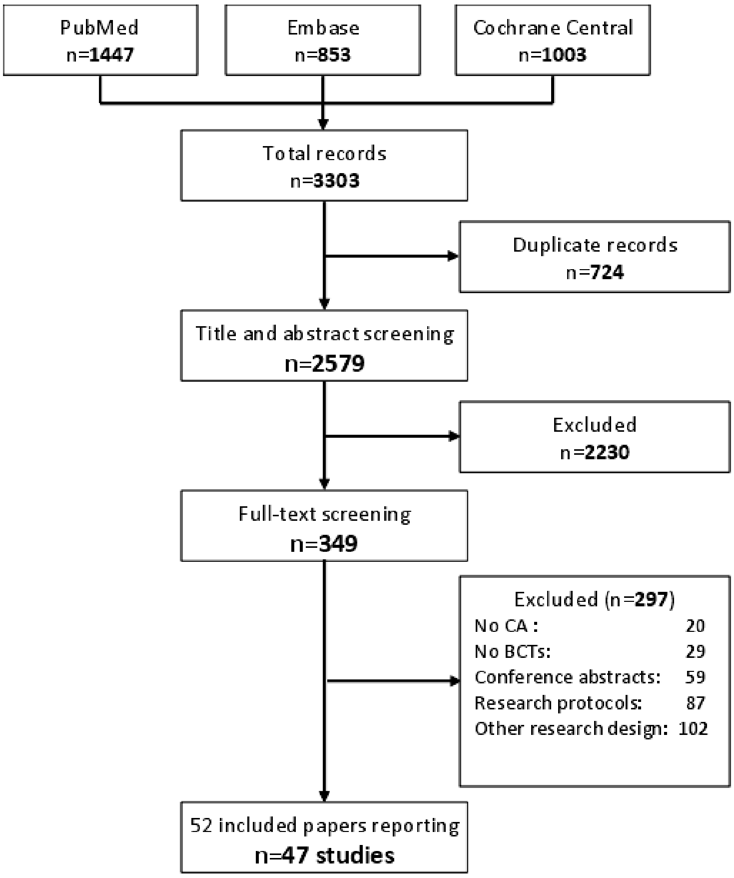
For this analysis, we assessed the 10 most frequently appearing patterns, for the overall data set and for each clinical domain. For the overall data set, the minimum threshold for algorithm support and confidence was set at 0.10 and 0.90, respectively, or itemset appearing in at least 10% of the data set (≥4 studies) and appearing together at least 90% of the time. For each clinical domain, the minimum thresholds were 0.20 for support and 0.90 for confidence to account for the fewer number of studies in each sub data set [31].

Results

Overview of Search Strategy

The search strategy retrieved 2579 papers after removing duplicates, of which 349 were eligible for full-text screening. Among these, 52 papers were finally included in this review. We reported 47 studies, as 4 studies were reported in 2 papers each and 1 study included a corrigendum. Figure 1 presents the study selection process.

Figure 1. Study selection flowchart. BCT: behavior change technique; CA: conversational agent.



Characteristics of the Included Studies

Multimedia Appendix 3 presents a summary of the studies included in this review [6,11,32-79]. Over half of the studies (26/47, 55%) were published from 2019 onward [11,32,34,37,40,42-46,48-55,58-61,65,66,71,72,76-78], including 6 published in the first quarter of 2021 [42,46,49,54,55,60]. All papers except 1 [32] were published in high-income countries, and 24/47 studies (51%) were published in the United States [6,32,34,36,39,43,45,47,48,51,52,54,56-58,61-64,67,69-75].

Most studies included a control group except 5/47 (11%) single-group pretest posttest trials [43,46,55,58,65,66], 3/47 (6%) feasibility studies [59-61], and 1/47 (2%) pilot study [48]. A total of 26/47 studies (55%) were RCTs [6,11,33,35-37,39-41,44,45,49,50,53,54,62-64,68-75,77,78]. In 36/47 studies (77%), the primary outcomes were associated with improvement of the target disorder [6,33,36,38-45,47-59,62-64,67,68,70-75,77-80], 5/47 studies (11%) reported technical-related primary outcomes (eg, technical performance, system crashes) [11,60,65,66,69,76], and 6/47 studies (13%) reported primarily user experience outcomes (eg, engagement with the CA, user satisfaction) [32,34,35,37,46,61]. Most interventions aimed to support treatment or monitoring (22/47, 47%) [6,33,35-44,46,48-50,53-55,59,60,80] or to promote healthy lifestyle change (18/47, 38%) [11,32,34,45,61-66,68-76,78,79]. Table 1 presents a summary of the included studies.

Table 1. Characteristics of included studies (N=47).

Study characteristics	Studies, n (%)
Year of publication	
Before 2019	21 (45)
2019 or after	26 (55)
Country	
United States	24 (51)
United Kingdom	6 (13)
Japan	3 (6)
Korea	3 (6)
Switzerland	3 (6)
Australia	2 (4)
France	1 (2)
Germany	1 (2)
India	1 (2)
Netherlands	1 (2)
Spain	1 (2)
Sweden	1 (2)
Study design	
Randomized controlled trial	26 (55)
Pilot study	9 (19)
Single-group pretest posttest trial	5 (11)
Feasibility study	5 (11)
Microrandomized controlled trials	1 (2)
Nonrandomized comparison study	1 (2)
Study outcomes	
Clinical	23 (49)
Clinical; user experience	12 (26)
User experience; clinical	6 (13)
Technical; clinical	3 (6)
Technical; clinical; user experience	2 (4)
Clinical; technical	1 (2)
Clinical focus of the interventions	
Lifestyle behavior change	17 (36)
Treatment and monitoring	16 (34)
Treatment and monitoring + education	4 (9)
Education	4 (9)
Education + lifestyle behavior change	3 (6)
Treatment and monitoring + lifestyle behavior change	2 (4)
Education + treatment and monitoring	1 (2)
Lifestyle behavior change + education	1 (2)
Clinical domains	
Mental health	19 (40)
Chronic disorders	14 (30)

Study characteristics	Studies, n (%)
Lifestyle modification	14 (30)

Clinical Domains

Mental Health Interventions

Most CAs focused on mental health (19/47, 40%) [6,32-47,79,80], either supporting mental well-being (5/19, 26%) for healthy individuals [46,47,79,80] or patients recovering from cancer [33]; enabling self-improvement interventions such as problem solving [34] or communications skills [35]; or assisting participants in the management of a mental health disorder (14/19, 74%) [6,36-46], including depression (with or without anxiety; 3/19, 16%) [6,36,37], emotional distress (2/19, 11%) [38,39], bipolar disorder [40], panic disorder [41], fear of heights [42], adult attention deficit disorder [43], substance use disorder [44], gambling [45], and social exclusion [46].

All except 2 interventions [44,47] included a control group, and 10/19 studies (53%) were RCTs [6,33-37,39,41,45,46]. A total of 6 studies included an active comparison with another digital intervention [34,38,39,46], a paper-based version of the CA intervention [40], or mood monitoring [33]. Besides, 6 studies provided information about the target disorder [6,35,37,41,43,48], and 10 experimental interventions (10/17, 59%) were reported as more effective than the comparisons [6,33-37,39,41,45,46].

Chronic Disorder Management Interventions

A total of 14/47 studies (30%) offered interventions focusing on a chronic disease other than mental illness [49-63]. Most studies (4/14, 29%) targeted a metabolic disorder including obesity (n=1) [63], prediabetes (n=1) [62], or type 2 diabetes (n=2) [51,56]. Three studies evaluated a pain management intervention for osteoarthritis (n=2) [57,58] or for general management of chronic pain (n=1) [54]. Other studies focused on asthma [61], atrial fibrillation [52,53], HIV [49], hypertension [50], insomnia [60], irritable bowel syndrome [55], and prostate cancer [59]. The interventions aimed to support treatment and monitoring tasks (8/14, 57%) or provide education (4/14, 29%).

Half of the included studies were feasibility or pilot studies, and 5/14 studies (36%) were RCTs [49,50,53,54,62]. Comparison interventions included a nurse-led instruction mirroring the CA intervention [50], physical activity monitoring using a pedometer [63], provision of information [57,58], treatment as usual [51-53], and waitlist controls [54,55]. Furthermore, 6/14 studies (43%) were single-group interventions without a comparison group [48,55,58-61]. Only 2 studies described the experimental interventions as more effective than the comparisons (2/8, 25%) [51,52,54].

Lifestyle Change Interventions

A total of 14/47 studies (30%) included interventions to support lifestyle modification [11,64-79], particularly increasing physical activity (10/14, 71%), either as the sole intervention (n=6) [64,69,74-77,79] or in combination with another approach such as diet improvement (n=2) [65-67], or diet improvement plus stress relief (n=1) [70]. Four studies (4/14, 29%) targeted an aspect of women's health including preconception care (n=3) [71-73,78] and breastfeeding support (n=1) [68]. One study offered a smoking cessation intervention [11]. In 12 studies, the interventions aimed to facilitate lifestyle change (12/14, 86%) [11,63-76,78], while 2 studies offered education [67,77].

Among this, 1/14 (7%) study was a single-group pretest-posttest trial [65,66], while most studies (11/14, 79%) were RCTs [11,63,64,68-75,77,78]. In 7/13 studies (54%) comparison interventions consisted of face-to-face versions of the intervention [74-76], abridged interventions that excluded the CA [11,64,65,70], or a similar version of the intervention with differing reward systems [77,79]. Other comparisons included information-only interventions (3/13, 23%), treatment as usual (1/13, 8%), or waitlists (2/13, 15%). Most experimental interventions were reported to be more effective than the comparisons (9/13, 69%).

Characteristics of CAs

Table 2 summarizes the characteristics of the included CAs.

A total of 39 CAs were included. Six CAs were reported in 2 or more manuscripts. Four CAs (Carmen [74-76], Tanya [52,53,68], Tess [37,62], and Todaki [41,43]) were reported in 2 papers each, and 2 CAs (Gabby [70-73] and MYLO [34,38,39]) were reported in 3 manuscripts. Three CAs were adapted for different target disorders. Embodied CA Tanya was used as an educational tool for patients with atrial fibrillation [52,53] and to offer breastfeeding support [68], CA Tess was used for mental health [37] and diabetes care [62], and Todaki was used to deliver CBT for panic disorder [41] and to manage adults with attention deficit disorder [43]. Finally, MYLO was used in student and older adult [38] populations by 2 distinct research groups.

The majority of CAs featured 1 or more anthropomorphic characteristics, such as the assignation of gender, name, or a human-like display. Most CAs (41/47, 87%) responded to a name, 27/47 CAs (57%) were presented as female agents, and 20/47 (43%) were embodied CAs. Most CAs used rule-based algorithms to design the flow of conversations, either by themselves (35/47, 75%) or complemented with AI (2/47, 4%). CAs were more often available through a smartphone app (14/47, 30%) or web page (13/47, 28%). In all but 3 CAs (44/47, 94%), the primary method for users' inputs was text; 7/47 of these CAs (15%) also accepted verbal or visual inputs, whereas 3/47 CAs (6%) received only verbal inputs. Almost 80% of all CAs (36/47, 77%) displayed a "coach-like" personality, characterized by an encouraging, motivating, and nurturing conversational style.

