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Understanding preferences for a mindfulness-based stress management program among caregivers of hematopoietic cell transplant patients

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ABSTRACT

Informal caregivers of allogeneic hematopoietic cell transplant patients experience significant levels of stress throughout the caregiving process. One strategy that has been shown to aid in stress management in other populations is mindfulness. The goal of this study was to understand caregivers' experiences with mindfulness and evaluate their receptiveness to a mindfulness-based stress management program. Data were collected via in-depth phone interviews from 18 caregivers (55% female). Results indicated that about half the sample was familiar with mindfulness and/or had practiced meditation. The majority indicated that they believed a mindfulness program would have been useful for them and that they would have been willing to participate. Most indicated that a program delivered once-weekly for 60 min, during both inpatient and outpatient phases, would be preferable through a combination of in-person and mobile-based delivery. These data provide critical information for the development of future mindfulness-based interventions for this caregiving population.

1. Introduction

Providing informal care for allogeneic hematopoietic cell transplant (HCT) patients entails significant responsibility during the acute transplant period (i.e., the initial 90 days of treatment) and through the next several years [1,2]. The HCT patient is required to have a caregiver who is reliable, in good health, and available for 24 h per day to provide the necessary physical and emotional support. Once deemed eligible, the caregiver must attend medical training in order to learn how to provide care for the patient. Training includes care for the administration of medications, nutrition, hygienic precautions, and the ability to identify early any symptoms of opportunistic infection. The caregiver must attend all patient appointments for the first 90 days post-transplant and is responsible for communicating with the transplant team [2]. Often, caregivers juggle this on top of their existing responsibilities, such as work or childcare, as well as previous responsibilities of the patient that the caregiver must attend to (e.g., paying bills) [1].

Extant literature has determined that caregivers experience high levels of stress during and after HCT. Prior to the transplant, caregivers indicate higher levels of anxiety, stress, and poor sleep when compared to the general population [3]. Post-transplant, caregivers have reported experiencing high levels of isolation, worry/anxiety about infections developing in the patient, low levels of social support, and permanent life changes due to caretaking [4]. Another study assessed caregivers' well-being several years post-transplant and found that when compared to the patients, caregivers reported lower levels of social support, decreased spiritual well-being, greater marital dissatisfaction, and higher loneliness. Further, when compared to a control group, they had 3.5 higher odds of depression [5]. Thus, it appears that caregivers experience elevated levels of emotional distress, and that caregiver distress can be higher than in the patients themselves.

Alleviating caregiver stress is obviously important for the caregivers' own quality of life, but the benefits could extend to the patient as well. Extant research has found that increased external social support (e.g., family and friends) among transplant patients is associated with better emotional and physical well-being [6], lower post-traumatic stress disorder symptom severity [7], decreased depressive symptoms [8,9], and lower distress [10]. As such, offering a stress management program to caregivers should not only aid the caregivers, but could also attenuate psychological symptoms among patients. One potential stress management strategy for caregivers that we discuss further here is mindfulness.

Mindfulness has been defined as directed, flexible cognitive processing that allows an individual to observe thoughts and emotions, without immediately reacting to them [11]. A central factor in this process is the ability to direct attention in a particular, purposeful way [12,13]. Through directing attention, individuals can alter automatic cognitive processes, and in turn increase cognitive flexibility (i.e., the

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experience is viewed from an outside, objective perspective) [13–17]. This ability to actively choose where to put attention could be very useful for caregivers, given the many tasks and responsibilities they have in caring for the patient. Further, it would allow the caregiver to be fully present with whatever is happening in that moment – organizing medication, having a conversation with the doctor, helping the patient to the bathroom. Although these tasks require close attention, having to manage so many responsibilities may naturally result in divided attention and subsequent mistakes/errors.

