

# "We Don't Have a Lot of Safe Spaces to Talk about These Things": Designing Digital Mental Health Tools to Support the Needs of Black Adults in the United States

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# "We Don't Have a Lot of Safe Spaces to Talk about These Things": Designing Digital Mental Health Tools to Support the Needs of Black Adults in the United States

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#### Abstract

**Background:** Depression and anxiety are associated with excess morbidity and mortality, constituting a major health care challenge. The prevalence of these conditions is increasing. In the U.S., the health-related burden of depression and anxiety may disproportionately affect Black adults, who face unique stressors impacting their mental health and barriers to accessing treatment.

**Objective:** This study seeks to explore the mental health experiences of non-treatment seeking Black adults, and how these experiences relate to their needs and preferences for the design of digital mental health (DMH) tools, through user-centered design methods.

**Methods:** This study included 25 non-treatment seeking Black adults (aged 18-61) with experiences of depression or anxiety to share their perspectives on how DMH tools can meet their needs. All 25 Participants engaged in an asynchronous online discussion group and completed a technology probe in which they used an automated mental health self-management text messaging tool for 18 days. A subset of participants (n=6) completed follow-up interviews to elaborate on their impressions of the program and design ideas.

**Results:** Participants described how racism and mental health stigma severely limit opportunities to discuss their mental health challenges, both within and outside the Black community. They endorsed text messaging as a convenient way to introduce mental health self-management skills but advocated for the integration of content that highlights and addresses the experiences of Black individuals, creating nonjudgmental spaces for discussing mental health experiences, and linkage to formal mental health treatment for those who want it.

Conclusions: Our findings suggest that it is critical to consider the role of racial discrimination and mental health stigma in shaping psychological well-being when designing inclusive and culturally sensitive DMH tools. Furthermore, DMH tools can provide non-treatment seeking Black adults with a supportive environment to address mental health concerns, which may otherwise be difficult to find due to stigma.

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# **Original Manuscript**

"We Don't Have a Lot of Safe Spaces to Talk about These Things": Designing Digital Mental Health Tools to Support the Needs of Black Adults in the United States

#### **Abstract**

**Background:** Depression and anxiety are associated with excess morbidity and mortality, constituting a major health care challenge. The prevalence of these conditions is increasing. In the U.S., the health-related burden of depression and anxiety may disproportionately affect Black adults, who face unique stressors impacting their mental barriers **Objective:** This study seeks to explore the mental health experiences of non-treatment seeking Black adults, and how these experiences relate to their needs and preferences for the design of digital mental health (DMH) tools, through user-centered design methods. Methods: This study included 25 non-treatment seeking Black adults (aged 18-61) with experiences of depression or anxiety to share their perspectives on how DMH tools can meet their needs. All 25 Participants engaged in an asynchronous online discussion group and completed a technology probe in which they used an automated mental health selfmanagement text messaging tool for 18 days. A subset of participants (n=6) completed follow-up interviews to elaborate on their impressions of the program and design ideas. Results: Participants described how racism and mental health stigma severely limit opportunities to discuss their mental health challenges, both within and outside the Black community. They endorsed text messaging as a convenient way to introduce mental health self-management skills but advocated for the integration of content that highlights and addresses the experiences of Black individuals, creating nonjudgmental spaces for discussing mental health experiences, and linkage to formal mental health treatment for who want **Conclusion:** Our findings suggest that it is critical to consider the role of racial discrimination and mental health stigma in shaping psychological well-being when designing inclusive and culturally sensitive DMH tools. Furthermore, DMH tools can provide non-treatment seeking Black adults with a supportive environment to address mental health concerns, which may otherwise be difficult to find due to stigma.

#### Introduction

The United States (US) is facing a burgeoning mental health crisis, and depression and anxiety are at the forefront of this crisis. Depression and anxiety are pervasive mental health conditions that affect 8.3% and 19.1% of adults each year, respectively [1,2]. They are often chronic and debilitating, with adverse downstream effects on education, employment, and quality of life [1,2]. The clinical presentation of depression and anxiety varies from person to person and between groups [3,4]. Symptoms of these conditions are common in Black adults and occur at a similar rate to that observed in White adults [5]; however, Black adults' experiences of depression and anxiety are more likely to be chronic and severe [3,6]. Notably, in the US, Black individuals' mental health challenges are compounded by experiences of structural racism, inequity, discrimination, and bias in society at large, as well as in health systems [7,8]. Black adults report higher numbers of chronic and acute stressors compared to White adults, including adverse childhood experiences, racial microaggressions, and both interpersonal and institutional maltreatment [9–11]. Moreover, research has found that stressful life events are associated with poorer mental health outcomes and an elevated risk of depression, anxiety, and suicide, as well as higher overall severity and chronicity of mental health problems [11,12].

Symptoms of depression and anxiety are less likely to be treated in Black people in the US [13], who may be deterred from seeking treatment by costs and other structural barriers like the limited accessibility of services in their neighborhoods, limited mental health literacy, and attitudinal barriers such as stigma and beliefs that treatment is ineffective [14]. Cultural factors in Black communities also have potential to heighten barriers to formal help-seeking. These include the belief that mental illness is a weakness or moral failing [15,16], as well as preferring faith-based management of mental health [17]. Estimates suggest that Black adults are less than half as likely to access mental health services compared to White adults [18].

Black adults who do seek and receive formal care may find that existing treatments fall short in addressing their needs. When given the choice, many Black individuals express a preference for providers who are the same race as them (i.e., patient-provider race concordance) [19]; however, underrepresentation of providers of color has made it difficult for most Black adults to achieve such concordance [20,21], which may lead to challenges building rapport with their provider [22], and less satisfaction with treatment [23]. Furthermore, available treatments may overlook culturally relevant aspects of mental health, such as stigma, spirituality, and racial identity [19,24]. Millions of Black individuals may therefore be looking for ways to manage mental health concerns outside of the formal care system.