Table 2. Characteristics of CAs[a] (N=47).

CA characteristics	Values, n (%)
Type of CA	
Embodied CAs	20 (43)
No visual representation	12 (26)
Human-like cartoon avatar	10 (21)
Nonhuman cartoon avatar	5 (11)
Gender	
Female	27 (57)
No gender assigned (no avatar/no human avatar)	16 (34)
Male	2 (4)
Defined by the user	2 (4)
CA “level of intelligence”	
Rule-based CAs	34 (72)
Artificial intelligence CAs	9 (19)
Rule-based + artificial intelligence CAs	4 (9)
Dialog modality	
Predetermined text	28 (60)
Free text	8 (17)
Predetermined and free text	7 (15)
Not specified	4 (9)
Delivery channel	
Smartphone app	14 (30)
Web based	13 (28)
Desktop	7 (15)
Messaging apps	6 (13)
Two or more delivery channels	6 (13)
Tablet computer	1 (2)
Users’ input modalities	
Text	37 (79)
Text + others (voice, images, video)	7 (15)
Voice (± video)	3 (6)
CA output modalities	
Text + others (voice, images, video)	29 (62)
Text	15 (32)
Voice (± images, video)	3 (6)
CA personality	
Coach like	36 (77)
Health care professional like	9 (19)
Not specified	2 (4)

[a] CA: conversational agent.

Type of CA and Clinical Domains

Embodied CAs were used to deliver almost two-thirds (9/14, 64%) of the interventions promoting lifestyle modification [64,65,68-76], 43% (6/14) of the chronic disease management interventions [49,51-53,59,60,63] and only 26% (5/19) of the mental health interventions.

By contrast, most mental health CAs did not include an avatar (8/19, 42%) [34,35,38-40,45,47,81], or they were represented by a nonhuman avatar (5/19, 26%) [6,33,41,43,44]. Human-like avatars were present in 1/19 (5%) mental health intervention [37], 6/14 (43%) chronic disease management interventions [54,55,57,58,61,62], and 3/14 (21%) lifestyle change interventions [66,67,77,78].

Behavior Change Theories and Techniques

Behavior Change Theories

A total of 12/47 (26%) studies incorporated a behavior change theory to guide the CA intervention design, including 4/14 (29%) studies targeting a chronic disorder [51,54,59,61], 7/14 (50%) studies [65,71-76,78,79] evaluating a lifestyle change intervention, and 1/19 study (5%) [37] on mental health. The Transtheoretical Model was the most used behavior change theory, either alone [37,71-73,78] or together with the Social Cognitive Theory [51,65,74-76]. In addition, 4/19 (21%) mental health studies and 2/14 (14%) studies targeting a chronic disorder based their interventions on theories derived from the behavior [34,38,39], communication [57,58], learning [59], or psychological domains [33] (Table 3).

The use of theories aimed to guide the design of the intervention or to monitor participants' stages of change as they progressed through the intervention, as exemplified by 3 studies [71-73,78] using the Transtheoretical Model and 1 study using the Health Action Process Approach [54]. It was not clear how the use of theories influenced the intervention design or the choice of BCTs. For example, 4 studies using the Transtheoretical Model included a wide variety of BCTs, ranging from 3 [78] to 10 [72,73]. Similarly, 4 studies [51,65,74-76] using the Transtheoretical Model and the Social Cognitive Theory incorporated between 6 [51] and 19 [75,76] BCTs.

Table 3. Behavior change theories informing the CA[a]-based interventions (N=47).

Theories guiding CA interventions	Studies, n (%)
No theory	29 (62)
Behavior change theories	11 (23)
Transtheoretical Model	4 (9)
Transtheoretical Model + Social Cognitive Theory	4 (9)
Theory of Planned Behavior + Self-Determination Theory + Technology Acceptance theories	1 (2)
Health Action Process Approach	1 (2)
Habit Formation Model	1 (2)
Behavior change theories + other theories	1 (2)
Unified Theory of Acceptance and Use of Technology + Cognitive Theory Multimedia Learning	1 (2)
Other theories	6 (13)
Perceptual Control Theory	3 (6)
Communication Accommodation Theory	2 (4)
Stress and Coping Theory + Broaden and Build Theory of Positive Emotion	1 (2)

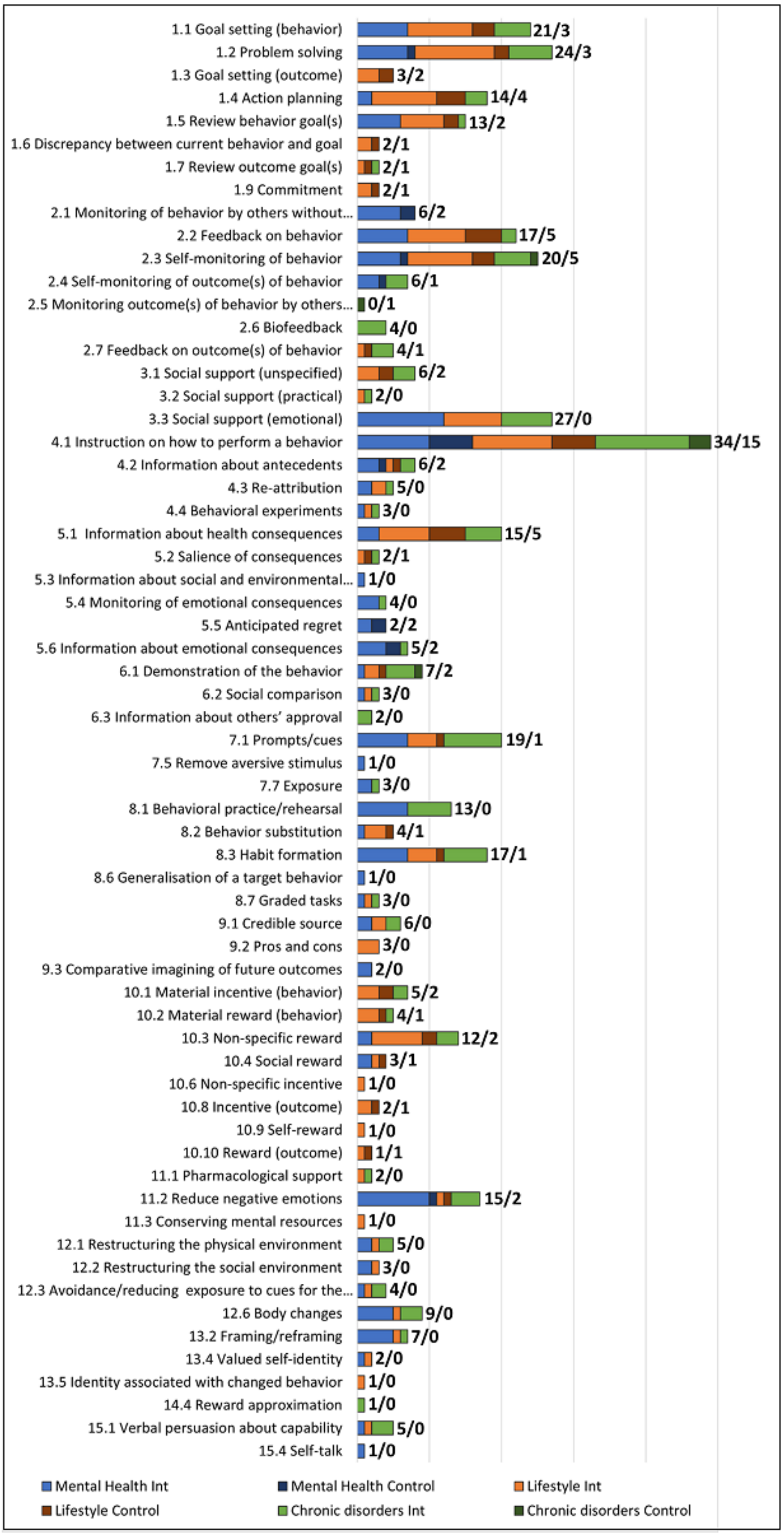
[a] CA: conversational agent.

Incorporated BCTs

The experimental interventions incorporated 63 BCTs from 15 categories, whereas the comparison interventions included 32 BCTs from 10 categories. However, only 24 BCTs were incorporated into experimental interventions in 5 or more studies, whereas 12 BCTs were reported in only 1 study each. The most incorporated BCT across interventions was 4.1 "Instruction on how to perform a behavior" (34/47, 72%), followed by 3.3 "Social support (emotional)" (27/47, 57%) and 1.2 "Problem solving" (24/47, 51%), whereas only 1 study included a BCT from category 14 (14.4 "Reward approximation") in the experimental intervention, and none included BCTs from category 16 "Covert learning." Figure 2 shows the frequency of presentation of all 63 BCTs in experimental and comparison interventions.

The average number of BCTs included in the experimental interventions was 9 (range 2-21 BCTs). By contrast, comparison interventions (n=38) included an average of 2 BCTs (range 0-17 BCTs).

Figure 2. Number of studies using each BCT in the experimental and comparison interventions. BCT: behavior change technique; Int: intervention.



Use of BCTs According to the Clinical Domain

The number of BCTs in experimental interventions was consistent across all clinical domains. Mental health interventions included an average of 8 BCTs (range 3-16 BCTs), chronic disorder management interventions included an average of 9 BCTs (range 2-18 BCTs), and lifestyle change interventions included an average of 10 BCTs (range 3-21 BCTs). The number of BCTs included in comparison interventions varied from an average of 2 BCTs in chronic disorder management (range 1-3 BCTs) and mental health interventions (range 1-2 BCTs) to a mean of 6 BCTs (range 1-17 BCTs) in lifestyle change interventions.

