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Research paper

Understanding coping strategies of cancer caregivers to inform mindfulness-based interventions: A qualitative study

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ABSTRACT

Introduction: Caregivers of allogeneic hematopoietic cell transplant (HCT) patients experience high levels of stress, and a better understanding of the commonly used coping strategies can guide intervention development. Mindfulness-based interventions are one promising approach that could augment and extend existing coping strategies. This study examined in-depth phone interviews conducted with HCT caregivers to gather information about coping strategies used to manage stress and other difficult emotions while taking care of their patient.
Method: Participants (N = 18; 55% female) completed phone interviews, which were transcribed and hand-coded for analysis. Thematic content analysis was used to code responses.
Results: Five primary coping strategy themes were reported: physical activity, spirituality, hobbies, social support, and avoidance. Caregivers also provided information about what they gained from the caregiving experience (*e.g.*, increased empathy).
Conclusions: Based on these findings and in an effort to move the intervention development field forward, a discussion is presented on how mindfulness-based strategies have the ability to augment existing coping strategies and perhaps modify unhelpful strategies.

1. Introduction

Caregivers of allogeneic hematopoietic cell transplant (HCT) patients report high levels of stress both during and after the transplant [1–3]. High stress is likely related to a number of factors including the potential emotional impact of a family member/friend who is undergoing an arduous cancer treatment and the significant amount of responsibility caregivers are asked to take on to care for the patient. For at least the first 90 days, caregivers are asked to be available 24/7 to care for the patient, which includes medication administration, arranging patient appointments, specific food preparation, extensive hygienic precautions, and identifying any early symptoms of infection [4,5]. High levels of stress have been shown to extend several years post-treatment [1]. Further, HCT caregivers may have few psychosocial resources to cope with the stress; one study found that when compared to the patients themselves, caregivers reported lower levels of social support, decreased spiritual well-being, greater marital dissatisfaction, and high loneliness [1].

Among general informal caregivers (not necessarily cancer caregivers), more time spent caring for the patient and higher caregiver strain were associated with shorter telomere length, a marker of cellular aging [6]. Another non – HCT cancer study found that long periods of hospitalization can contribute to increased stress among caregivers, which may have implications for the HCT population, given their length of stay in the hospital [7]. Importantly, interventions designed for caregivers have the ability to improve mental health [8,9]. For instance, results from a meta-analysis of cancer caregivers recommended that empirically-based interventions developed for caregivers have the potential to not only impact caregiver health (*e.g.*, coping skills, quality of life), but also that of the patient [9].

One approach that may aid in successful caregiver coping is enhancing the use of mindfulness-based strategies. Mindfulness has been defined as the ability to direct attention to the current moment, without judging it as good or bad [10,11]. Theoretical models posit that mindfulness functions through various mechanisms including increased cognitive flexibility, the ability to shift perspective/decenter, increased emotion regulation, and enhanced attention [12–14]. Mindfulness practices aim to cultivate a sense of nonjudgment and acceptance toward experiences (*e.g.*, emotional states, physical sensations), all while maintaining focus on the present moment. Previous research has posited that mindfulness-based strategies may aid caregivers in managing

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stress [15,16]. By practicing mindfulness, cancer caregivers can cultivate the ability to attend to specific tasks important in that moment (*e.g.*, food and medication prep), as well as have a tool to help manage worry and apprehension surrounding their patient's health status. Previous research has found that among cancer caregivers who were close family members of an individual diagnosed with cancer, higher acceptance was associated with greater life satisfaction [17].

In order to develop behavioral interventions that alleviate stress in this caregiving population, a better understanding of current coping strategies used by these individuals is needed. By understanding current coping strategies, interventions can be designed to augment what caregivers already do that is helping them manage stress and perhaps curb unhelpful coping (*e.g.*, avoiding difficult emotions or situations). This study examined in-depth phone interviews conducted with allogeneic HCT caregivers to gather information about coping strategies used to manage stress and other difficult emotions while taking care of their patient in the acute phase of the transplant process.

In an effort to bridge the gap between currently used coping strategies among allogeneic HCT patients and intervention development, here we present those coping strategies most commonly reported by participants in our study, followed by a brief discussion of how these strategies may align with a mindfulness-based intervention. Thus, this paper is meant to move the intervention development phase forward by making recommendations on how mindfulness and existing coping strategies might intersect.