Another primary component of mindfulness is *how* attention is directed. Through mindfulness exercises, individuals are encouraged to take a nonjudgmental stance towards their experiences [12,13] – in other words, to not judge a given thought/emotion/sensation as good or bad, right or wrong. Cultivating this attitude toward life experiences may be particularly beneficial to cancer caregivers, given the high degree of worry and apprehension surrounding their patient's diagnosis and course of treatment. In fact, among cancer caregivers who were close family members of an individual diagnosed with cancer, higher acceptance (i.e., being accepting of things you cannot change) was associated with greater life satisfaction [18]. Overall, this nonjudgmental awareness taught via mindfulness can result in the reappraisal of a given situation [19–21] (e.g., from “I'm a terrible caregiver” to “The worry I am experiencing about my husband's health is normal, and we will continue to talk with the doctor regarding the next steps in his cancer treatment”). Importantly, the ability to reappraise or reframe a stressful situation has been associated with posttraumatic growth/benefit finding among cancer patients and caregivers [22,23].

Finally, mindfulness has been associated with a host of positive health outcomes including decreased negative affect [24–29], increased positive affect [28,30–32], and increased self-efficacy [33–36]. Mindfulness may also have physiological benefits, including reducing stress directly (e.g., decreased cortisol) [37,38]. Creswell proposes a stress buffering effect of mindfulness, which states that mindfulness not only lowers an individual's general experience of stress, but also reduces reactivity to stress when it occurs [39]. Importantly, this model posits that mindfulness is most beneficial for those who experience levels of high stress. For example, when exposed to a stressful situation, individuals with high levels of mindfulness had lower stressor cortisol reactivity activity than individuals exposed to a non-stressful situation [40].

Currently, cancer centers usually provide stress management services on an as-needed basis through social workers and support groups to caregivers. Most services are available only at the hospital or clinic; logistically, these sessions can be difficult to attend, especially after patient discharge. To our knowledge, the only other study that has evaluated a caregiver-only behavioral intervention for this population [41,42] identified challenges and limitations of providing such a treatment, including participants not engaging in all aspects of the treatment and the need for flexibility in scheduling treatment sessions. Further, this study examined an intervention that was primarily rooted in a cognitive-behavioral approach. As such, the current study not only gathered caregivers' responses to a proposed mindfulness-based treatment for the management of stress and general emotional support, but also collected their feedback regarding the logistics of implementing a stress management intervention during the active phase of the patient's treatment in an effort to consider these challenges and limitations in subsequent program design. To date, a few small-scale, single-arm studies have investigated mindfulness-based interventions for the cancer patient-caregiver dyad with promising results [43–45]. Nonetheless, no prior work has attempted to provide a mindfulness-based treatment to caregivers-only within this population, and therefore this research fills an important gap in the existing literature.

The current study collected information from allogeneic HCT caregivers on their perceptions of whether a mindfulness-based stress management program would have been useful for them during the active transplant period of their patient. These discussions took place via in-depth phone interviews. Caregivers were individuals caring for patients that were at least one year post-transplant. Information regarding the timing of intervention delivery (e.g., during the hospitalization period of the patient vs post-discharge) and best modality (e.g., in-person vs mobile-based) was also gathered. This study had three primary aims. Aim 1: To determine caregivers' general level of familiarity and prior experience with mindfulness. Aim 2: To determine whether caregivers would be open and willing to try a mindfulness-based stress management program. Aim 3: To determine the ideal time point and modality for the delivery of a stress management program for caregivers.

2. Method

2.1. Participants

Participants were eligible if the following criteria were met: 21 years of age or older; a caregiver of a patient diagnosed with hematologic cancer; caregiver's patient must have received an allogeneic HCT at the cancer center at least one year prior but not more than three years ago; caregiver's patient must be currently relapse-free; able to provide informed consent; and able to speak and write in the English language (accommodations were made for a participant who had difficulty hearing over the phone; for this person, the set of interview questions was mailed, and the hand-written responses were returned to study staff).

2.2. Measures

2.2.1. Demographics

Demographic information was collected from participants during the initial phone screen which included gender, age, marital status, and race/ethnicity.

2.2.2. General familiarity with mindfulness

Participants were first asked whether they had ever heard of mindfulness before (yes/no). They were then asked “When you hear the word mindfulness, what does it mean to you?” Finally they were asked “Have you ever practiced anything related to mindfulness before?”

2.2.3. General familiarity with meditation

Participants were asked “When you hear the word meditation, what does it mean to you?” followed by “Have you ever meditated before?”