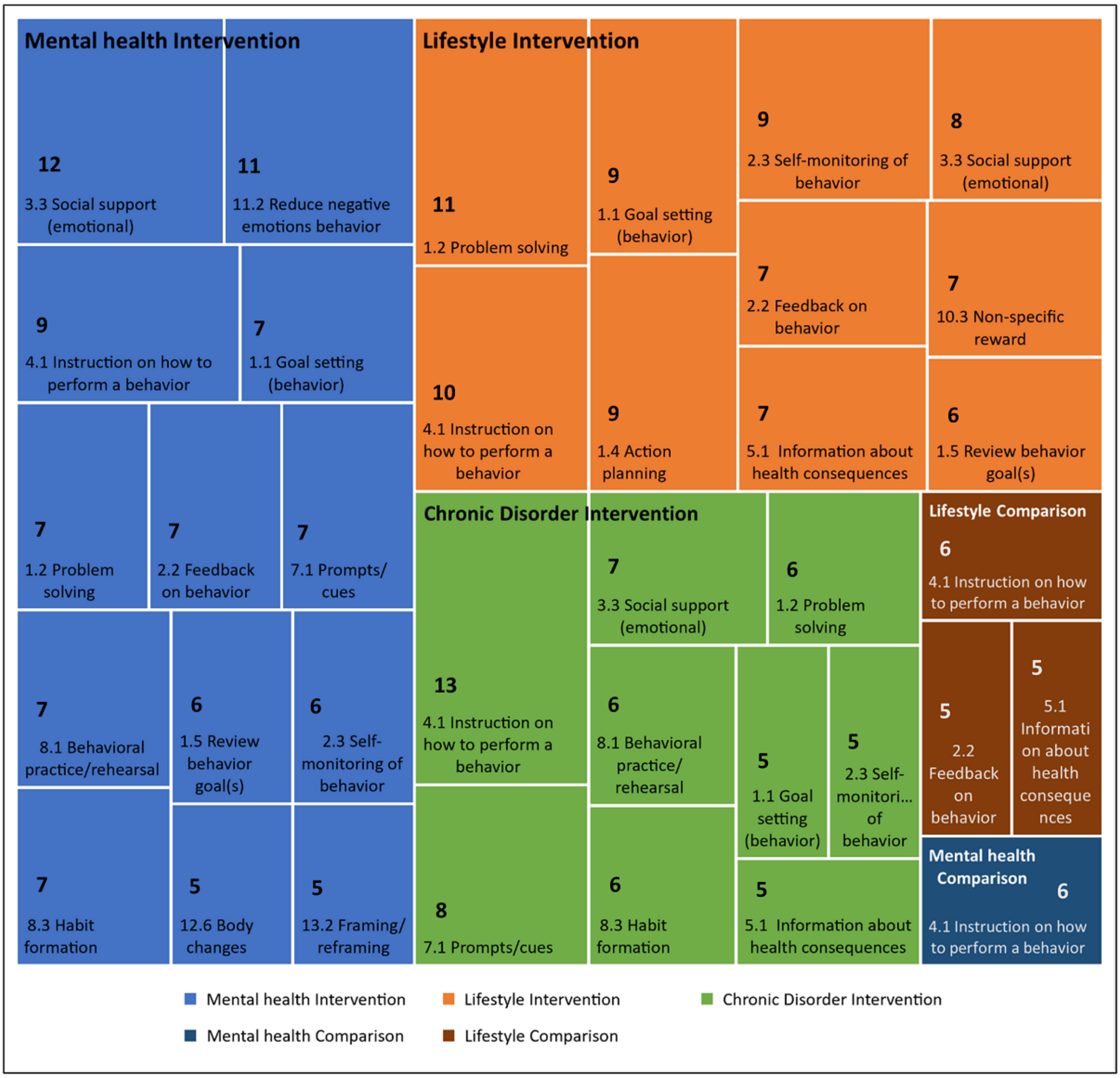
Mental health interventions incorporated 41 BCTs in experimental interventions. The most common BCTs were 3.3 “Social support (emotional)” (12/19, 63%), 11.2 “Reduce negative emotions” (11/19, 58%), 4.1 “Instruction on how to perform a behavior” (9/19, 47%), and BCTs 1.1 “Goal setting (behavior)," 1.2 "Problem solving," 2.2 "Feedback on behavior," 7.1 "Prompts/cues," 8.1 "Behavioral practice/rehearsal," and 8.3 "Habit formation" that were included in 7/19 (37%) studies each.

Lifestyle change interventions included 46 BCTs. The most common BCT was 1.2 "Problem solving" (11/14, 79%), followed by 4.1 "Instruction on how to perform a behavior" (10/14, 71%) and BCTs 1.1 "Goal setting (behavior)," 1.4 "Action planning," and 2.3 "Self-monitoring of behavior," included in 9/14 (64%) studies each.

Chronic disorder management interventions included a total of 41 BCTs. Almost all studies included BCT 4.1 "Instruction on how to perform a behavior" (13/14, 93%), followed by 7.1 "Prompts/cues" (8/14, 57%), 3.3 "Social support (emotional)" (7/14, 50%), and BCTs 1.2 "Problem solving," 8.1 "Behavioral practice/rehearsal," and 8.3 "Habit formation," all included in 6/14 studies (43%).

Figure 3 presents a summary of the most commonly used BCTs according to the clinical domain. Multimedia Appendix 4 presents a table summarizing the use of each BCT according to the clinical domain.

Figure 3. Commonly used BCTs according to the clinical domain. BCT: behavior change technique.



BCT Clustering According to the Clinical Domain Using FIM

The overall data set (n=47) generated 206 rules with an average support of 0.12, suggesting that the rules applied to at least 12% of the data set or about 6 studies. In general, 26% of the studies included BCTs 4.1 "Instruction on how to perform a behavior" and 8.1 "Behavioral practice/rehearsal," whereas 23% of the studies included BCTs 4.1 "Instruction on how to perform a behavior," 7.1 "Prompts/cues," and 8.3 "Habit formation."

The mental health domain (n=19) generated 45 rules with an average support of 0.22. About one-quarter of studies (26%) included 1 of 3 rules: the first itemset included BCTs 1.5

"Review behavior goal(s)," 2.2 "Feedback on behavior," and 3.3 "Social support"; followed by the itemset comprising BCTs 3.3 "Social support" and 12.6 "Body changes"; and the itemset containing BCTs 3.3 "Social support," 4.1 "Instruction on how to perform a behavior," and 11.2 "Reduce negative emotions." Conversely, the lifestyle change domain (n=14) generated 1322 rules with an average support of 0.24. About 64% of the studies included BCTs 1.2 "Problem solving" and 2.3 "Self-monitoring of behavior," whereas 57% of the studies also included BCT 1.1 "Goal-setting (behavior)." Finally, the chronic disorder management domain (n=14) generated 230 rules with an average support of 0.23. Most studies (93%) included BCT 4.1 "Instruction on how to perform a behavior," whereas 57% also included BCT 7.1 "Prompts/cues."

Multimedia Appendix 5 presents a table describing the top 10 itemsets for all included papers and each clinical domain.

Use of BCTs According to the CA Type

Interventions delivered by any type of CA included an average of 9 BCTs. However, the number of BCTs in experimental interventions varied by type of CA: embodied CAs included 2-19 BCTs, CAs represented by an avatar included 3-14 BCTs, and CAs with nonspecified or nonvisual representation incorporated 4-21 BCTs.

Embodied CAs included a total of 49 BCTs in the interventions. The most common BCTs were 3.3 "Social support (emotional)" (14/20, 70%), and BCTs 1.2 "Problem solving," 2.3 "Self-monitoring of behavior," and 4.1 "Instruction on how to perform a behavior," which were found in 13/20 (65%) studies each. By contrast, CAs represented by an avatar included a total of 38 BCTs in the interventions. The most common BCTs were 4.1 "Instruction on how to perform a behavior" (13/15, 87%), and BCTs 3.3 "Social support (emotional)" and 7.1 "Prompts/cues" included in 10/15 (67%) studies each. Finally, CAs with nonspecified or nonvisual representation incorporated a total of 47 BCTs. Four BCTs (1.2 "Problem solving," 4.1 "Instruction on how to perform a behavior," 7.1 "Prompts/cues," and 8.3 "Habit formation") were included in 6/12 (50%) studies, and BCT 11.2 "Reduce negative emotions" was included in 5/12 (42%) studies. Multimedia Appendix 6 provides further information about the use of BCTs according to the type of CA.

Discussion

Principal Findings

This scoping review included 47 studies reporting behavior change interventions delivered by CAs, targeting chronic disorders, lifestyle change, and mental health. The interventions included a total of 63 BCTs, but only 24 were consistently found in 5 or more interventions. The BCTs represented aspects of health education (BCT 4.1), self-management (BCTs 1.1, 1.2, and 2.3), and social support (BCT 3.3). Several behavior change theories informed the intervention design in 12/47 (26%) studies of the included studies. However, studies informed by the same theory employed different sets of BCTs. Our findings align with previous systematic reviews reporting that similar BCTs were frequently incorporated into effective lifestyle change interventions [82], or into digitally delivered interventions [15]. We did not find a relationship between the use of theories, the type of theory used, and the number and type of BCTs included in the interventions. Furthermore, a small number of studies [11,61] guided the intervention design, using modified BCT taxonomies that addressed smoking cessation [11] and diet modification [61]. These data suggest that the choice of BCTs may be primarily determined by the target behavior rather than the use of a behavior change theory. The impact of using a behavior change theory is nevertheless unclear. A 2010 systematic review [83] reported that the use of a behavior change theory was associated with increased effectiveness of the interventions, although just over 20% of studies included a theory. Conversely, a systematic review by Van Rhoon et al [15] reported the use of theories in 16/21 (76%) studies but did not assess intervention effectiveness. In addition, a recent overview of systematic reviews [84] reported the use of theories in the intervention design of 19%-52% of the included studies, although there was no clear association with the intervention effectiveness.

The categorization of studies in 3 distinct clinical domains suggested different prioritizations in mental health, lifestyle change, and chronic disorders, although the delivery of health education, evidenced by the frequent occurrence of BCTs 4.1 "Instruction on how to perform a behavior," 8.1 "Behavioral practice/rehearsal," and 8.3 "Habit formation," was consistent across all clinical domains.

Mental health interventions frequently included BCTs 3.3 "Social support (emotional)" and 11.2 "Reduce negative emotions." Specifically, BCT 3.3 may be associated with the use of psychotherapeutic techniques such as cognitive behavioral therapy or motivational interviewing, while the inclusion of BCT 11.2 suggests the use of relaxation techniques and mindfulness to support stress management and emotional regulation. Therefore, behavior change in mental health settings appeared to be closely interlinked with the therapeutic strategies. Concurrently, the inclusion of other BCTs, such as instructions to perform a behavior (BCT 4.1), goal setting (BCT 1.1) and reviews (BCT 1.5), problem solving (BCT 1.2), and feedback (BCT 2.2), may be aligned with general principles of patient participation in decision making [85], as well as highlight the importance of health education [86,87], particularly relevant in self-initiated digital interventions.

Lifestyle change interventions frequently included problem-solving (BCT 1.2) techniques to help users better understand their barriers to behavior change, and goal setting (BCT 1.1) and self-monitoring (BCT 2.3) to work toward the target behavior. These BCTs were often included together and this may suggest a synergistic relationship. At the same time, the importance of ensuring adequate health literacy to improve population outcomes was emphasized by the frequent inclusion of BCT 4.1 "Instruction on how to perform a behavior."

Chronic disorder management interventions favored not only the inclusion of instructional BCTs, such as guidance to perform a target behavior (BCT 4.1) but also reminders (BCT 7.1 "Prompts/cues") to facilitate the acquisition of new routines (BCT 8.3 "Behavioral practice/rehearsal"). Self-management of chronic illnesses is essential to ensure improved patient outcomes and adequate quality of life but requires that individuals engage in a steep learning curve as they adapt to living with a long-term condition and develop new habits.