Recent efforts have included consideration of digital mental health (DMH) tools to address unmet needs, bridge gaps in care, and provide culturally sensitive mental health services. For instance, studies have sought to understand Black adults' preferences for the design of chatbots to support managing chronic conditions [25], chatbots and voice assistants to support Black older adults in seeking online health information [26,27], and DMH tools to better support Black women in the perinatal period [28]. However, limited work has focused on the needs of Black Americans in the context of scalable tools like automated text messaging programs for mental health self-management. Text messaging is a particularly accessible method for delivering mental health support [29]. In the US, cellphone ownership is almost universal, and high rates of text messaging extend across racial and ethnic groups and socio-economic factors [30,31]. Moreover, since text messaging is a built-in tool on the mobile phone, and among the most frequently used communication methods, it has extremely high reach and low barriers to entry [32]. Access can extend to individuals who may not own modern smartphones or reliably access a data plan [29]. Text messaging is also cost-effective in terms of program development, maintenance, and deployment [29]. Thus, it may constitute an

appropriate modality for equitable, accessible DMH tools. Prior research suggests that Black adults send and receive text messages frequently and may be more likely to use text messaging overall compared to White adults [31]. Black adults also find text messaging to be a suitable approach for treating various health concerns [33].

To address gaps in the literature and address the unmet needs of individuals who face barriers to traditional care, this study applies user-centered design methods to examine how Black adults who are not engaged in formal mental health treatment envision using a text messaging intervention to manage depression and anxiety symptoms. We recruited Black adults in the US who self-reported experiences of depression or anxiety and sought—through an online discussion group and parallel text messaging-based technology probe—to deepen our understanding of their perspectives related to mental health support and how DMH tools might help to meet their needs. We posed the following two research questions: 1) What types of mental health challenges are faced by Black adults who are not engaged in formal treatment, and 2) How should digital tools deliver support to users to address their challenges, particularly in the context of automated text messaging? Answering these questions can help align scalable DMH tools to the needs of Black people in the US, with potential for broad impact in addressing their unmet mental health needs and advancing mental health care equity.

#### **Methods**

This section describes how we worked with Black adult participants to understand their needs and preferences for DMH tools.

#### **Participants**

Participants were recruited through social media advertising (Instagram, Facebook) and through free online self-screening surveys for depression and anxiety -- i.e., the 9-item patient health questionnaire (PHQ-9) [34], or 7-item Generalized Anxiety Disorder scale (GAD-7) [35] -- hosted by Mental Health America, a large non-profit mental health advocacy organization. Individuals were invited to learn more about the study opportunity by following a link displayed in their social media feed or alongside their screening results. Interested individuals then completed an additional survey to assess study eligibility, with inclusion criteria specifying that participants should 1) identify as Black or African American, including individuals who also identify as mixed race, 2) self-report a history of depression or anxiety symptoms (whether or not they were professionally diagnosed), 3) reside in the US, 4) be 18 years of age or older (or 19 years of age or older in Nebraska, reflecting the state's age of majority), 5) have English language abilities sufficient to read, understand, and participate in study procedures, and 6) own and be willing to use a personal mobile phone. Individuals were excluded if they were currently seeing a therapist, counselor, or psychologist, or taking medications for their mental health symptoms. Individuals were also excluded if they reported a serious mental illness (e.g., bipolar disorder, schizophrenia); if they had visual, voice, hearing, or motor impairments that would prevent completion of study procedures; or if they reported suicidal ideation with a current plan and intent to act. Furthermore, as the study involves receiving automated text messages, we confirmed that individuals provided the study team with a valid US mobile phone number prior to enrollment. Of the 27 individuals who met eligibility criteria and enrolled in the study, 2 did not participate in the online discussion group and were not sent automated text messages or invited for follow-up interviews. Demographic characteristics for the remaining 25 participants are represented in Table 1.

**Table 1:** Participant demographics.

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	Characteristic	Discussion (n=25)	Group	Interview (n=6)	
Age, mean (SD)					
	Years	34.76 (10.96)		27.17 (10.59)	
Depression/Anxiety					

Symptoms, M (SD)			
	PHQ-9	9.96 (5.70)	10.33 (6.02)
	GAD-7	10.36 (5.63)	13 (3.95)
Gender, n (%)			
	Female	20 (80)	6 (100)
	Male	5 (20)	0 (0)
Race, n (%)			
	Black or African American	25 (100)	6 (100)
	More than one race <sup>a</sup>	1 (4)	0 (0)
Recruitment Source, n (%)			
	Mental Health America	3 (12)	0 (0)
	Social media	22 (88)	6 (100)
Highest Level of Education, n (%)			
	Some high school or less	1 (4)	1 (16.7)
	High school graduate	5 (20)	1 (16.7)
	Some college	11 (44)	2 (33)
	Associate's degree	4 (16)	1 (16.7)
	Bachelor's degree	2 (8)	1 (16.7)
	Post-bachelor's education	2 (8)	0 (0)
Mental Health Treatment History, n (%)			
	Has seen a mental health professional	10 (40)	2 (33.3)
	Previously prescribed medication for a mental health condition	7 (28)	o (o)

<sup>&</sup>lt;sup>a</sup> Participants who identify as Black or African American in addition to another race.

#### **Procedure**

## Asynchronous Online Discussion Group

To increase comfort discussing issues related to racial identity and mental health, participants were informed that all other study participants identified as Black or African American and had experiences of depression or anxiety. Participants were asked to create a pseudonymous account on the study platform, FocusGroupIt.com. The platform was programmed to release a new prompt every 3 days for 24 days (8 total prompts). Prompts centered on understanding participants' mental health needs and management strategies, how these are impacted by racial identity, their perceptions and experiences of technologies as a method of mental health support, and ideas for how automated text messaging tools could be adapted to meet their needs. Each prompt posed a series of questions related to a specific topic (see Multimedia Appendix 1).

Participants were compensated based on the number of prompts to which they responded. They could earn additional compensation by replying to at least one other participant's response to each prompt. Text-based responses were automatically recorded by FocusGroupIt.com and downloaded at the study's end.

