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Research Article

Acceptability of an Online Brief Mindfulness Intervention for Sickle Cell Disease Pain

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ABSTRACT

Background: Sickle Cell Disease (SCD) pain negatively impacts the quality of life among People Living With Sickle Cell Disease (PWSCD). New intervention methods, including Mindfulness Based Interventions (MBIs), have been used to manage various forms of chronic pain but their potential for addressing pain among PWSCD has not been extensively studied. The aim of the study was to evaluate the acceptability of a 20-minute, video adaptation of the Mindfulness-Oriented Recovery Enhancement (MORE) program for addressing pain among PWSCD: Mini MORE.

Materials and methods: PWSCD (N=32) were recruited *via* advertisements on online platforms and their responses to semi-structured interview questions were gathered for analysis. Thematic analysis using the method of constant comparison based on Grounded Theory was used to analyze the transcribed responses.

Results: The study revealed three main themes: (1) Pain; (2) pain triggers and management; (3) social support and stigma; and (4) preferences and recommendations for the Mini MORE video. The needs and preferences of PWSCD identified from this study are expected to help improve mindfulness interventions for alleviating SCD pain or other forms of chronic pain.

Conclusion: This study demonstrated that the Mini MORE video, a brief mindfulness intervention, could be a potential method for mitigating pain among PWSCD. Feedback from participants on how to improve the Mini MORE video will inform the adaptation of future mindfulness videos for addressing pain among PWSCD. Health practitioners and researchers should further investigate the potential opportunities for using MBIs to manage pain or treat other diseases.

Keywords: Sickle cell disease; Pain management; Mindfulness practice; Intervention; Mindfulness oriented recovery enhancement; Acceptability

INTRODUCTION

Sickle Cell Disease (SCD) is a genetic disease that affects approximately 100,000 people in the U.S [1]. SCD pain negatively and severely impacts the quality of life among People Living with Sickle Cell Disease (PWSCD). For example, the international Sickle Cell World Assessment Survey (SWAY) found sizable proportions of PWSCD reporting that SCD pain negatively impacted their emotions (60%), limited their school achievement (51%) and reduced their ability to work (53%) [2]. Simulation modeling has suggested that PWSCD lose approximately $700,000 in lifetime income compared with a matched non-SCD population [3].

While traditional, behavioral methods of managing SCD pain have shown limited efficacy, recent findings indicate Mindfulness

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Based Interventions (MBIs) may be promising. A meta-analysis of different mind-body interventions for chronic pain found that MBIs produced the largest effect size for improving in pain outcomes [4]. Mindfulness Oriented Recovery Enhancement (MORE) was one of the most effective MBIs included in this meta-analysis. The traditional MORE programs is an eight-week, sequence treatment that unites complementary aspects of mindfulness training, cognitive behavioral therapy, and positive psychology to disrupt the downward spiral of chronic pain [5-7]. A recent meta-analysis of MORE trials (k=8) found moderate to small effects in favor of MORE for chronic pain (SMC=-0.60, $p<0.001$) and psychiatric symptoms, such as anxiety and depression (SMC=-0.34, $p<0.001$) [8]. A brief MORE format (i.e., Mini MORE) has been developed to introduce pain patients to the core principles of MORE in a single, 15-20 minute session as the traditional, eight-week MORE format may be inaccessible to some patients due to time or resource constraints. Results from three randomized controlled clinical trials indicate Mini MORE immediately decreased acute pain and psychiatric symptoms, while also improving pain-related outcomes four to six weeks after exposure [9-12].

Given Mini MORE's promising results among individuals with a variety of pain-related conditions and the lack of effective behavioral treatments for SCD pain, we conducted an observational pilot study among PWSCD experiencing pain (N=32) in which Mini MORE was delivered through an asynchronous, online video format to further increase accessibility [9,12]. Results indicated association between Mini MORE exposure and significant improvements in clinical symptomatology among PWSCD. PWSCD also reported decreased pain intensity (Δ=-1.7, $p<0.001$, Cohen's d=2.19) and pain unpleasantness (Δ=-2.1, $p<0.001$, Cohen's d=2.20). Collectively, findings from our pilot study suggest continued exploration of Mini MORE for SCD pain may be useful.

As a next step in this research program, the current qualitative study conducted semi-structured interviews with the Mini MORE PWSCD pilot study sample with the aim of gaining a more comprehensive understanding of PWSCD's experience with and acceptability of using the Mini MORE to address SCD pain.

MATERIALS AND METHODS

Recruitment

Online advertisements on platforms, including paid ads on Facebook and Nextdoor, as well as free ads on Facebook Groups and Reddit were used between October 25 and November 8, 2022 to recruit participants (N=32) in the United States living with SCD. The ads linked directly to a Qualtrics survey with screening questions. In order to be eligible, PWSCD needed to be 18-30 years old, residing in the U.S. and diagnosed with SCD based on self-reporting. Those who were not eligible were told that their information would be destroyed for confidentiality. Those who were eligible were called to confirm they were a unique person to ensure spam and bots were not enrolled as part of the study. Initially, 71 PWSCD were screened over the phone and 32 participants agreed to and completed the Zoom interviews. The Zoom meetings were conducted with cameras on and were recorded for later analysis and transcription. More details about the broader recruitment methods and sample are available online [13].