In general, the relationship between the number and type of BCTs and the effectiveness of the interventions was inconsistent and appeared to be determined by the clinical domain. Effective lifestyle change interventions tended to include a higher number of BCTs, a finding that was not replicated in the other clinical domains. At the same time, lifestyle change interventions were comparatively more effective than those in other clinical domains, particularly chronic disorders. Effective interventions in the lifestyle change and mental health domains frequently included BCTs related to goal setting and planning, timely provision of feedback, health education, and rewards on completed tasks. Previous studies reported varied results. A 2017 systematic review of 48 studies [82] evaluating the management of overweight and obesity in adults found small pooled effect sizes for short- and long-term diet and physical activity interventions. Effective interventions included a larger number of BCTs, particularly BCTs encouraging goal setting and self-monitoring of behavior. Similarly, a systematic review on the BCTs and technical features of digital interventions for the prevention of type 2 diabetes [15] found that effective interventions included a larger number of BCTs or BCTs related to social support, goal setting, and feedback.

There was an unexpected relationship between the CA types and the clinical domain, manifested by a predominance of embodied CAs in lifestyle change interventions, and the use of nonhuman or nonavatar CAs in mental health interventions. The reasons for these findings are unclear and beyond the scope of this review; however, further research may help clarify the role of avatars, or virtual humans, if any, in delivering behavior change interventions. Other reviews have reported the use of embodied CAs to support mental health interventions, particularly autism [20,24], but methodological differences limit the comparisons with our findings. Provoost et al’s scoping review [4] used a broader definition of embodied CA, while a systematic review by Laranjo et al [87] included only AI-based CAs.

Strengths and Limitations

This scoping review has several strengths. First, we used a comprehensive literature search of peer-reviewed and gray literature that prioritized the sensitivity of the search terms to capture a broad range of publications reporting the use of CAs in health care. However, relevant studies may have been omitted. Second, we included studies reporting on a wide variety of physical and mental health conditions, and categorized the studies into 3 distinct clinical domains, revealing differences in the type of BCTs selected in each domain.

There are also some limitations. First, many studies did not provide exact BCT codes when describing the interventions, therefore categorization of BCTs was inferred from the paper’s description by the research team, based on thorough analysis, rigorous team discussion, and reviews to establish consensus. Second, given the descriptive nature of scoping reviews, we were unable to explore in more depth the relationship between the choice of BCTs and the effectiveness of the intervention, or the type of CA used to deliver the intervention.

Future Research and Practice Recommendations

This review has highlighted several areas that warrant further research. First, reporting guidelines to ensure accurate reporting of the BCTs included in behavior change interventions according to standardized taxonomies, such as the BCTTv1 [14], should be implemented. Such guidelines would facilitate reproducibility of research, assessment of active intervention components, and evidence synthesis. Second, further research is needed to increase our understanding of the impact of behavior change theories in the design of interventions, the choice of BCTs, and the effectiveness of the intervention. Third, the impact of CAs to deliver behavior change interventions should be further explored, particularly the influence of a conversational interface on engagement, adherence, and effectiveness of the intervention when compared with less interactive digital technologies. Furthermore, comparisons between rule-based CAs and those incorporating machine learning or natural language processing should be further investigated. Fourth, the possible role of the type of CA in delivering behavior change interventions, as suggested in our findings, should be further explored. Fifth, the relationship between the ideal combination of BCTs required to design effective interventions may be evaluated using data mining techniques such as FIM or multiple correspondent analysis. Lastly, the relationship between behavior change interventions and mental health requires further evaluation.

The use of CAs to deliver behavior change interventions appears promising, particularly to support lifestyle change, although better reporting of BCTs included in the interventions is warranted to facilitate analysis of active components, design more effective interventions, and ensure reproducibility of research. The role of CA types in delivering behavior change interventions should be further explored.

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Authors' Contributions

LTC conceptualized the study and provided supervision at all steps of research. LTC and LM designed the study. LM, AIJ, WWTG, and NYWL extracted data and conducted the analysis. LM and AIJ wrote the manuscript. MHRH, TK, RA, and SM provided critical review of the manuscript. All authors approved the final version of the manuscript and take accountability for all aspects of the work.

Conflicts of Interest

TK is affiliated with the Centre for Digital Health Interventions, a joint initiative of the Department of Management, Technology, and Economics at ETH Zurich and the Institute of Technology Management at the University of St.Gallen, which is funded in part by CSS, a Swiss health insurer. TK is also a cofounder of Pathmate Technologies, a university spin-off company that creates and delivers digital clinical pathways. However, neither CSS nor Pathmate Technologies was involved in this research. The other authors declare that they have no competing interests.

Multimedia Appendix 1

PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) checklist.
[DOCX File , 108 KB-Multimedia Appendix 1]

Multimedia Appendix 2

PubMed search strategy.
[DOCX File , 17 KB-Multimedia Appendix 2]

Multimedia Appendix 3

Characteristics of included studies.
[DOCX File , 42 KB-Multimedia Appendix 3]

Multimedia Appendix 4

Use of BCTs according to the clinical domain. BCT: behavior change technique.
[DOCX File , 25 KB-Multimedia Appendix 4]

Multimedia Appendix 5

Frequent Itemset Mining (FIM).
[DOCX File , 20 KB-Multimedia Appendix 5]

Multimedia Appendix 6

Use of BCTs according to the CA type. BCT: behavior change technique; CA: conversational agent.
[DOCX File , 426 KB-Multimedia Appendix 6]

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Abbreviations

AI: artificial intelligence
BCT: behavior change technique
BCTTv1: Behavior Change Technique Taxonomy version 1
CA: conversational agent
CENTRAL: Cochrane Central Register of Controlled Trials
FIM: frequent itemset mining
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews

RCT: randomized controlled trial

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Original Paper

Digital Technology Access and Health-Related Internet Use Among People Experiencing Homelessness in Hungary: Quantitative Survey

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Abstract

Background: In recent years, there has been an increase in the use of digital technology for personal health and well-being. Previous research has revealed that these technologies might provide vulnerable populations, including those who are homeless, better access to health services and thus a greater chance of more personalized care.

Objective: However, little is known about the relationship between technology and health among people experiencing homelessness in Central and Eastern Europe. This study is part of a series of studies by the Digital Health Research Group at Semmelweis University (Budapest, Hungary) in cooperation with the Hungarian Charity Service of the Order of Malta; it aims to assess the existing technological resources available for the homeless population and their health-related internet use characteristics to set the ground for potential health policy interventions, enabling better access to health services by strengthening the digital components of the existing health care system.

Methods: Between April 19, 2021, and August 11, 2021, a total of 662 people from 28 institutions providing social services for people experiencing homelessness in Budapest, Hungary, were surveyed about their access to digital tools and internet use patterns. For selected questions, the responses of a representative sample of the Hungarian population were used for comparison as the reference group. Chi-square tests and logistic regression analyses were performed to identify variables affecting internet use for health-related reasons.

Results: The results demonstrated a considerable level of internet use in the homeless population; 52.9% (350/662) of the respondents used the internet frequently compared with 81.3% (1220/1500) of the respondents in the reference group. Among the homeless group, 69.6% (461/662) of the respondents reported mobile phone ownership, and 39.9% (264/662) of the respondents added that it had a smartphone function. Moreover, 11.2% (70/662) of the respondents had already used a health mobile app, and 34.6% (229/662) of the respondents had used the internet for medical purposes. On the basis of these characteristics, we were able to identify a broadly defined, digitally engaged group among people experiencing homelessness (129/662, 19.5%). This subpopulation was inclined to benefit from digitalization related to their personal health. Multivariate analysis demonstrated that internet use for health reasons was more significant for younger respondents, women, those with higher levels of education, and those with no chronic conditions.

Conclusions: Although compared with the general population, health-related internet use statistics are lower, our results show that the idea of involving homeless populations in the digital health ecosystem is viable, especially if barriers to access are systematically reduced. The results show that digital health services have great promise as another tool in the hands of community shelters for keeping homeless populations well ingrained in the social infrastructure as well as for disease prevention purposes.

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KEYWORDS

homelessness; digital technology; internet; access; internet use; homeless shelter; digital equity; mobile phone

Introduction

Homelessness in Hungary

Homelessness is a complex set of social, economic, and health challenges at both the individual and community levels. The term itself represents a generic expression for people who live on the streets (rough sleepers), people without permanent living arrangements, or those with inadequate habitations. In Hungary, according to the law, people experiencing homelessness are persons without any registered place of residence or whose registered place of residence is the accommodation for homeless individuals [1].

Although previous research has acknowledged the difficulty in the assessment of the scale of homelessness across Europe [2], it has been noted that the number of people experiencing homelessness is increasing in the European Union [3]; approximately 700,000 people are homeless on any given day, and this number has increased by 70% in the last 10 years [1]. In Hungary, systematic resources on homeless populations are scarce, meaning that there is a lack of basic demographic studies, and no public databases are available on the estimates of the size of the group.

Homelessness, Inequalities, and Health

The state of homelessness can be described as both a cause and a consequence of poor health status, social exclusion, and marginalization [2]. According to research, the health effects produced by homelessness include significantly higher rates of bacterial and viral infections, diabetes, hypertension, and cardiovascular disease compared with populations with adequate housing options [4]. Similar results emerged when looking at the life expectancy of homeless and general populations; on average, a decrease by 11 years for homeless men and 15 years for homeless women was measured [4].

Furthermore, earlier research suggests that despite the poor health status of homeless populations, health services designed for their treatment are often described as insufficient and limited in their accessibility, availability, and appropriateness [5]. An earlier study conducted in the United States also noted a medicalization process among homeless services and the practice of providing services for homeless individuals to conform them to specific behaviors [6]. As a result, underdiagnoses and undertreatment of health conditions are strongly prevalent [7,8], significantly underpinning the necessity to develop novel approaches and interventions to address health inequalities that have existed for decades, as such disparities lower life expectancy and strengthen social exclusion.

Digital Tools and Digital Inclusion as Potential New Approaches

The COVID-19 pandemic has accelerated the adoption of digital technologies in health care systems in many countries that experienced various types of lockdowns between 2020 and 2022. The World Health Organization's assessment of the European digital health landscape describes that during the COVID-19 pandemic, many digital health tools moved from being viewed as a potential opportunity to becoming an immediate necessity, and their use increased substantially [9]. The pandemic is also believed to have demonstrated that the lack of broadband access to the internet has an influence on the social determinants of health [10].

Although the expansion of the digital component of health care systems is considered a forward-looking development, it has raised accessibility issues for vulnerable strata, such as homeless populations. Physical barriers in the form of lack of access to technological equipment, as well as educational barriers in being unable to use the technology, may contribute to the inaccessibility of services and resources, further depriving a segment of the population that is already marginalized. This very possibility would negatively impact behaviors and stressors and might further contribute to poorer health outcomes for those who are digitally excluded, widening the already existent digital inequality landscape [11,12].