#### Text Messaging Technology Probe

Partway through the study (beginning after the 3rd prompt), participants were enrolled to receive automated text messages from Small Steps SMS for 18 days. The program delivers support for self-management of depression and anxiety symptoms via daily interactive dialogues [36,37]. The content of the messages is drawn from 11 evidence-based psychotherapy strategies and includes a variety of formats such as psychoeducation messages that introduce each strategy and how it works, peer stories, opportunities to write or receive supportive messages, and skill-building exercises (see Multimedia Appendix 2). Peer-generated content within the program (stories, supportive messages) was previously collected from prior research participants and edited and curated by research staff prior to inclusion; thus, there was no "live" communication between participants. The number of messages sent each day varies based on participants' interactions with the program; participants who respond more frequently may receive a greater number of messages (e.g., follow-up questions). Participants could engage with Small Steps SMS as much or as little as they wanted. They could also elect to end all messages by sending "STOP," although no participants did so. Participants were asked to reflect on their experiences with and impressions of Small Steps SMS in the discussion group.

#### **Interviews**

Participants were invited to complete optional one—on—one semi—structured interviews, lasting about 20—25 minutes, at the end of discussion group activities. Interviews gave participants the opportunity to voice ideas or thoughts they did not share in the discussion group and provide additional feedback on Small Steps SMS and ideas for DMH tools. In total, 6 participants completed interviews. All interviews were conducted via the Zoom teleconferencing program by a member of our research team. Participants were able to turn their video on or off based on their preferences. With participants' permission, interviews were audio recorded and transcribed.

#### **Ethical Considerations**

Study activities were approved by the IRB of the researchers' institution. Participants were compensated \$7 for responding to each online discussion group prompt, and \$2 for replying to at least one other participant's response to each prompt, for a total possible compensation of \$72 for all discussion group activities. Participants who completed interviews were compensated an additional \$8. Our research team includes mental health clinicians and researchers, human-computer interaction researchers, and research staff. Our team includes individuals who are and are not Black. All interviews were conducted by a team member who is Black so that interviews were built on a foundation of shared experience, increasing participants' comfort and depth of the discussion. Clinical psychologist team members provided input throughout the study to ensure participants' wellbeing and safety. All individuals who completed the screening process or participated in the study were given a list of resources for accessing 24/7 mental health support, if needed (e.g., suicide prevention hotline, crisis text line). Participants agreed to follow a code of conduct which advised them to engage with respect and to avoid disclosing personally identifying information or details about methods of suicide or self-harm. Responses in the discussion group were monitored daily for compliance with the code of conduct. Across all activities, research staff had a risk management protocol in place, such that participants' sharing of any information signaling risk to themselves or others would prompt the research team to contact the participant and administer further risk assessments. No such risks emerged and therefore no follow-up was conducted.

## **Data Analysis**

Discussion group and interview data were subject to thematic analysis [38]. Three coders, who are authors of this paper, first became immersed in the data by reading discussion group and interview

transcripts. They performed open coding to identify preliminary codes and then met to discuss and prioritize these codes, guided by assessment of each code's relevance to the research questions. Prioritized codes and their definitions were captured in a shared codebook. The coders then applied the shared codebook to overlapping transcripts using the qualitative data analysis software Dedoose, and subsequently met to discuss and resolve coding discrepancies and to refine and consolidate the codebook. After four overlapping coding rounds, discussions ceased to yield codebook revisions, at which point the coders divided the uncoded transcripts and applied the final codebook. Key themes were identified that encompassed the coded data, which were discussed with the rest of the research team for feedback. Excerpts were selected to illustrate each theme.

#### **Findings**

The Black adults in our study reported facing profound challenges in managing their mental health concerns and were receptive to using technology to help overcome these challenges. In the following sections, we describe the primary themes. First, we describe the unique mental health challenges participants faced related to navigating discrimination and stigma, and the lack of perceived outlets for sharing their experiences. Next, we describe participants' receptivity to an automated text messaging program that allows them to address their mental health concerns independently through a convenient medium. Finally, we describe how participants envision that digital tools can be designed to meet the unique mental health needs of Black adults through integrating culturally appropriate content written by and for Black individuals, creating safe spaces for disclosure of mental health concerns, and supporting help-seeking beyond the DMH tool among interested users.

#### **Mental Health Challenges of Black Adults**

Black adults in our study overwhelmingly reported being distressed by their mental health symptoms, which included a lack of motivation, fatigue, reduced pleasure in daily activities, loneliness, a sense of overwhelm, and anxiety, among others. As the sections below describe, participants' everyday experiences of depression and anxiety were compounded by habitual negative experiences that relate to race, particularly experiences of discrimination, stigma, and invalidation.

#### The role of racism and discrimination in mental health.

When asked how mental health issues differ for Black individuals than for other groups, participants highlighted that they face pervasive exposure to discrimination and racism across multiple domains of life, which negatively impact their mental wellbeing. Some participants referred to these experiences as "anti-Blackness." For example, P5 stated:

Black people unfortunately have to deal with everyday anti-Blackness and racism that exacerbates existing mental health issues. If we are not encountering it in our day to day lives personally, then we are inundated with instances of racism in the news and social media (P5).

Many participants noted that instances of anti-Blackness could be harmful even when directed towards others, such as when accounts of anti-Blackness are shared among Black community members or broadcast publicly on media channels.

Participants described several specific effects that anti-Blackness had on their mental health, including increasing anxiety and decreasing motivation and energy level. P6 felt that repeated instances of discrimination were linked to their anxiety, relaying that, "We deal with discrimination and injustices and fear and it affects our mental health because we are more prone to be on edge and anxious about certain things and situations" (P6). Others connected anti-Blackness to "burn out" and withdrawal, such as P25:

For most of us, we are surrounded by whiteness in school, work, and even socially, but there is a level of masking that can lead to feeling burned out, and then social anxiety about re-

entering those spaces can pop up. I remember reading about Black workers dreading the return to the office due to the amount of microaggressions they had avoided while working from home (P25).