Interviews

Semi-structured interview questions were created in consideration of two aspects-lived experiences of PWSCD and qualitative feedback from participants on how to improve the Mini MORE video for managing SCD pain. Accordingly, the interviews were conducted in two parts. The first part occurred before the participants watched the Mini MORE video and was asked to describe their experiences with SCD pain. The second part of the interview was conducted after Mini MORE was delivered and focused on what the participants liked and disliked about the video as well as recommendations for improving it. After the interview, participants were emailed an individualized link to audio recordings of supplemental practices (e.g., mindful reappraisal) and were encouraged to use the recordings as much as they wanted. Finally, participants received a $10 Amazon gift code for completing our initial screening over the phone and a $20 Amazon gift code for completing the Zoom interview. No compensation was provided for listening to the supplemental practice recordings.

Analysis

Google's Speech-to-Text Application Programming Interface (API) was used to transcribe audio files. These transcribed texts were reviewed manually and any inaccuracies or errors from the API were rectified. Thematic analysis was conducted using the method of constant comparison based on Grounded Theory [13,14]. The authors engaged in three rounds of inductive coding to analyze the semi-structured interview data. Throughout this process, the authors iteratively discussed and refine emergent codes and themes. The first round involved open coding which led to the emergence of codes including pain sites, stigmatization, triggers, and methods for pain management. The second round of coding focused more on the reactions and feedback of participants regarding the video itself. Codes including feedback on the length of the video, feedback on the speaker in the video, and conditions for continued use of mindfulness videos arose during this round. In our last round of coding, refinement (e.g., merging and deletion of codes) of codes was conducted to create major themes. Pain triggers and management, for instance, which were initially considered to be separate themes, were merged into one theme during this round based on the realization that the personal ways for managing pain from each participant are connected with the pain triggers that manifest differently across individuals.

RESULTS

Most participants who were screened to be eligible and participated in interviews were male (n=19; 59.4%), African Americans (n=31; 96.9%) and were young adults ranging from 18 to 30 years old with an average age of 26.06 as shown in Table 1.

Category	Groups	Interviewee
N		32
Age (mean, SD)		26.06 (2.96)
Race (%)	White	0 (0)
	African American	31 (96.9)
	American Indian or Alaska Native	0 (0)
	Asian	0 (0)
	Native Hawaiian or Pacific Islander	0 (0)
	Other	1 (3.1)
Ethnicity (%)	Not Hispanic or Latino	23 (71.9)
	Hispanic or Latino	9 (28.1)
Gender identity (%)	Female	13 (40.6)
	Male	19 (59.4)

Table 1: Demographics of study population.

Content analysis of interviews revealed 3 major themes: (1) Pain; (2) pain triggers and management; (3) social support and stigma; and (4) preferences and recommendations for the Mini MORE video.

Pain

Frequently mentioned pain sites were the back, chest, arms and joints. Words such as sharp and stabbing were often used to describe the nature of the pain. Some participants also associated fatigue, headaches and loss of appetite with SCD. The frequency of the occurrence of pain or crisis episodes varied considerably among participants from every day to once a year. The worst cases involved infections or complications such as pneumonia. One participant depicted her SCD pain to be more severe than that of an arm fracture.

Pain triggers and management

There were some common situations that participants said could potentially aggravate SCD pain. Some of them were changes in seasons, cold weather, and exposure to rain. Higher stress was also associated with more severe and frequent pain. For coping with pain, taking medications including Tylenol and Oxycodone, regular intake of vitamin A and C, having more vegetables in the diet, and visiting SCD specific clinics were the most common approaches. Keeping the room dark was one of the more uncommon methods mentioned for dealing with pain.

Social support and stigma

Pain was only a part of the entire lived experiences of the participants. Many of them have been going through stigmatization where they were perceived as weak and incapable of standing up for themselves. Participant 27 used the expression "fragile glass" as a metaphor for how others view them while participant 28 expressed frustration with people not having interest in getting into a relationship with a SCD patient due to stigma. Moreover, they were emotionally and mentally drained by the inability to enjoy everyday activities, including participation in social gatherings, while also having to witness the death of individuals within their close network due to SCD, as in the case of participant 28 whose father died from SCD recently. In addition, narratives from PWSCD revealed that support networks were crucial for managing SCD pain. Participant 27, for instance, explained the importance of her support groups as safe havens that protect her from stigma. The quote from participant 29 also illustrated the need for support networks and how they are not always available for everyone.