2.2.4. Usefulness of mindfulness strategies

Participants were given a general definition of mindfulness and then two different types of mindfulness strategies were presented to them (informal and formal). Specifically, participants were told “A common definition of mindfulness is the ability to stay focused on the present moment without judging it as good or bad. This basically means that a participant in our program would learn skills to help keep them focused on the present moment in order to help manage stress and make clearer decisions. People who participate in mindfulness programs have reported better quality of life, lower levels of stress, and better mood.” For the informal strategy, a general definition of this type of skill was provided, followed by some examples (e.g., focusing on breathing or the sounds you hear as a way to bring your focus back to what you're doing in a given moment). For formal, a description of a type of formal meditation was given (20 min of sitting meditation on the breath). For both informal and formal, participants were queried about their general reaction to the strategy, which included two questions about usefulness and willingness to use the strategies: “How useful do you think this type of strategy would have been for you?” and “How willing would you have been to try what I just described?”

2.2.5. Modality for intervention delivery

Several questions were asked related to how the intervention should actually be delivered. Variables of interest were: number of days per week for sessions to be held, length of each session, format (in-person, via technology [mobile/app-based/website]), and timing (while patient is inpatient, after discharge, or both).

2.2.6. Entering program

In order to potentially increase our ability to recruit for a mindfulness-based program in the future, we asked participants what type of information would have increased the likelihood that they would have enrolled in a mindfulness program when they were actively caring for the patient in the hospital.

2.3. Procedure

Participants (N = 18) were identified via chart review and by clinical staff to establish initial eligibility and relationship to the patient. Next, potentially eligible caregivers were sent a letter via the mail explaining the goals of the study. This mailing contained a cover letter explaining the mail-out, an opt-out letter for any individual not interested in participating, and the informed consent document (to be reviewed over the phone with study staff). If we did not receive an opt-letter within two weeks of the mail-out, caregivers were contacted via phone. This phone call confirmed what was found in the patient chart regarding eligibility criteria and collected any remaining information (including relevant demographic information). Additional details of the study were discussed and the caregiver was given time to ask any questions. If interested in the study, the verbal informed consent process was conducted over the phone. Following consent, a phone interview date and time was scheduled.

Consented participants were then contacted for a semi-structured phone interview which was audio-recorded. The interview contained two phases. The first phase collected information on the participants' general experiences being a caregiver, including emotions experienced and coping strategies. The second phase collected information related to caregivers' knowledge and experience related to mindfulness, whether they would have been interested in a mindfulness-based program when they first started the transplant process with their patient, and their opinions on timing and mode of delivery for this type of intervention. This paper will present data collected in the second phase, as this information directly informs the development of a mindfulness-based intervention for this caregiving population.

Following completion of the phone interview, participants were compensated for their time by receiving a gift card of $20. When the gift card was mailed out to the participant, the mail-out included a note thanking them for their participation in the study. At the completion of the study, all participants were mailed a letter providing them with details on the general findings of the study.

Interview audio recordings were transcribed by research staff. Answers to closed-ended questions were entered into SPSS for descriptive statistical analysis. Responses to the open-ended questions were analyzed for common themes by four study staff, trained in qualitative analysis and familiar with the mindfulness and caregiving literature. Using the constant comparison method, the research team conducted multiple rounds of coding to establish inter-rater reliability (kappa > .7) prior to fully coding all transcripts for analysis. Common themes are presented here. All procedures were approved by the cancer center's Institutional Review Board (Protocol #: 19176).

3. Results

Following a chart review of potentially eligible caregivers (518 medical charts were reviewed), a total of 43 caregivers were identified as potentially eligible and mailed study packets. Six opt-out letters were received back to the clinic, and therefore we contacted 37 individuals via phone. Of those, 18 did not complete the phone screen for various reasons (10 lost to contact/voicemails left and never heard back; 3 had a wrong number or phone was disconnected; 3 were not interested; 1 was too busy; and 1 was not the caregiver of the patient). Thus, of the 37 contacted, 19 participants were screened, deemed eligible, scheduled for the phone interview, and completed the interviews. However, it was later discovered that one participant's patient received the transplant for an illness other than cancer; this was overlooked in the initial medical chart review, as this person should have been ineligible for the study. Thus, this caregiver's data are not reported below, and the final sample included 18 participants.