P25's account highlights the extent to which anti-Blackness pervades participants' lives, indicating schools and workplaces as common settings for microaggressions. Participants emphasized the work that goes into navigating White spaces, observing that this continuous effort could exhaust them and hinder their success in both school and the workplace.

Participants further explained that the feeling of being inundated with anti-Blackness can also impact one's self-concept and self-worth. P25 described:

I feel like sometimes being bombarded with images and videos of Black people being killed at the hands of police and other forms of state sanctioned violence, even the election of a white supremacist president to the highest office in the land, it can really feel as though my life doesn't matter, even though it does absolutely (P25).

In this statement, P25 linked exposure to what they described as "state-sanctioned violence" and feelings of worthlessness.

P7 agreed, stating, "It's just like what did we do so wrong for people to hate us so much? Being treated like that makes a lot of people feel unworthy & they may want to harm themselves" (P7). Their experiences suggest that feelings of worthlessness can contribute to self-harm ideation.

#### Disclosure and the risk of invalidation

Many participants wanted to disclose their experiences with anti-Blackness to others, as well as discuss how their mental health was impacted as a result of these experiences. For instance, P15 shared, "open and honest conversation can bring upon a wealth of relief" (P15), suggesting that disclosure might aid in reducing mental health symptoms. Although participants expressed interest in mental health disclosure, they perceived limited opportunities to discuss their experiences, particularly those related to anti-blackness. In fact, participants were wary to discuss these issues with Black and non-Black individuals alike, including healthcare providers. P14 summarized this sentiment: "A lot of us really don't like talking to therapists, family or friends. So, we keep it bottled on the inside and try to deal with it our self" (P14).

Participants overwhelmingly avoided disclosing how racism impacted their mental health and wellbeing to non-Black individuals, primarily citing fears of invalidation. P5 described:

Dealing with discriminatory behavior can be so exhausting and depressing, not to mention the added frustration having our experiences of racism be downplayed or outright dismissed by non-Black people (P5).

This comment suggests that a dismissive response to one's disclosure can have a compounding effect on the initial instance of discrimination. Another participant feared that disclosure could activate damaging stereotypes, relaying that:

In my personal experience, it was and is still sometimes hard for me to be vocal without being labeled as the "angry black woman". I've been working on not dimming my own light because of someone's ignorance (P1).

Despite wanting to share their experiences broadly with confidents of other races, participants were attuned to potential negative repercussions that discouraged and often prevented disclosure.

Many participants thought that therapy could hypothetically create a supportive environment for disclosing and processing their experiences. Yet, concerns about invalidation extended to mental health care providers. For example, P18 reported:

It is hard for [therapy] to work, because not everyone can understand the feelings black people feel unless they experienced it themselves. It is important that the feelings of Black individuals are not invalidated (P18).

A preference for Black providers was endorsed by many participants. P15 thought that having shared experience would allow them to disclose more candidly to a provider, describing that, "It makes it

easier to be understood without shame or saying something that might be offensive to a non-black individual" (P15). Some also described that providers should understand the history of racial injustice in the US. P25 stated:

I think support systems must be well-versed in the cultural and historical foundation that plays out in our daily life. I think individual, as well as group therapy, led by those who have the training and cultural background, is a great start (P25).

While many participants thought they could benefit from working with providers who could understand their experiences, they largely expressed skepticism that such providers would be available to them.

Finally, participants' concerns about disclosure often extended to other Black individuals, particularly when sharing details of their mental health issues. Many participants described mental health stigma within the Black community, and felt that sharing their struggles with family, friends and other community members could lead to judgement or ostracism. P21 explained:

I feel like there's this stigma within the African American community, especially with surrounding mental health. I know I've been told by family members – not immediate family members, but kind of distant family members like, "Oh, therapy is not for our people; our type of people don't go to therapy.' We don't broadcast our problems; we kinda internalize it (P21).

A similar sentiment was relayed by P15, who shared:

I have loved ones who think that talking about depression means I need to be placed in a mental facility. It is sad because some of them unknowingly need to seek therapy but most likely will not because they fear the stigma behind it (P15).

Some participants connected negative attitudes about mental health treatment to religious beliefs. P11 stated:

African Americans deal with shame, and backlash for having depression and or anxiety. I grew up with a Christian mother and grandmother that tells you to pray about everything. Mental illness in general in the black community is a taboo thing (P11).

While some participants felt that attitudes relating to mental health treatment were shifting such that Black communities were becoming more accepting, P25 shared a mixed perspective:

I am proud of the evolution our community has experienced when it comes to [mental health], but I also feel saddened for all of us who suffered without support, and were forced to just 'pray' it away (P25).

Overall, participants faced a dilemma. They felt a strong desire to have their experiences acknowledged and understood by others but perceived few appropriate outlets within which to share, leading many to keep their mental health struggles private. As we describe in the next section, DMH tools were largely perceived positively since they provided a low-burden and private method for receiving day-to-day support.

# Receptivity toward an Automated Text Messaging Program

Although participants in our study were ambivalent about formal mental health care, they largely saw the value of self-guided tools to help them manage their mental health privately, particularly when tools took advantage of convenient communication channels.

# Introducing and Normalizing Self-management

After they began receiving messages from Small Steps SMS in the technology probe, many described the program as favorable to face-to-face treatment, relaying that it felt more comfortable and approachable. P16 believed the program empowered them to become more proactive in their own mental health. They described:

I think this program would be very beneficial for African Americans like myself. Especially when we are not ready to talk to someone face to face ... I would definitely sign up for the

program to help me cope with my anxiety and depression (P16).

Indeed, some participants reported they tried out the strategies supported by Small Steps SMS, such as P15, who emphasized their success in challenging negative thoughts (one of the strategies the program supports). They described, "But reading those different tips and the different self-care things that were said, how to take that negative thought and kind of turn it into a positive one, that's been very helpful" (P15).