Reactions and feedback to the Mini MORE video

Every participant was either not aware of what mindfulness practice was or has only used it for recreational purposes (e.g., meditation as part of a yoga class). The majority (n=19; 59.4%) of the participants responded that they would want videos that were 10 minutes long or less and, in general, did not seem to prefer any video that was too long for their attention span. Morning or evening before going to bed was the most popular time of the day for watching mindfulness videos. 25% (n=13) of the participants said they wanted either a doctor or a person with professional qualifications either in psychology or philosophy as the speaker of the video. 15.6% (n=5) wanted a person that shared similar demographic traits (e.g., age, race, ethnicity) or someone who had experienced SCD before.

Participants used expressions including relaxing, soothing, calming, stress reducing, really good, and enough hope for the pain to go away to describe their experiences with the video. The ability of Mini MORE to be able to take away the participant's attention away from their surroundings, reality and pain was noted frequently as well.

The participants, however, made suggestions on potential changes to the videos. First, some participants wanted the voice of the speaker to be more soothing and monotone and also found certain uses of figurative language as unrealistic. Second, some participants thought the video would become more immersive if peaceful music, images of nature; clips of someone else following the meditation instructions given in the video and affirmative content were included in the video.

Daily reminders were brought up by 12.5% of the participants (n=4) as a way to ensure the consistent use of mindfulness resources to help with pain as illustrated by one of the quotes from the following. But above all, the satisfaction that the Mini MORE video yielded seemed to be the primary incentive for the continued use of the video. Lastly, 68.8% (n=22) of the participants answered that they would feel comfortable or be

interested in sharing their experiences with mindfulness to an online community such as a Facebook Group.

DISCUSSION

This qualitative study conducted semi-structured interviews to describe the various aspects of SCD including pain, stigma, and trigger situations, and evaluate the acceptability of Mini MORE for addressing SCD pain. This study demonstrated that the Mini MORE intervention video for SCD pain was acceptable to participants with generally favorable reactions.

Critically, this study presented future directions for researchers interested in exploring mindfulness as a means to manage pain that comes from SCD or other diseases. For instance, designers of future mindfulness videos may want to consider creating multiple versions of the video with different lengths. Approximately 60% of participants indicated a preference for limiting videos to ten minutes, which suggests those Mini MORE videos of ten minutes or less may be more acceptable. Fortunately, preliminary evidence suggests that ultra-brief MBIs may also be capable of producing immediate and long-term pain-related benefits. For example, a recent randomized control trial found a three-minute, nurse-led mindfulness intervention immediately decreased surgical patients' pain intensity, pain unpleasantness, and pain medication desire [15]. Relatedly, repeated use of an ultra-brief (i.e., 30 second) mindfulness practice was found to be associated with improvements in non-SCD chronic pain two months later [16].

Participants also expressed a desire for the Mini MORE video to be more visually interesting or immersive. Suggestions included changing the images accompanying the mindfulness instruction and adding some visual or auditory aspects of nature throughout the video. This latter suggestion is empirically supported. A recent randomized controlled trial conducted on a non-clinical population found that watching a video of others meditating while meditating relative to watching a nature scene or nothing at all most effectively induced a state of mindfulness in novice practitioners and strengthened their feelings of social connectivity [17].

Incorporating social connectivity during video guided mindfulness practice appears particularly relevant for PWSCD. Participants shared common experiences of SCD-related stigmatization and noted the benefit of social support and connecting with others with SCD. Future adaptations of the Mini MORE video could include a speaker with SCD that can share their experiences with mindfulness and pain management. The video could also be accompanied by an online community where PWSCD share their experiences with mindfulness. Future trials could also explore the addition of specific elements to improve initial engagement, such as the incorporation of affirmations, or elements to improve continued mindfulness practice, such as daily practice reminders.

Despite study strengths, including being one of the first known studies to qualitatively examine the acceptability of a brief MBI for SCD pain and the majority of participants expressing satisfaction with Mini MORE, study limitations should also be noted. First, participants self-reported their diagnosis of SCD and study methodology did not allow for medical verification of a SCD diagnosis. Future studies may want to rely on blood or genetic testing or partner with SCD clinics for a more rigorous verification of SCD status. Second, participant responses were also self-reported and thus may be subject to social desirability bias. Researchers may want to increase sample size and recruit participants mainly from offline sites including SCD clinics to improve the generalizability of the studies. Third, as stated in the results section, most participants were male (n=19; 59.4%), African Americans (n=31; 96.9%) and young adults ranging from 18 to 30 years old. Therefore, insights and takeaways from this study may not be necessarily relevant to certain groups of the SCD population that were not sampled.

CONCLUSION

This study demonstrated that the Mini MORE video, a brief mindfulness intervention, could be an acceptable and accessible pain intervention among PWSCD. Qualitative feedback from participants will help inform future adaptations of Mini MORE for PWSCD. Health practitioners and researchers should further investigate the potential opportunities for using brief MBI interventions to manage pain conditions.

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DECLARATION OF INTEREST

No potential conflict of interest was reported by the author(s).

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