Participants (N = 18) were 55% female with an average age of 61.60 (SD = 8.52). The majority were married/partnered (83%), White (83%), and non-Hispanic (83%). Most participants indicated being the spouse of the patient they were taking care of (72%), followed by being a parent (16%), sibling (6%), or child (6%).

3.1. General familiarity with mindfulness

Regarding participants' general familiarity with mindfulness, half of participants indicated that they had heard of mindfulness before, whereas half of the sample had not. When explaining what mindfulness meant to them, participants provided statements that generally fell into the following categories: awareness/where you put your attention, relaxation, focus, and a way of coping. When asked if they had ever practiced anything like mindfulness, 44% reported yes, 50% reported no, and 6% was unclear (one participant indicated no, but then went on to describe a mindfulness strategy).

3.2. General familiarity with meditation

Regarding meditation, 44% indicated that they had ever meditated before and 50% did not (one participant's response was unclear). When asked about the meaning of meditation, many participants referenced the ability to be focused (e.g., focus your mind; focus on something specific) and sitting down. Some people indicated that meditation is thinking of something peaceful or good, or calming the mind/self. Others said it was clearing the mind, reflecting on something, or prayer.

3.3. Usefulness of mindfulness strategies

When asked about usefulness and willingness, 78% indicated that the informal mindfulness strategies would have been useful and 83% reported that they would have been willing to try informal mindfulness strategies as a caregiver if asked to do so as part of a mindfulness-based program. When asked the same questions about formal mindfulness practices, 89% stated they thought formal meditation would have been useful for them, and 83% indicated that they would have been willing to try formal meditation as a caregiver.

3.4. Modality for intervention delivery

Participants were asked a series of questions related to how they would have liked to receive a mindfulness-based intervention. Table 1 presents a detailed description of what participants reported. Regarding frequency, the most consistent response was one time per week, followed by two or more times. The majority indicated that sessions lasting 30–60 min would be preferable. Regarding format, most indicated that a combination of in-person and mobile/app-based/website would be useful. Regarding when during the transplant process caregivers thought it would be best to receive a mindfulness-based intervention, slightly fewer than half reported only wanting to receive the intervention during the initial transplant period when the patient was inpatient, whereas most thought that implementing the program during both the inpatient and outpatient (after the patient is discharged to the local area) would be useful.

Table 1
Modality for intervention delivery.

Frequency	
Less than once per week	5%
Once per week	39%
Twice or more per week	17%
Other (e.g., vary by patient preference)	22%
Unclear	17%
Length	
Less than 30 min	17%
30–60 min	61%
Greater than 60 min	5%
Unclear	17%
Format	
In-person	33%
Mobile/app-based/website	6%
In-person and mobile	61%
Timing	
Inpatient period	40%
Outpatient period	5%
Both inpatient and outpatient	55%

3.5. Entering program

Participants provided various suggestions regarding what would have increased the likelihood that they would have participated in a mindfulness-based program. The most common responses were that: the program be presented/offered to them early in the caregiving process; the intervention be informed by what other caregivers went through (e.g., previous caregivers contributed to the intervention content); the program be recommended by other caregivers who already completed it and/or from the physician; flexible scheduling of sessions; and that an emphasis on the importance of caregiver self-care is provided when the program is initially introduced. The most common barrier reported was that it would have been difficult to leave their patient to attend this type of program. One person stated that the term "mindfulness" may turn some people off.

4. Discussion

The primary goal of this study was to collect information from caregivers of allogeneic HCT patients on their perceptions of a mindfulness-based program, followed by gathering their suggestions on how to make implementing this type of program feasible. Overall, about half the sample was familiar with mindfulness and had practiced meditation at some other point in time. Importantly, after hearing a general description of the mindfulness-based program and examples of the types of exercises that would be included, the majority of the sample indicated that they believed this type of program would have been useful for them and that they would have been willing to try this type of program. Most participants indicated that a program delivered once-weekly for no more than 60 min, during both the inpatient and outpatient phases, would be preferable. A combination of in-person and mobile-based delivery was also endorsed by most participants. Lastly, participants provided several useful suggestions for recruiting potential caregivers into this program (e.g., presenting the program as an option early on; hearing that it was useful for other caregivers). That said, taking time for themselves (and leaving their patient's side) was indicated as a barrier to recruitment.