Participants also appreciated that the program had helped establish that their mental health issues were normal. Some discussed that this sense of normalization allowed them to be more accepting of and open about their own challenges, like P16:

I really enjoy getting the text messages. It really helps when I'm down and depressed and keeps my mind off things for that moment ... it's like having your own personal counselor no judgment at all that makes me feel comfortable and to open up about my feelings more (P16).

Normalization was achieved, in part, through the user-generated content integrated throughout Small Steps SMS in the form of peer stories and support messages. P18 described:

Usually I don't like reading long messages, but if it was a story about how [a person] overcame something and the lessons that they learned from it, I actually loved reading those because it felt really personal and like something I could relate to (P18).

#### Similarly, P5 reported:

I was not expecting to receive instances of people's personal experiences, and it was honestly my favorite part of the experience. I think having people share their experiences makes me feel less alone (P5).

Thus, despite being delivered through an automated program, firsthand stories could provide a sense of relatability and social support that was otherwise lacking.

#### Convenience of text messaging

Participants also liked that digital tools like Small Steps SMS were convenient, addressing several barriers to traditional mental health treatment, including time and cost. P15 reflected that, "This program is convenient as it does allow someone the comfort of seeking help without the hassle of an in-person visit. Programs like this one are time and money saving" (P15).

The system was perceived to be convenient since it operated via text messaging, a function of the mobile phone that participants all routinely used, and because messages were brief and required little active engagement. For example, P24 described:

Well, I guess one thing for me in particular, since I'm very much a workaholic, was the reminders of little self-care things I thought was nice. And just the reminders to kinda take some time to just decompress, so to speak (P24).

At the same time, participants appreciated that the system allowed two-way communication. This was described by P11: "I liked the fact that some of the messages were interactive and required some participation" (P11). While participants endorsed the low burden of receiving push messages, they also recognized that asking the user for input and participation could add value.

# Tailoring Digital Mental Health Tools for Black Adults

Participants described several ways the program, and other DMH tools, could be adapted to help them navigate the specific mental health challenges that emerge for Black adults.

## Adapting Content to Reflect Black Individuals' Experiences

Participants suggested that Small Steps SMS should directly address the unique challenges faced by Black adults with mental health concerns. P15 described, "The program should list some common topics black people face on a daily basis such as racism, various traumas, and other systematic barriers" (P15). Participants also endorsed educating users on the mental health effects of racism. P5 shared:

I think having topics such as systemic racism and the adverse effects on the mental health of Black Americans could be very beneficial since it serves to validate the daily injustices we face due to attitudinal racism (P5).

In addition to facilitating understanding of bias and discrimination, participants wanted the program to provide actionable guidance for navigating these challenges. P7 suggested, "support should help just by letting us know that everyone isn't racist or mean and teach us how to properly cope and deal with these things" (P7). Similarly, P19 thought that the program should help connect users with resources around a range of issues faced by Black individuals:

Well racism and injustice is still alive and kicking. Social issues, high unemployment rates, policing problems ... we deal with a lot ... maybe provide information for different avenues to assist with resolving problems (P19).

Participants felt that content addressing these issues should reflect Black voices. P15 described, "anything that can be shared from someone that identifies as the same race with me, that's positive" (P15). Similarly, P17 expressed interest in using a program "especially if the content sent was authored and curated by Black Voices with Blackness in mind" (P17). Some participants expressed a particular interest in non-professional content written by other Black Americans. P11 shared,

I would like to see relatable stories that highlight being African American, the stigma of mental health treatment/ diagnosis in our community, juggling parenting, working, and on top of that battling mental health. The stories should vary in outcomes, successful and failed outcomes (relatable) uplifting stories, funny stories, inspirational stories (P11).

Several participants also endorsed integrating quotes from famous Black individuals, including "well known people, like Oprah" (P25). Similarly, P18 shared:

Sending inspirational quotes by famous Black people I think would help. Because they will see people who are like them who have been in situations that are stressful and have made it through the situations. So that would be encouraging (P18).

Participants saw value in integrating diverse Black voices into the content of a messaging program, including professionals, peers, and celebrities.

# Constructing safe spaces for social sharing

Although the version of Small Steps SMS used in our technology probe featured user-generated content composed by other individuals with mental health concerns, many participants thought that the system should go farther in how it supports social interaction.

Participants overwhelmingly endorsed facilitating direct conversation between Black users of a DMH tool, often drawing inspiration from the discussion group through which we conducted the study, which allowed them to compose long-form messages and engage with one another while maintaining anonymity. These features led to a sense of safety, as P16 described: "I definitely appreciate that I can be open and honest about my feelings without negative judgment. [This discussion group] has been very beneficial for me and my mental health" (P16). P15 agreed, stating:

This group is nice, and I, too, would consider this a safe space. I feel that I can be open and honest and will get back the same in return. I do not feel worried about being judged, I can be completely who I am, and still feel valued (P15).

This comment suggests that a safe space is one where all participants can be uninhibited in expressing themselves, without fear of judgment.

Some participants spoke to the importance of establishing safety by ensuring that forums were accessible only to Black individuals with mental health concerns. For example, P25 suggested "making sure there is gatekeeping to protect the space, so that it's only for people who are Black American (or Biracial) and with a history of mental wellness challenges" (P25). P23 shared this view, explaining that gatekeeping is essential given the scarcity of outlets for people like them: "I feel like it should be only catered to black Americans with mental issues because we don't have a lot of safe spaces to talk about these things at all" (P23). However, one participant who identified as

multiracial relayed past experiences in which they had felt excluded from Black spaces and expressed that the program should explicitly include adults with mixed racial backgrounds. They stated:

I think it'd be nice if you kind of opened it up to, maybe not people who were just fully African American, but that also identify as African American, but something else as well, because I feel like oftentimes, people try to take that away from people (P21).