A systematic review analyzing studies from 2015 to 2021 with the research questions (1) "What mobile health–related technology is used by homeless populations?" and (2) "What is the health impact of mobile technology for homeless populations?" found that most homeless participants across the 17 studies included in the review owned a mobile phone or smartphone and 80% (1205/1507) owned a mobile phone. Age appeared to be a significant factor regarding ownership and use, and confirmatory responses to questions on access to mobile internet services, smartphone functions, and apps dropped significantly [11]. Heaslip et al [11] mentioned the lack of charging points, limited or no access to data traffic, and anxiety over potential theft and harassment as barriers to mobile phone use. Other barriers presented were privacy concerns and distrust in the management of data, tracking of information, the government, and the "system" [11]. Beyond physical barriers and trust issues, access to digital health might be hindered by the lack of skills required for their use. Populations at risk for limited health literacy, such as homeless populations [13], are similarly vulnerable to having challenges with digital tools [14]. Poor IT skills among homeless populations have been implicated in poor mental health outcomes [14].

However, despite existing barriers, several studies have reported the interest of the homeless population in digital health tools [11]. Atkins et al [15] noted that their study participants were positive about using a mobile phone to obtain advice and help address issues such as depression, anxiety, self-harm, abuse, substance use, emotional problems, insomnia, and stress. In all, 3 studies showed that interest in appointment and prescription reminders among homeless populations is prevalent [15-17].

Early Examples: Attitudes Toward Digital Health Among Homeless Individuals in Hungary

As the above literature review supports, physical barriers to accessing technologies and educational barriers in relation to digital technologies might strengthen the already existing digital inequalities to the detriment of homeless population, whereas the use of the internet was shown to be significantly associated with better self-rated health in older adults [18,19] and more favorable health behaviors concerning cancer prevention [20]. Studies conducted mainly in the United States, Canada, and the United Kingdom, focusing less on continental Europe or lower-income countries, suggest these findings [11].

The main aim of this study was to examine whether these assumptions are valid in the context of Hungarian homeless population and to suggest recommendations for public health policy makers. Thus, the main research questions were whether (1) homeless populations use digital tools for health-related reasons in Hungary and (2) clearly identifiable variables, such as the institutional and social services environment, age, education, or other demographic data can be associated with such use. In the case of social institutional characteristics, we assume that existing barriers and potentials of unique institutions to digital inclusion might be considered and offered as background information for potential interventions for digital inclusion, which we aim to examine as part of the second research question.

This study fits into a broader set of research undertaken by the joint action of the Digital Health Research Group at Semmelweis University and the Hungarian Charity Service of the Order of Malta (HCSOM), aiming to analyze the relationship between digital health and homeless populations in Hungary. Previous research has studied the attitudes of homeless individuals toward telecare services, with the main finding being that trust in the general health care system leads to trust in digital health solutions [12]. This study also served as an assessment tool for analyzing the viability of a telecare system planned to be launched by the HCSOM.

Methods

Participating Institutions

Homelessness can be categorized using different methods; Edgar et al [21] identified 6 different groups. As for the classification and definition of “homelessness” in this study, we decided to include all individuals who had engaged with institutions providing homeless services according to the categories of the European Typology of Homelessness and Housing Exclusion, the standard used by European Union member states for reporting on homelessness and precarious housing circumstances [22].

Altogether, 6 types of institutions providing social services for homeless populations participated in the study (Table 1). Although family shelters are not considered a part of the homeless social services according to the law in Hungary (these institutions are operated under the Child Protection Act), they were included in the study based on the housing instability of their clients and the temporary nature of the provided accommodation.

Table 1. List and characteristics of participating institutions and social services (N=662).

Type of service	ETHOS[a] classification	Client	Participating institutions (N=28), n (%)	Participants, n (%)
Street outreach service	1.1	Rough sleepers	4 (14)	106 (16)
Day shelter	N/A[b]	Homeless persons (no accommodation offered)	5 (17.9)	167 (25.2)
Night shelter	2.1	Homeless persons (accommodation offered only for short periods)	7 (25)	145 (21.9)
Temporary shelter	3.2-7.2	Homeless persons (accommodation offered for longer periods with a maximum of 1+1 years)	7 (25)	178 (26.8)
Temporary shelter with a focus on health improvement	3.2-7.2	Homeless persons with severe health status (accommodation offered for longer periods with a maximum of 1+1 years)	2 (7.1)	40 (6)
Family shelter	7.2	Homeless families (accommodation offered for longer periods with a maximum of 1+1 or 2 years)	3 (10.7)	48 (72.5)

[a] ETHOS: European Typology of Homelessness and Housing Exclusion.

[b] N/A: not applicable.

The Surveying Process

The research team formulated a questionnaire (Multimedia Appendix 1) based on the Digital Inclusion Survey used in a report by Pathway, the United Kingdom’s leading homeless health care charity [23]. The original questionnaire was translated to Hungarian by 2 independent medical translators, and their versions were merged by a consensus meeting. This Hungarian draft questionnaire was adapted to the local specialties during a workshop with social workers of the HCSOM. Before administering the questionnaire to a wider population, a test survey with 10 participants was completed to check its clarity and intelligibility. The selection of test group members was managed by one of the participating social establishments. To maximize the impact of the test survey, it was requested to use a diverse group of homeless clients with respect to gender, age, health status, and type of accommodation. Subtle changes in wording were applied during the finalization of the survey material based on this feedback.

Between April 19, 2021, and August 11, 2021, the research group surveyed 662 people in Budapest, Hungary, with the cooperation of 28 institutions that provide various social services for homeless individuals. The respondents participated in the study on a voluntary basis. Our research team contacted the institutions, and their social workers asked homeless clients to fill out the questionnaires in a paper and pencil form. Social workers were allowed to help in the interpretation of questions but were not allowed to influence the answers. When a respondent was using multiple social services (eg, day and night shelter), we asked individuals to complete the questionnaire at the institution that provided the most relevant service for them to reduce duplicate responses.

The questionnaire enquired about sociodemographic data (age, gender, level of education, self-defined homelessness, and length of being homeless) and health status (frequency of medical visits, existing medical diagnoses, and self-assessment of health status). Questions 6-10 were used to gather information about health knowledge and general literacy skills, whereas questions 11-13 and 14-17 asked about access to mobile phones and the internet. Next, questions 18-21 inquired about internet use habits and questions 22 and 23 about potential barriers and enablers of internet access. Question 24 presented a set of statements about digital health literacy, and question 25 asked about mobile apps.

Reference Group

For the questions "How frequently do you visit a medical doctor/do you use medical services?" "Do you have any chronic disease or a long-term health problem?" "Have you ever used the Internet for any purpose? If yes, have you used it in the last six months?" and "Have you ever used any health-related mobile applications?" the responses of a representative sample of the Hungarian population were used as a reference group to provide more context. This representative survey was conducted by the Digital Health Working Group of Behavioral Institute of Semmelweis University between October 5, 2021, and October 13, 2021, and consisted of responses from 1500 Hungarian people in the framework of the "E-Patients in Hungary" study [24].

Statistical Analysis

As part of the quantitative analysis, we descriptively examined frequencies, averages, and percentage distributions. Use of technology and its various correlates (demographic variables and variables related to access to health services) were compared with a single variable analysis using Pearson chi-square test, with a significance level of *P*<.05.

In the multivariate analysis, a binary logistic regression model was used. The method was used to examine the background factors for the question "Have you ever used the internet for health reasons?" which is the dependent variable. The control variables were gender, type of institution and social service, level of education, age, frequency of medical visits, and prevalence of chronic illness. Independent variables affecting the dependent variables were selected using enter regression. The significance of the regression coefficients of the given variables was described using *P* value of the Wald. Variables with *P*<.05 were retained in the final model.

Data were analyzed using SPSS (version 26; IBM Corp) statistics software [25].

Ethics Approval

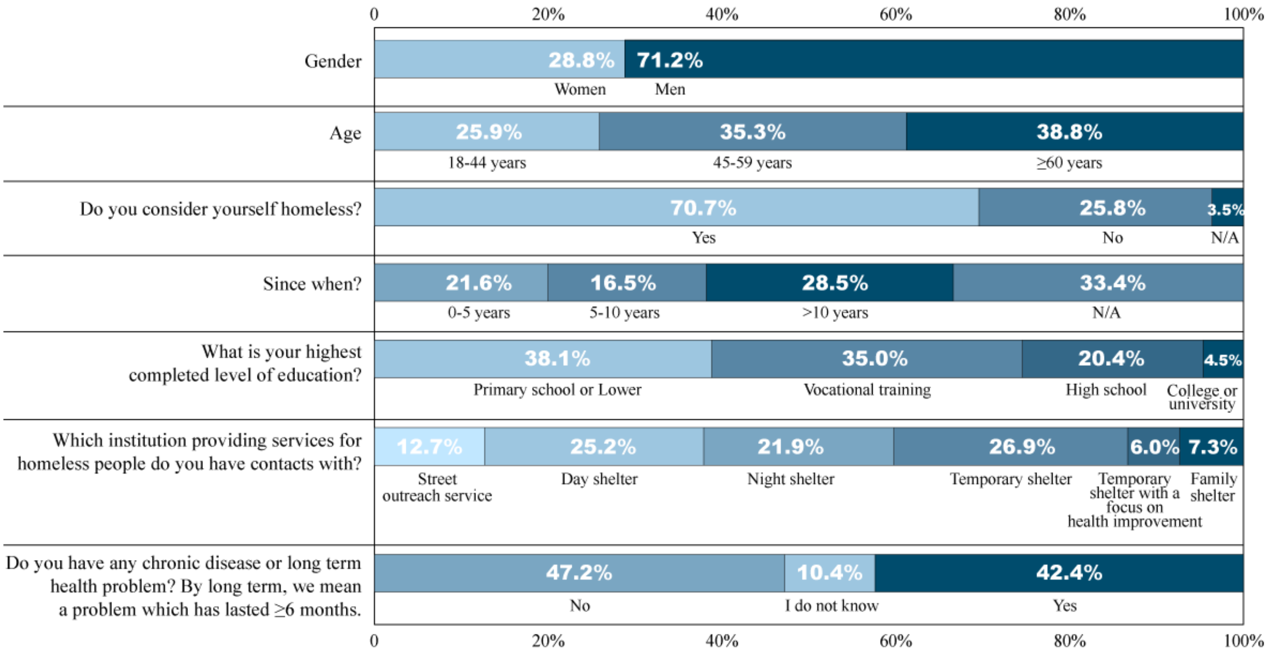
The data collection was anonymized. Written informed consent statements were obtained in all cases, and ethics approval for the study was issued under TUKEB:133/2020 and IV/10927/2020/EKU by the Scientific Research Ethics Committee of the Medical Research Council of Hungary.