Information gathered through these interviews can be used to aid in the development of stress-management interventions for allogeneic HCT caregivers. Given some of the unique responsibilities of these caregivers (e.g., needing to be with the patient at all times for about 90 days post-transplant), one potential concern is that caregivers may not be interested in enrolling in a stress management program that focuses on themselves. Indeed, taking time away from the patient was identified as a barrier to entering this type of program. To our knowledge, the only other intervention developed for this population was a cognitive-behavioral therapy (CBT) treatment [41,42]. In this study, the authors emphasized the need for flexibility in scheduling treatment sessions, as the caregivers often wanted to spend time with their patient. Nonetheless, our findings here indicate that caregivers would have been interested in being offered a stress management program. Further, findings from Laudenslager and colleagues indicated that a CBT-based intervention was feasible with this population, despite the need for flexibility in scheduling sessions [41,42].

Receptivity to a mindfulness-based program is also a potential concern [46], particularly among those with no prior knowledge of mindfulness or meditation (or even misperceptions of these practices). Although we found that about half the sample had not heard of mindfulness or meditation before, after hearing descriptions of what these terms do mean, the majority of the sample reported that this type of program would have been useful for them and that they would have been willing to try this type of program. Such findings suggest that moving forward to develop a mindfulness-based program for this population would be beneficial, all while including psychoeducational information on the definitions of mindfulness and meditation.

Given these caregivers spend so much time with their patient, logistical concerns about meeting regularly with this caregiving population were high. Information gathered in this study provides crucial information about the frequency and timing of an intervention, along with how to provide the intervention itself. It appears that a program delivered once per week for no more than 60 min would be ideal, and that the program should span across both the inpatient and outpatient phases. Finally, it seems that most caregivers would appreciate an intervention that involved both in-person and mobile-based delivery. Indeed, Simoneau and colleagues [42] recommended that future work with this population should utilize mobile-based technology to better reach caregivers, which corroborates with what we heard from our sample. Potential ways to incorporate mobile-based delivery could be a phone application that includes mindfulness practices (e.g., meditation recordings), reminder notifications to practice being mindful throughout the day, or even videos with mindfulness content. To aid in retention, delivering the session content via skype or some other video-conferencing application could also be useful.

Limitations of this study should be noted. First, caregivers were interviewed 1–3 years post-transplant of their patient. Although this was purposeful in that we wanted to talk with caregivers who had experienced the entire caregiving process, we may have missed information that only current caregivers could provide. Second, when asked about mindfulness and meditation, only a description of these terms/practices was provided. Caregivers did not get the opportunity to actually practice these exercises and then give their feedback. Third, we only interviewed caregivers of allogeneic HCT patients. Thus, caution should be taken when generalizing these findings to other caregiver populations. Fourth, it is important to note that this study collected data on the intentions of caregivers, and not actual behavior. Thus, it is possible that additional issues could arise upon the implementation of a mindfulness-based intervention that was not captured here. Fifth, our definition of mindfulness and reported outcomes associated with mindfulness programs could have influenced the responses of participants. Our goal was to provide a brief summary of mindfulness that would be similar to what we would tell participants upon recruiting them to a mindfulness intervention. Thus, we believed a brief definition combined with typical outcomes observed in other research would be most useful.

5. Conclusions

In sum, this study presents the first data on perceptions of a mindfulness-based intervention for caregivers of allogeneic HCT patients. Vital information was collected on usefulness/willingness to engage in a mindfulness-based intervention, along with timing and modality of intervention delivery. Such findings can guide the development of future programs for this population, with specific emphasis on mindfulness-based interventions.

Additional information

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Conflicts of interest

The authors have no competing interests to declare.

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