Participants also discussed how creating a safe environment for disclosure would require moderation, or the active involvement of individuals whose job is to establish and uphold community guidelines. Participants once again took inspiration from the study's discussion group, which was moderated by study staff. P17 described, "I think being a highly moderated and regulated platform allows people to speak about their mental health candidly while maintaining anonymity" (P17).

Finally, a sense of safety was one in which sharing was optional and could happen over time as participants became comfortable. Many described that reading about others' experiences was valuable regardless of their own desire to share providing a sense of reassurance and connection, or an understanding that they were not alone. P9 reported, "I appreciate this group. It showed me I'm not losing my mind that there are other women going through the depression, anxiety etc" (P9).

Ultimately, if they felt confident in the safety of the social environment, many participants expressed that they could benefit by disclosing more candidly. They drew from their positive experiences in the discussion group to highlight the value of interaction, boundaries, and moderation, all of which allowed them to feel they could share freely, without the risk of invalidation that characterized many other spaces they inhabited in their day-to-day lives.

#### Connecting to Other Sources of Support

While participants in this study were not involved in formal care, many saw the potential value in it, and this sometimes increased over the course of the study. Participants described that a program like Small Steps SMS may initially appeal to them because of its focus on privately managing one's concerns, but that overtime it might inspire individuals to seek support from other outlets. For example, P3 reported, "I think this opened my mind to possibly seeking mental health counseling" (P3). Similarly, P5 described, "when I read stories of people reaching out to their pastors or their therapists, or a trusted friend, it just reminded me that I could seek out someone in my own circle" (P5).

Recognizing this possible evolution in attitudes around treatment, participants wanted a DMH program to help users locate Black mental health care providers, who were perceived to be equipped to provide culturally sensitive support. For example, P24 reported:

I think it would be great if the system had an option to see resources for POC [people of color] in their area. Maybe team up with black therapists on this as well. Another idea, would be the option to chat with a black therapist (real person) if necessary or if the AI alone isn't tailored to the individual enough (P24).

Participants agreed that such features must be optional but saw value to integrating resources within a DMH tool to allow users flexibility in how to continue their mental health journeys.

Some participants also indicated that using the Small Steps SMS program and participating in the discussion group could inspire greater disclosure of their mental health challenges to important people in their lives. To support these behaviors, participants suggested that a DMH tool could provide guidance for navigating mental health stigma within Black communities. P18 reflected that: It is hard for [Black people] to accept that we need help. I think this program will give many people the push they need to get help or even talk to family or friends. especially if it introduces people to resources that helpful for mental health (P18).

While many participants were initially receptive to Small Steps SMS because it could be used privately, they thought the program should support transitions in how individuals cared for their mental health, including greater willingness to engage in formal and informal help-seeking.

#### **Discussion**

#### **Principal Results**

Digital mental health tools demonstrate potential to increase access to mental health support, but these tools must address the specific needs of racially and ethnically diverse populations to advance health equity. In the US, the need for mental health support is particularly acute among Black individuals, who have increasing rates of mental health symptoms but face major barriers to receiving mental health care [13,39–41]. Our goal in this study was to understand the challenges faced by Black adults in the US, and to clarify their preferences and perspectives for the design of DMH tools that can be used outside formal care, including automated text messaging tools. Our findings suggest that participants perceived anti-Black racism to affect their mental health daily, and that these experiences translated into a deep need for disclosure and social validation that they could not easily satisfy in their daily lives. While they deemed automated text messaging and self-management to be acceptable and approachable, they also suggested ways to better represent their experiences within program content, as well as complementing pre-scripted content with safe opportunities for social sharing and pathways to access support beyond the DMH tool. Below, we discuss the implications of our findings for understanding the mental health challenges of Black Americans and for designing DMH tools for this population.

#### Understanding Mental Health Challenges and Disclosure Needs of Black People

Our study suggests that participants made many connections between incidents of anti-Black racism and their affective states, thoughts, and behaviors, including linking exposures to racism to changes in their mood, anxiety level, productivity, and feelings of devaluation. They also emphasized that these effects are cumulative, reducing educational or career achievement and self-esteem and potentially leading to burn out and even suicide or self-harm-related thoughts and behaviors.

Participants in our study reported that they were affected not only by firsthand experiences of discrimination, but also by exposure to others' experiences as conveyed via social networking applications and mainstream news. Exposure to state-sanctioned violence was especially upsetting. The implication of this finding is significant given the highly publicized nature of events like the murder of George Floyd in 2020, with video footage of the murder disseminated widely both through news media and social media. These findings underscore a need to better understand the effects of vicarious experiences of anti-Black racism, including how these effects may be shaped by the type of event (e.g., institutional discrimination, violence, microaggressions), the channels through which experiences are shared (e.g., news media, social media, face-to-face), and accompanying commentary and contextualization. Additional research should examine strategies to mitigate the harms of vicarious trauma without compromising opportunities to access the benefits of sharing, such as building public understanding, spurring collective action, or coping with personal distress.

Findings from our study suggest that mental health disclosure, particularly in relation to instances of anti-Black racism, was viewed by participants as a pathway to coping. Conversely, inhibition was perceived as unhealthy, leading participants to feel the pressure of their "bottled up" distress. This view of disclosure as a potential solution for intense negative emotions is widely held in US culture [42,43]. In one model from clinical psychology, disclosure is compared to a fever; as both a sign of an underlying destructive process, and a restorative force [42]. There is some evidence for such views; Pennebaker, in his "expressive writing" paradigm proposed that the act of writing about troubling thoughts and feelings could spur various benefits for writers, even if what they wrote was never shared with others [44]. The benefits of private writing may include relieving stress, facilitating the development of new perspectives, coping with illnesses and traumas, or improving general health and wellbeing [45]. However, the effectiveness of disclosure as a coping strategy, as well as its associated health benefits, may largely depend on cognitive processing of stressors, which

plays a crucial role in race-based trauma recovery and adjustment [46,47]. In parallel, a body of literature has accumulated on the unique benefits that can come from social sharing of emotions, which may include eliciting social support, discovering alternative perspectives, prompting reciprocal disclosure, and potentially deepening relationships [48–50]. Despite its potential benefits, social sharing is complicated when disclosing identities or experiences that are stigmatized [51,52]. Concerns about how one's disclosure will be received are common, and anticipating negative reactions can lead to selective disclosure or non-disclosure [53,54], which is consistent with our findings.