Results

Demographics

The research group surveyed 662 adults in Budapest, Hungary, recruited from 28 social institutions providing services for people experiencing homelessness. Of the respondents, 71.2% (459/662) were men. Of the recruited participants, 38.8% (247/662) represented the age group of >60 years, whereas participants aged 18 to 44 years accounted for only 25.9% (165/662). The mean age was 53.9 years with an SD of 13.08 years. The majority, 70.7% (468/662), considered themselves homeless, whereas 25.8% (171/662) of the respondents did not consider themselves homeless. A total of 66.6% (441/662) of respondents also indicated how long they were experiencing homelessness: 21.6% (143/662) had been homeless for 1 to 5 years, 16.5% (109/662) for 5 to 10 years, and 28.5% (189/662) for >10 years, with a mean of 11.35 years and an SD of 9.27 years. Most of the respondents had only primary education (252/662, 38.1%) or vocational training (232/662, 35%), whereas 20.4% (135/662) of the respondents had graduated high school, and 4.5% (30/662) of the respondents said they had completed their college or university education. The key demographic parameters are shown in Figure 1.

Figure 1. Key demographics of the homeless group. N/A: not applicable.



Health Status

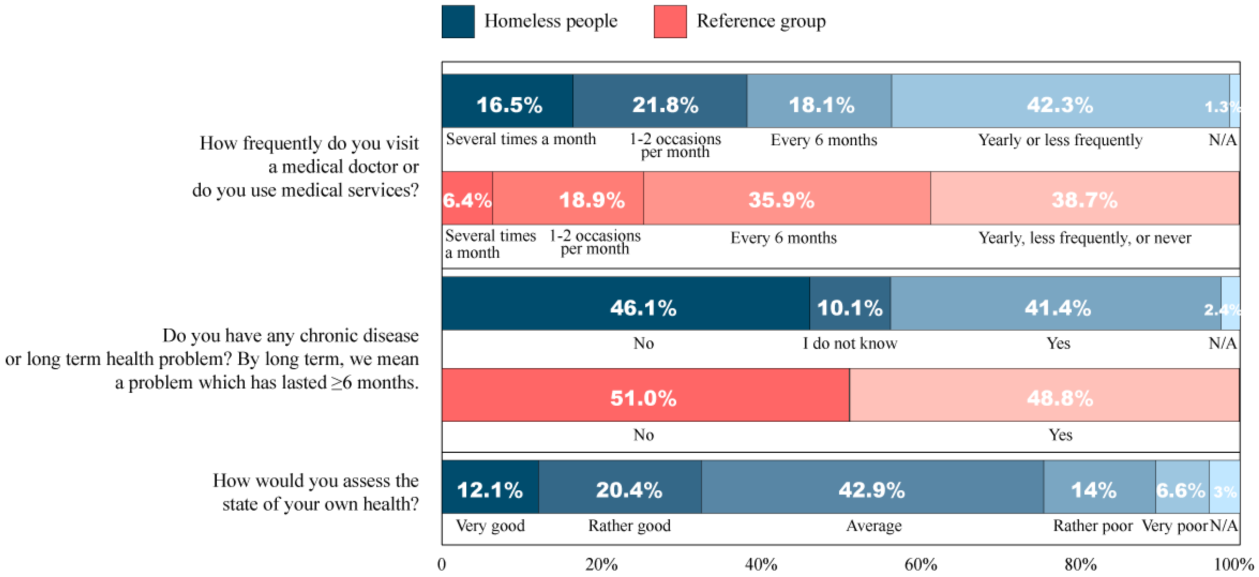
As key independent variables, we surveyed the health status of the respondents and compared them with the data of the reference group. A total of 16.5% (109/662) of the respondents said that they visited their physician or used health care services more than once a month, which was relatively frequent compared with the reference group, wherein 6.4% (96/1500) respondents said they visited their physician weekly, more than once a week, or more than once a month. Within the homeless group, 21.8% (144/662) of the respondents said they visited their physician every 1 or 2 months, which is almost the same as the result for the reference group (284/1500, 18.9%). The main difference was that most of the homeless group, 42.3% (280/662), visited their physician only yearly or less frequently, whereas 35.9% (539/1500) of the reference group said they used health care services 1 to 2 occasions per year, and only 13% (195/1500) of the respondents reported going to the physician's office yearly.

Of the homeless participants, 46.1% (305/662) reported no chronic diseases or long-term illnesses requiring treatment lasting for ≥6 months, but there was only a slight difference in the distribution of those who did (274/662, 41.4%). Those who had a chronic disease listed chronic obstructive pulmonary disease, asthma, diabetes, hypertension, mental illnesses, and chronic heart conditions among others. For the reference group, 48.8% (732/1500) of the respondents responded that they had a long-term illness, whereas 51% (765/1500) said that they did not have any.

Regarding the homeless group evaluating their own health, 12.1% (80/662) and 20.4% (135/662) of the respondents said "very good" or "rather good," respectively, whereas most people (284/662, 42.9%) considered it "average." In addition, 14% (93/662) and 6.6% (44/662) of the respondents said they considered their health "rather poor" and "very poor," respectively (Figure 2).

When asked about what channels they were using when informing about medical issues, 20.5% (136/662) of the respondents said they were searching for it on the web. This came in third after asking the primary care physician for information (352/662, 53.1%) and the social worker in the social institution (260/662, 39.2%), which meant they might have been consulting the internet for medical purposes more often than they asked their family members or friends (108/662, 16.3%).

Figure 2. Key demographics concerning health status of the homeless group. N/A: not applicable.



Access to Technology and Web-Based Services

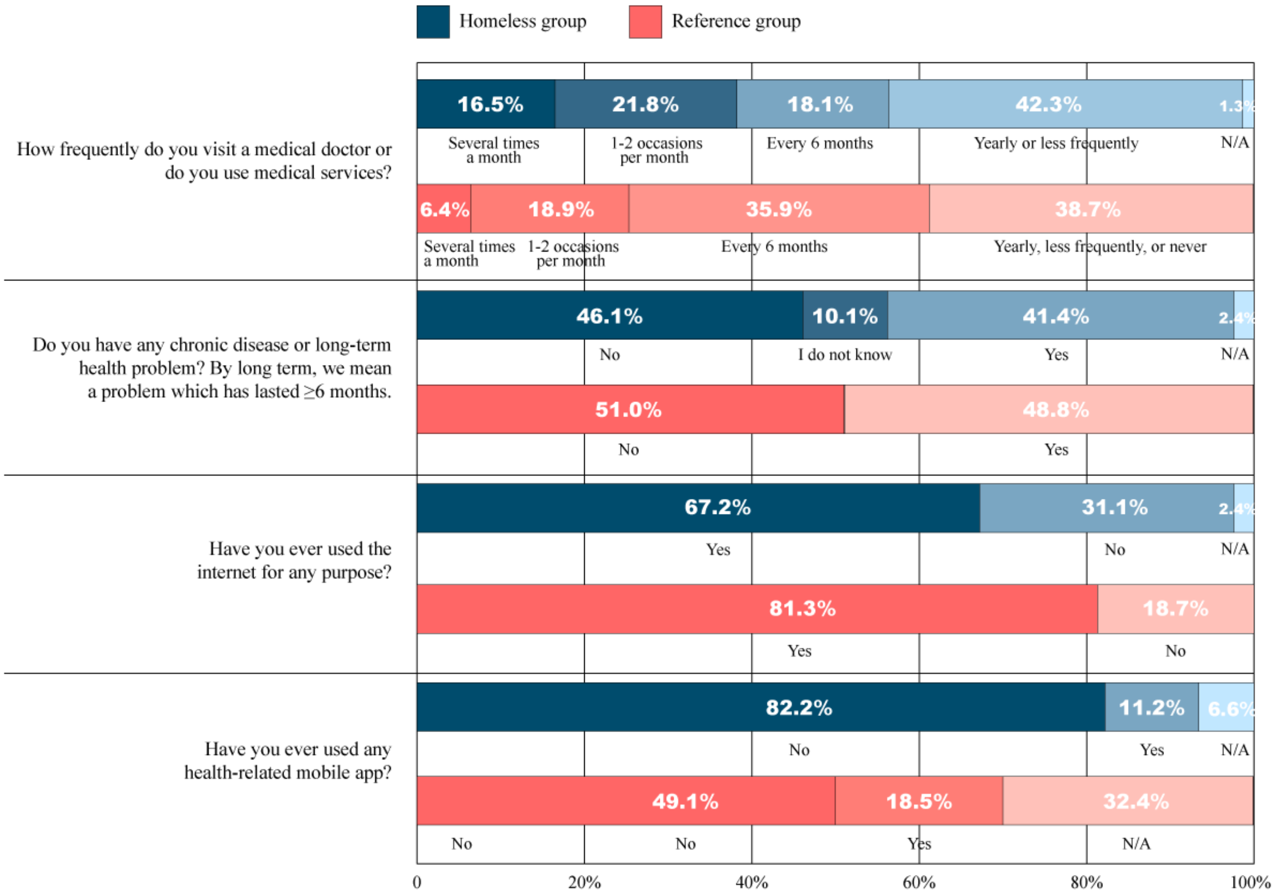
For the multiple-choice question, “How do you access the internet at the moment?” 98 people (98/551, 17.8%) said that they had their own smartphone with a data contract, 100 people (100/551, 18.1%) said that they had their own smartphone using a pay-as-you-go facility, 118 people (118/551, 21.4%) said that they had their own smartphone and accessed the internet via free Wi-Fi hotspots, 136 people (136/551, 24.7%) said that they accessed the internet through a publicly available PC in social institutions or shelters, only 15 people (15/551, 2.7%) said that they had their own PC, and 84 people (84/551, 15.2%) responded with “Other.” In the latter category, answers included the use of other people’s phones, “internet cafés,” or ownership of a tablet, but a frequent response was that they had no means to access it, they did not care, or they did not use it. Only a few people access the internet in multiple ways (70/662, 10.6% in 2 ways, 12/662, 1.8% in 3 ways, and 4/662, 0.6% in 4 ways), while more than half of the respondents have access to it in only one way (359/662, 54.2%) or in no way (217/662, 32.8%).

In the reference group, 81.3% (1220/1500) of the respondents said that they used the internet frequently, whereas in the homeless group, 67.2% (445/662) of the responses were affirmative when asked if they ever used it for any purpose (Figure 3). Of those who used it, 52.9% (350/662) said they had used it in the past 6 months. However, daily use was significantly less, 34.6% (229/662), and an additional 10.6% (70/662) of the respondents said that they were using it more times a week. No correlation with age, type of institution and social service, gender, education, length of homelessness, or frequency of medical visits was found after cross-tabulation.

Most respondents of the homeless population (461/662, 69.6%) said that they owned a mobile phone. In addition, 39.9% (264/662) of the respondents also said that their mobile phone had a smartphone function, and 11.2% (74/662) of the respondents of the homeless group said that they had used at least one mobile health (mHealth) app, whereas this ratio was 18.5% (277/1500) in the reference group. In the homeless group, those who responded positively to the questions mentioned using apps for step counting, accessing emergency help, obtaining relevant medical information, and providing health data. mHealth apps were associated with 2 variables. Chi-square test results were significant for the type of institution and social service (P=.02) and frequency of medical visits (P=.03), meaning that mHealth apps were more frequently used in temporary shelters than in any other type of institution and social service, and with an increasing frequency of medical visits, the frequency of mHealth app use also increased.