Some work has examined how complexities of disclosure increase for individuals who have multiple stigmatized identities [55–57], reflecting that systems of oppression related to each identity can interact with one another to transform and sometimes magnify the experience of bias [58]. As described in our findings, participants found that identifying as a Black person with mental health concerns could compound the burden of racism and mental health stigma, and reduce disclosure opportunities. Participants greatly desired to discuss the role racial discrimination played in their day-to-day mental health and wellbeing, but they were subject to judgment from non-Black individuals when sharing about anti-Blackness, and they anticipated stigma from Black individuals when sharing about their mental health struggles. The resulting unmet need for disclosure provides an important backdrop for introducing DMH tools for Black people.

#### **Design Considerations for DMH Tools Catering to Black Americans**

Our findings can help to inspire design and refinement of DMH tools to better match the priorities and needs of Black people in the US. Below, we discuss opportunities to deliver self-management support and culturally tailored content through text messaging, to construct safe digital spaces for social sharing, and to provide pathways to other forms of care.

# Representing Black Experiences and Voices in Text Messaging Programs

Following our technology probe, participants reported positive views of automated text messaging as a modality for mental health support. The text messaging program was recognized for its capacity to support private and convenient self-management, which allowed them to bypass disclosure or helpseeking. Past work has suggested that Black women may have privacy concerns about receiving oneto-one mental health support via text message [59], but these issues did not emerge in our study. This may reflect that an automated program is less likely to raise concerns about misrepresentation of identity, or the fact that messaging was introduced after participants had built rapport with study team members and with each other. The nature of the messages themselves was also innocuous relative to some DMH approaches, which may reduce concerns about accidental exposure of messages. In line with past work [60,61], program content avoided assuming that users embraced clinical labels or had formal diagnoses. Furthermore, messages did not extensively probe about personal aspects of users' lives. Individuals were occasionally invited to share details about their lives in response to open-ended questions, but responses were optional and typically brief. Messages were largely push-based and supported learning and applying eclectic self-management practices. These findings are generally encouraging regarding automated text messaging programs for Black people in the US.

Many of participants' concrete suggestions for adapting the text messaging program centered on the content. Participants advocated for representing issues related to race and elevating voices of Black people. Suggested topics included racism and discrimination, stigma, and daily life stressors affecting Black communities (e.g., unemployment, policing). Participants wanted the program to be clearly designed "for them" as Black people with mental health concerns. A primary avenue to achieve this is including Black voices. Efforts may extend to the didactic content (e.g., written by

Black mental health professionals) and stories of peers managing similar challenges. Although the stories in our text messaging probe were not designed to represent the issues of Black people in particular, our findings suggest they were relatable based on shared mental health challenges. Relatability could likely be further enhanced through including stories explicitly written by Black Americans. These content-related suggestions are feasible to implement within a text-based program, including through crowdsourcing methods [62], or potentially soliciting stories directly from users of the DMH tool, as part of their therapeutic disclosure process [60].

#### Integrating "Safe Spaces" within DMH Tools

While some design ideas focused on content that could be integrated within the existing structure of Small Steps SMS, others pushed the boundaries of what an automated text messaging program can deliver. We had initially conceived of the text messaging program as a technology probe, and the discussion groups as a space for collecting data, but participants equally took inspiration from the discussion group in proposing design directions for DMH tools, reflecting on the features that could best support the construction of a "safe space" within which they could share without the risk of invalidation. In other studies, asynchronous discussion groups have been used not only to establish understanding of users but as delivery tools for social support [63]. Our findings suggest that these groups may provide an appealing approach to support Black individuals' mental health. Participants identified benefits of the direct interaction the group affords via its threaded conversations, the group's moderation processes, and the boundaries of group membership. Although less frequently highlighted by participants, the group also featured anonymity, researcher-constructed discussion prompts, a text-based format, and asynchronicity. In what Walther [64] termed "hyperpersonal communication," asynchronicity can allow participants time to deliberately present themselves, while the reduction of nonverbal cues in text-based exchanges allows readers to focus on the content of the disclosures, potentially supporting idealization of one another and bonding that may even exceed what face-to-face communication allows.

There are various technologies that could potentially be applied to construct digital "safe spaces" for therapeutic disclosure. Our discussion group shared many similarities with online support groups, which individuals can use to connect with geographically dispersed strangers, and which are typically bounded by a shared experience or identity, creating a comfortable context for disclosure of sensitive issues [65]. Many online support groups include features like interactivity, anonymity or pseudonymity, and moderation [66,67]. Using SMS or messaging apps could potentially allow for both interpersonal and programmatic support via the same technology. However, it is important to consider the specific context under which DMH tools facilitate the disclosure of distressing events, particularly traumas. Disclosure alone, if not accompanied by appropriate support and guidance, may increase emotional arousal, which has the potential to be harmful for individuals [46,68]. Thus, moderators may require specific training in responding to trauma disclosures and linking individuals to appropriate resources.

Regardless of the technology used, constructing supportive peer-to-peer communication environments is generally less scalable than delivering fully automated tools, particularly when forums are moderated and when boundaries are enforced around membership. In our study, participants' eligibility was vetted, and staff were trained in a code of conduct, risk management protocols, and moderation procedures. They also reviewed, daily, all new messages posted within the group and acted, if needed, to uphold the code of conduct and ensure safety. Such human labor is often the most complex or costly aspect of a DMH program [69,70], although efforts are underway to make moderation processes more scalable, such as through crowdsourcing [71], or automation [72,73], although these efforts must be complemented by appropriate human-in-the loop review [74,75]. While challenging, providing moderated social spaces may be essential to address the paucity of disclosure opportunities Black people experience and their specific fears of invalidating responses.