For the question of how experienced they considered themselves when it came to internet use, 10% (66/662) of the respondents said “very much so,” 14.5% (96/662) of the respondents said “rather experienced,” and 21.5% (142/662) of the respondents said “mediocre,” whereas 10.3% (68/662) of the respondents considered themselves “rather not experienced,” and the most prevalent response, 35.3% (234/662), was “not at all” experienced. A total of 8.5% (56/662) did not respond to the question. When cross-tabulating self-reported technology literacy with age, education, gender, homelessness, type of institution and social service, and frequency of medical visits, chi-square tests were significant for age (P<.001), type of institution and social service (P=.01), and education (P=.01), meaning that with age, the level of self-reported technological literacy decreased, whereas with higher levels of education, self-identified technology literacy increased. Most of the respondents did not consider themselves as experienced technology users; this most significantly characterized the clients of temporary shelters with a focus on health improvement, whereas most experienced technology users made use of the social services of daily and family shelters.

Figure 3. Health and internet use characteristics of the homeless and reference groups. N/A: not applicable.



Barriers and Enablers of Internet Use

For the multiple-choice question, “What barriers, if any, restrict your internet use?” of the 682 responses, 210 (30.8%) said that nothing hindered it; 104 (15.2%) said there were not enough free Wi-Fi hotspots; only 46 (6.7%) said they had a smartphone, but they did not have a data contract or pay-as-you-go facility; and 52 (7.6%) said that they had internet access, but they did not know how to use the internet. Of the 682 responses, 146 (21.4%) said that they did not have a smartphone and 60 (8.8%) said that there were not enough publicly accessible PCs (eg, in institutions providing social services). In addition, of the 682 responses, 64 (9.4%) said that they could not access the internet anywhere.

For the question, “What would help you use the internet more?” of the 598 responses, 145 (24.2%) wished to have a smartphone, 110 (18.4%) responded better access (they had a smartphone but did not have an available internet connection option), another 56 (9.4%) also responded better access (they used PCs in institutions providing social services, but only a limited number of devices were available), 135 (22.6%) responded more knowledge (they did not know how to use the internet, and it would have helped if they could get assistance); however, for most people, 152 respondents (25.4%), the question was not relevant as they already used the internet as much as they wanted.

Health-Related Internet Use

For the question, “Have you ever used the internet for health reasons?” 34.6% (229/662) of the homeless population said that they did. In the reference group, 10.7% (160/1500) used it every day, 18.4% (276/1500) weekly, 18.2% (273/1500) monthly, and 24% (360/1500) less, encompassing 71.3% (1069/1500) of the representative sample. This means that the general population used the internet for medical purposes more than twice as frequently as the homeless population.

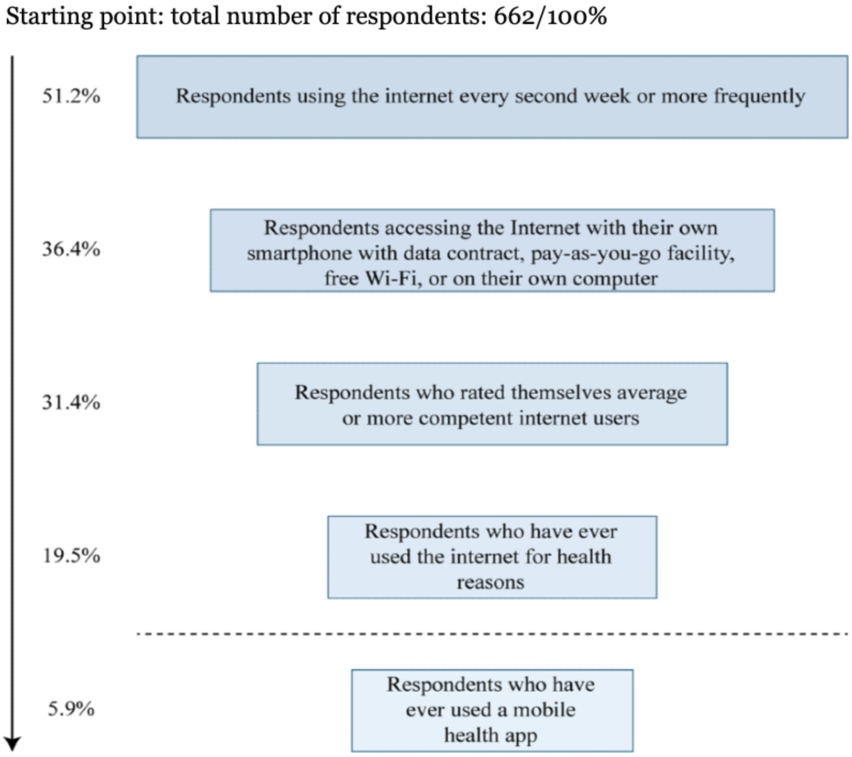
When cross-tabulating with gender, age, type of institution and social service, education, frequency of medical visits, and self-evaluation of health status, chi-square tests were significant for gender (*P*=.007), age (*P*<.001), and frequency of medical visits (*P*=.01), meaning that younger women respondents and those who went to the physician’s office more frequently tended to use the internet more frequently for health-related issues.

A Digitally Engaged Group of People Experiencing Homelessness

In the course of our analysis, we found a specific subpopulation in the sample identified as a “digitally engaged group of people experiencing homelessness.” The members of this group were specific in the sense that they did not need further digital inclusion. This group was selected for further analysis based on the following inclusion criteria.

First, we selected respondents who said that they were using the internet at least every second week (339/662, 51.2%). In the next step, we asked the respondents who reported smartphone ownership with data contract, pay-as-you-go facility, or free Wi-Fi or computer or tablet ownership to the question “How do you currently access the internet?” (241/662, 36.4%). We then filtered out the respondents who did not have a sense of being an average or more competent internet user (208/662, 31.4%). Furthermore, we selected those who responded “yes” to the question whether they had ever used the internet for health-related reasons (129/662, 19.5%). We also considered filtering the subpopulation based on the question “Have you ever used any health-related mobile application?” but as only 18.5% (277/1500) in the reference group responded positively to the question, we expected a significantly lower number in the homeless population, bordering analyzability. In contrast, the low number in the reference population indicates that mHealth app use is not necessarily meaningfully associated with overall health-related digital engagement. Thus, we created 2 subpopulations, a more broadly defined and a more strictly defined group, and analyzed their characteristics separately (Figure 4).

Figure 4. Flowchart for selecting the digitally engaged group of people experiencing homelessness.



When the selected subgroup included 19.5% (129/662) of the total homeless population, significantly more women were included in the subpopulation (47/129, 36.4%) than the original population (186/662, 28.8%). When cross-tabulating with gender, age, education, frequency of medical visits, prevalence of chronic illnesses, and type of institution and social service, chi-square test results were significant for the prevalence of chronic illness (*P*=.047); therefore, respondents with chronic illnesses were more likely to use the internet frequently for health-related reasons. Although the institutional setting was not an associative variable, temporary shelters (40/129, 31%) and day and night shelters (28/129, 21.7% and 22/129, 17%, respectively) housed most respondents in the subpopulation (90/129, 69.7%).

Of the 662 participants, we filtered out those who had never used a health-related mobile app (Figure 4). The selected subgroup included 5.9% (39/662) of the respondents of the total studied population. The gender ratio became balanced, which means that more women (14/39, 36%) were included in the subgroup than in the original population (186/662, 28.8%). When cross-tabulating with gender, age, education, frequency of medical visits, prevalence of chronic illnesses, and type of institution and social service, the chi-square test results were significant for the institutional setting (*P*=.03) and education (*P*=.04), which means that digital engagement of a homeless person tended to depend on the type of homeless shelter the respondent frequented, and respondents with higher levels of completed education tended to be more digitally engaged.

Multivariate Analysis

Chi-square test results showed that gender, age, and frequency of medical visits were associated with health-related internet use; however, to analyze which demographic or health status variables influenced health-related internet use, a binary logistic regression model was necessary.

The dependent variable was health-related internet use, and we entered gender (1=woman and 2=men), age (as a continuous variable), type of institution and social service (6 categories), education (4 categories), frequency of medical visits, and the prevalence of chronic conditions in the model.

The logistic regression model was found to be significant (Nagelkerke R^2=0.154). After controlling for all the abovementioned variables, we found that health-related internet use showed a strong dependency on age and a statistically significant association with gender, level of education, and the prevalence of chronic conditions (*P*<.05). This means that younger homeless women who did not have any chronic conditions tended to use the internet more for health-related issues (Table 2).

Table 2. Results of the logistic regression model (Nagelkerke R^2=0.154)[a].

	B (SE)	Wald test (*df*)	*P* value	Exp (B)
Gender (1=female; 2=male)	−0.480 (0.222)	4.660 (1)	.03	0.619
What is your highest completed level of education?	—[b]	9.186 (3)	.03	—
What is your highest completed level of education? (1=primary school)	0.458 (0.483)	0.899 (1)	.34	1.581
What is your highest completed level of education? (2=vocational training)	−0.191 (0.480)	0.158 (1)	.69	0.826
What is your highest completed level of education? (3=high school)	−0.141 (0.495)	0.081 (1)	.78	0.869
How frequently do you visit a medical doctor or do you use medical services?	0.155 (0.099)	2.453 (1)	.12	1.168
Do you have any chronic disease or a long-term health problem? By long-term, we mean a problem which has lasted six months or longer.	−0.481 (0.238)	4.077 (1)	.04	0.618
Age	0.049 (0.009)	30.033 (1)	<.001	1.050
Which institution providing services for homeless people do you have contacts with?	—	3.607 (5)	—	—
Which institution providing services for homeless people do you have contacts with? (1=outreach service)	0.606 (0.458)	1.752 (1)	.19	1.833
Which institution providing services for homeless people do you have contacts with? (2=day shelter)	0.356 (0.397)	0.804 (1)	.37	1.428
Which institution providing services for homeless people do you have contacts with? (3=night shelter)	0.058 (0.431)	0.018 (1)	.89	1.059
Which institution providing services for homeless people do you have contacts with? (4=temporary shelter)	0.109 (0.434)	0.063 (1)	.80	1.115
Which institution providing services for homeless people do you have contacts with? (6=family shelter)	0.223 (0.585)	0.145 (1)	.70	1.249
Constant	−2.052 (0.838)	6.002 (1)	.01	0.128

[a] Dependent variable: Do you ever use the Internet for health reasons? (0=no; 1=yes).

[b] Not available.