#### Extending Openness Beyond the DMH Tool

Despite not being involved in formal mental health care, many participants were open to the possibility of seeking it in the future. The primary barrier they reported was their limited ability to find providers with shared racial backgrounds. Many participants described that they would connect to formal mental health services that are designed with Black people in mind. They suggested that a DMH tool should increase understanding and availability of culturally appropriate services, including by providing directories of Black clinicians and connecting users to immediate technology-delivered care from Black providers (e.g., teletherapy). Thus, participants challenged the division of support into formal and informal programs, suggesting that these should be integrated.

Furthermore, some participants found that using the text messaging program and engaging in the discussion group changed how they felt about treatment. Some described a more general change in openness, such that they considered sharing about their mental health with close others to whom they had not previously disclosed. Others noted that their engagement with Small Steps SMS helped them recognize gaps in their existing support systems, prompting them to seek additional or alternative forms of help. Designing for ongoing help-seeking and eventual termination would recognize the evolving nature of individuals' support needs, and the ways that different forms of informal, formal, and interpersonal support may be complementary over the long-term.

#### **Limitations**

This study has limitations. First, although we sought to minimize barriers to participation, our sample represents those willing to discuss mental health issues and interact with researchers. Given our research focus on DMH tools, our sample may also represent those who are interested in or comfortable with technologies. In addition, our study included web-based and SMS components, which limits our ability to speak to the needs of those who lack access to a mobile phone or internet. Our sample overrepresents women. This is typical in DMH research but limits our ability to represent the needs of Black men. Mental health stigma can be especially high for Black men [16], leading for some to argue for programs specifically targeted or tailored to Black men [76]. Our study also included anyone reporting their race as Black or African American, therefore encompassing individuals from diverse ethnic and cultural backgrounds, including individuals who may be African American, Black Caribbean or African migrants and immigrants, or second-generation immigrants, among others. However, we did not collect data on these backgrounds or how they shaped participants' experiences and views. Future research should consider within-race ethnic differences when designing and tailoring DMH tools. Our inclusion criteria also allowed for multiracial participants (if they also identified as Black or African American), but their representation in our sample was low. The needs of multiracial individuals are important to consider, especially when tools introduce boundaries based on racial identity or background.

# **Comparison with Prior Work**

Our findings add to a growing literature establishing the negative effects of pervasive racism, bias, and discrimination on the health of Black adults [7,77,78]. Past work has examined the effect of racism on outcomes like chronic stress, general mental and physical health, and cardiometabolic conditions [79,80]. For example, one study, which used data from Gallup and the US Census before and after the 2020 death of George Floyd to examine anger, sadness, depression, and anxiety among Americans, found that these emotions and symptoms spiked among Black people [81]. In addition, by leveraging mobile phone technologies, research has begun to examine the in-the-moment effects of experiences of discrimination, which may lead to longer-term outcomes [82,83].

Our work provides support for some established approaches to inclusive design of DMH tools. Past work suggests that story-based text messages (i.e., narratives) can be a valuable form of mental health support and are well-received when they are perceived to be authentic, when they balance

positivity with a realistic portrayal of the narrator's struggles, and when narrators are relatable to the receiver [62]. The relatability of narratives has also been enhanced by closely matching the circumstances of the story authors and receivers, such as where African American veterans compose narratives of managing hypertension for other African American veterans with the same condition [84]. Inclusive design may also involve creating a "safe space" wherein users can directly interact with those with shared identities and express themselves authentically [89]. Some work has sought to support conversation with peers via texting, including as one-to-one text chats. Work by Ybarra et al. [85] facilitated one-to-one chat between sexual minority adolescent boys alongside pre-scripted automated messages that supported practicing safe sex and HIV prevention. Moderated group chats have also been applied to improve psychosocial functioning [86], increase preventive care [87], and support outpatient psychiatric care [88].

Furthermore, past work has emphasized the need for technologies to support transformations that occur, over time, in individuals' social needs as they use a DMH program. For example, individuals may move from needing informational support when considering and initiating behavior change to needing partnership and accountability when maintaining their change [90]. Our findings suggest a similar need for technologies to align with changes in openness to help-seeking. This may include framing help-seeking as an evolving process, demystifying it, and prompting periodic consideration of the sorts of help a person might want, as well as having external resources available to participants at any time. Decision-making tools may also help the user arrive at the appropriate treatment approach given their current priorities [91,92]. Such processes of deciding and committing to continue or leave treatment are built into some psychotherapies (i.e., termination) [93], but largely have not been explored in relation to DMH tools. Such an approach might avoid a common problem in which users report that their disengagement with a tool, even if that tool has met their needs, becomes a source of guilt and stress that is counterproductive to their mental health [94].

#### **Conclusions**

Despite the potential for DMH tools to help address racial disparities in mental health care, this has yet to be achieved. To contribute to the design of tools that can reach and benefit Black adults outside of formal care, this paper examined how non-treatment engaged Black adults perceived an existing automated text messaging tool and how they envisioned DMH tools being designed and refined to better reflect their experiences and meet their needs. Participants shared that the mental health challenges of Black individuals differ from other racial groups in that they are compounded by inequity, discrimination, and bias, and that these issues must be directly addressed within mental health tools. Participants endorsed text messaging as a medium for delivering convenient and non-stigmatizing self-management support but also endorsed platforms that can facilitate moderated conversations between individuals with shared racial backgrounds, emphasizing that such opportunities are essential since they lack other "safe spaces" within which to discuss the role of race in their mental health. Future work should consider how text messaging can support social interaction between Black participants, as well as considering other platforms that can construct a safe social environment to complement self-management programs.

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# **Supplementary Files**

# **Multimedia Appendixes**

Discussion group prompts analyzed in the present study.

URL: http://asset.jmir.pub/assets/073f78ffac3ddcced90e08660cdcd025.docx

Example participant SMS interactions in the present study.

URL: http://asset.jmir.pub/assets/4266de1e4e344bdf9e47167a088dd0d0.docx