Discussion

Principal Findings

Homeless adults experience an early onset of geriatric conditions, a complex set of chronic diseases, and premature mortality [26,27], as their access to adequate health care services is generally poor. Such disparities lower life expectancy and strengthen social exclusion. To mitigate health inequalities among homeless populations, digital technology [12], a new health determinant, can be considered on a broader scale. In a previous study by the Digital Health Research Group [12] at Semmelweis University that examined the attitudes and openness of homeless individuals regarding telecare in a Hungarian sample, a significant fraction of people experiencing homelessness with mid- or long-term residency in homeless shelters was open to the use of telecare via live web-based video consultation. As a step forward in assessing the feasibility of launching a comprehensive telehealth project and disseminating other well-being programs, the research team conducted this survey assessing existing access to digital platforms (smartphones and internet) and barriers in both physical and educational spaces among homeless populations.

On the basis of our findings, the surveyed homeless population showed an aptitude toward health-related technology use and had partial access to digital tools. Overall, the results respond to our first research question positively, that is, homeless populations use digital tools for health-related reasons.

A significant proportion of respondents had a mobile phone (461/662, 69.6%), and a lower but still significant number of respondents possessed a smartphone (264/662, 39.9%). These findings are congruent with the results presented in the literature, although according to our findings, the ownership of devices and access to the internet lag behind that of Western countries. In 2013, McInnes et al [28], in a systematic review, found that mobile phone ownership ranged from 44% to 62%, computer ownership from 24% to 40%, computer access and use from 47% to 55%, and internet use from 19% to 84% in this population. In 2017, Rhoades et al [29] found that the vast majority of homeless individuals (94%) owned a cell phone, more than half owned a smartphone, and 51% accessed the internet on their cell phones. One-third of the participants reported no internet use in the past 3 months [29]. In 2021, Thurman et al [30] analyzed feasibility studies related to mHealth interventions among people experiencing homelessness and found that 52% of the participants (n=31) reported having a personal cell phone, and of those with phones at baseline, the majority (87%) reported that their phones were capable of SMS text messaging, picture messaging, and mobile app use.

Our results showed that people experiencing homelessness turn to their family physician and social workers the most frequently for help with medical issues, but their third most frequent choice is the internet (20.5%), even before asking family members or friends. In total, 34.6% (229/662) of the respondents said they had used the internet for medical purposes, and 11.2% (74/662) of the respondents had already used a medical mobile app.

In addition, we have to consider technological limitations. The first iPhone was launched in 2007, which introduced the concept of smartphones, the spread of smartphone-based internet use, and personalized web-based searches. Technological adoption is slower in lower socioeconomic groups, and previous studies found that rates of smartphone and internet use among homeless populations were lower than those among housed, low-income adults of any age [31], which might explain the generally lower internet use statistics for this specific group. This is in line with the findings of Von Holtz et al [32] showing that, while experiencing homelessness, participants experienced a 68% less likelihood to access the internet than when they were housed; however, our main results show that the idea of involving homeless populations in the digital health ecosystem can already be based on solid use patterns, which can be further extended.

Age as a Key Predictor of Health-Related Internet Use

On the basis of our findings, the response to our second research question, that is, clearly identifiable variables, above all institutions and social services, and beyond that, age, education, or other demographic data can be associated with health-related internet use, had to be partially rejected. Neither chi-square tests nor the binary regression model showed statistically significant results. The type of institutional access and social services provided did not relate to access and use of digital tools and the internet, except for the digitally engaged subgroup. In contrast, our logistic regression model showed that age, gender, level of education, and prevalence of chronic conditions are variables that statistically significantly influence health-related internet use.

In line with our results, Harris et al [33] found age to be a key sociodemographic variable affecting the use of technology by homeless individuals. The participants of that study felt that the shift in the United Kingdom to more digital social services had assumed that users were well versed with IT, although this may not be the case.

Although age seemed not to play a key factor in homeless individuals accessing technology, as most of the respondents had a mobile phone (461/662, 69.6%), mostly representing the age group of >60 years, it might be a crucial factor when it comes to their own perception of competence in using web-based services and health-related internet use. Younger respondents (age group 18-44 years) considered themselves rather competent, whereas older respondents (age groups 45-59 years and >60 years) did rather not or did not at all consider themselves competent when it came to using the internet. Moreover, the regression model showed that the younger a homeless respondent was, the more likely they were to use the internet for health-related reasons.

Gender, Level of Education, and Prevalence of Chronic Conditions

The regression model showed that gender was an explanatory factor when it came to health-related internet use, which means that women in the homeless group tended to use digital tools mainly for health-related purposes. This is congruent with the trends in the general population, as Resch et al [34] found that women were more engaged in using the internet to search health-related information in Germany (n=1006), and Rising et al [35] through the 2017 and 2018 National Cancer Institute Health Information National Trends Survey (n=6789) found that in the United States, women were more likely than men to use digital health tools. As a noteworthy limitation, it has to be mentioned that women were almost 2.5 times more underrepresented in the sample (186/662, 28.8%), which might have influenced mHealth use patterns along gender lines.

Regarding the level of education, those who had completed higher levels of education were more inclined to use digital health tools, although only 4.5% (30/662) of the sample said they had completed college or university education, which, similar to the gender composition of the sample, might influence use patterns. In contrast, this finding is congruent with the self-assessment of technological literacy. Chi-square test results were significant for education (P=.01) when cross-tabulating with self-assessment of digital competencies, meaning that with higher levels of education, the sense of technology literacy increases, which might result in more frequent use.

Concerning the prevalence of chronic conditions, the results showed that homeless individuals without chronic diseases or any long-term illnesses tended to use the internet more for health-related purposes, which might originate from the pattern that those who were more concerned about their own health tended to use a diverse tool kit for health care and well-being, including digital tools, whereas those with serious chronic illnesses might tend to neglect their state because of their struggle to accommodate basic human needs or lack of resources for accessing care [36].

Overall, the results of the regression model were in line with trends in the general population: younger and more educated people tend to use digital health tools [37,38], and this finding means that in the course of planning health care interventions for homeless populations, patterns observed in the general population might be taken as a base for further action.

Digitally Engaged Homeless Subpopulation

The homeless population was a diverse group in terms of health-related internet use and access to digital tools, with a significant number of digitally engaged participants. When analyzing the data, the research team found 2 broadly interpretable digitally engaged homeless subpopulations: a subpopulation without health-related mobile app use (129/662, 19.5%) and another with such use (39/662, 5.9%). Generally speaking, both digitally engaged groups included more women and younger respondents than the homeless population, which was in line with the findings of the regression model. The overall results were also congruent with previous literature stating that low-income populations rely on smartphones rather than computers for internet access; the latter was less frequent than owning a smartphone in our sample as well [31].

A chi-square test on the association between demographic factors and the more broadly defined subgroup showed that the type of institution and social service as well as the level of education—the higher the level of completed education, the more substantial digital engagement—mattered as factors for becoming digitally engaged. Temporary shelters (40/129, 31%) and day and night shelters (28/129, 21.7% and 22/129, 17%, respectively) housed most respondents in the subpopulation (90/129, 69.7%), which means that long-term living conditions seem to be associated with digital inclusion. The same pattern emerged in the more strictly defined subgroup; a chi-square test on the association between demographic factors showed that only the type of institution providing social services mattered as a factor for becoming digitally engaged. Almost half of the selected subgroup used temporary shelters, whereas very few digitally engaged users were found among rough sleepers and those who used emergency accommodations.

Barriers and Enablers of Internet Use

Rice et al [39] reported that mobile phones can facilitate communication with family or friends and provide social support, which in turn has been shown to be associated with more favorable health outcomes [40]. In contrast, two-thirds of the participants of a cohort of 350 adults experiencing homelessness aged >50 years in Oakland, California, reported using their phones to communicate with their health care providers, suggesting both interest and feasibility [31].

However, several studies have shown homeless population's interactions with technology to be significantly affected by lack of resources and the structural constraints [33], which was also shown by our results. As the main barriers to accessing technology, respondents mentioned affordability of digital tools or data contracts, the low number of free Wi-Fi hotspots, and PCs available at social institutions. To foster internet use, a significant number of respondents suggested overcoming these barriers rather than urging the need for educational assistance.

In line with previous studies, in the context of homeless populations in Hungary, increasing public access to high-speed internet and providing discounted smartphones for high-need, low-income individuals may also increase access to the internet [41]. Moreover, Budapest lacks an adequate number of free Wi-Fi hotspots, and thus needs more of such hotspots installed [42]. As Raven et al [31] noted, private sector technology and telecommunication companies might also be incentivized to fund initiatives that increase the use of their services among underserved populations, thereby increasing access to reliable mobile technology.

Strengths

Studies examining health and technology-related behaviors in homeless populations tended to be conducted predominantly in the United States and Canada compared with little examination of the use of technology of homeless populations in other countries [11]. Thus, as Heaslip et al [11] also noted, further research is needed in the United Kingdom, Europe, and lower-income countries. This study aims to fill that gap by examining the accessibility and use of health-related technology in Central and Eastern Europe, more specifically in Hungary.

Compared with other studies that examine homeless populations in specific areas, the sample size of this study (N=662) is considered notable and large enough to draw statistically significant conclusions.

Limitations

The study sample represents urban homeless populations from Budapest, Hungary, where socioeconomic conditions might differ from those living in the countryside. Homeless population recruited in our study had a connection to the social infrastructure; therefore, rough sleepers and other people who were not connected to any social initiatives were not represented.

The research team relied exclusively on self-reporting of mobile phone ownership, internet access, and internet use and did not attempt in any way to verify these reports (eg, via phone bills, direct observation, or other methods).

Conclusions

Although health-related internet use statistics are lower than those in the general population, the results showed that the pattern of use is similar. The idea of involving homeless populations in Hungary in the digital health ecosystem is not far-fetched, but a rather viable concept, especially if barriers to access are systematically reduced and the enablers of use strengthened.

During the development of a digital ecosystem, several factors might be considered, such as the role of the institutions providing social and medical services. From an infrastructural point of view, the unavailability and poor affordability of devices and subscriptions and the lack of publicly available free Wi-Fi hotspots were mentioned as barriers to digital technological access. All these factors might be improved by making adequate changes, enabling more Wi-Fi hotspots and installing more publicly available computers in social institutions. In addition, an internet service scheme specifically designed for the homeless population (eg, prepaid services available for medical purposes) could facilitate a shift toward better digital health.

It is important to note that despite all the barriers to accessing digital technologies, our research identified a digitally engaged homeless subgroup, whose members are actively using digital tools for health purposes. With a deeper analysis of this group, characteristics, motivations, and potentials for widening access and use could be delineated, and this group could form a baseline for holistic and appropriate digital public health interventions.

Our preliminary analysis in this group already showed that the characteristics of accommodation also play a role in assessing the accessibility of homeless populations to digital health services. People experiencing homelessness with a more stable housing solution tend to be more open to digital technology and have more access to their own digital resources than others with less stable conditions. This information might be fruitfully used when planning further complex and holistic digital health programs for homeless populations centered on institutions as already available resources for further development.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Digital health access and literacy survey for people experiencing homelessness.
[DOCX File , 12 KB-Multimedia Appendix 1]

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Abbreviations

HCSOM: Hungarian Charity Service of the Order of Malta
mHealth: mobile health

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