2. Method

2.1. Participants

Participants in this study met the following eligibility criteria: 21 years of age or older; a caregiver of a patient who was diagnosed with a hematologic cancer who received an allogeneic HCT at the cancer center at least one year prior but not more than three years ago; caregiver's patient must have been relapse free; able to provide informed consent; and speak and write the English language (one participant was mailed the interview questions due to difficulty hearing).

2.2. Procedures

All procedures were approved by the cancer center's Institutional Review Board (IRB). Following an initial chart review by clinical staff, potentially eligible participants were contacted via mail (sent a letter explaining the study, an opt-out letter, and the informed consent document). Participants were contacted two weeks later if no opt-out response was received. Eligibility criteria was confirmed (if originally collected from the patient chart) and then additional information was gathered (*e.g.*, relevant demographic data). The verbal informed consent process was completed via phone, and for those who agreed to participate, an interview date was scheduled. Participants then completed the semi-structured phone interview and were compensated with a $20 gift card. Data presented here include questions regarding their general experiences as a caregiver, including specific coping strategies they used at that time to manage distress and other difficult emotions (these coping data are presented here).

All interviews were recorded and transcribed for qualitative analysis. We conducted thematic content analysis using the constant comparison method to identify themes within and among the interview transcripts relevant to coping strategies and mindfulness [18]. Coders included the first, second, third, and last author, and the first author was the lead coder; coders were all trained in qualitative analysis and familiar with the theoretical models of coping and mindfulness. All individuals coded two transcripts, met to discuss results, and then coded two additional transcripts, at which point inter-rater reliability (kappa > 0.7) was met. Coders then continued rating transcripts until all were completed. Specific coping-related themes were then derived, which are reported here. All procedures were reviewed and approved by the cancer center's institutional review board. Hard copies of data were stored in a locked filing cabinet; electronic data was de-identified and stored in password-protected files that were accessed by members of the study team.

2.3. Measures

2.3.1. Demographics

Demographic information was collected from all participants and included age, gender, marital status, and race/ethnicity. We also collected information on relationship of caregiver to the patient.

2.3.2. Coping

Participants were asked about coping strategies used during both the hospitalization phase and post-discharge phases of their patient's treatment. Specifically they were asked, "What did you do to cope with stress and [any other emotion they had previously mentioned] during the hospitalization?" When the questions shifted to the discharge phase, participants were asked what they did to cope at that time, if it was any different from the hospitalization phase. We specifically asked about these two time periods separately, as the role of the caregiver is fairly different across each. For the hospitalization phase, the patient is inpatient for about 3–4 weeks, with the patient's primary care being the responsibility of the medical team. Post-discharge, which typically lasts 90 days, primary care for the patient shifts to the caregiver [4].

2.3.3. Personal gains

Participants were queried about whether they personally gained anything from the caregiving experience with the question, "Overall, what do you think you gained as a person and/or emotionally from going through the experience of caretaking?".

3. Results

After an initial chart review, 43 individuals were identified as possibly eligible and were mailed study packets. Six individuals returned opt-out letters. Thus, 37 individuals were contacted by phone and 18 were not eligible for various reasons (*e.g.*, not interested, phone disconnected). A total of 19 participants were screened, deemed eligible, consented to the study, and completed the phone interviews. However, it was later learned that one participant did not meet one eligibility criterion (received the transplant for a non-cancer illness); thus, this person's data were not used in the final analysis. Participants were 55% female with an average age of 61.60 (SD = 8.52) years. Most were married/living with a partner (83%) and non-Hispanic White (83%). The majority reported being the spouse (72%) of the patient they were caring for, followed by parent (16%), sibling (6%), or child (6%). All patients received their cancer treatment at the same cancer center where data were collected.

Five primary themes related to coping emerged and are discussed in more detail below – physical activity, spirituality, hobbies, social support, and avoidance. Participants were also queried about anything they may have personally gained throughout the caregiving experience and those data are also presented here. Following the presentation of each theme, we briefly discuss how that particular coping strategy may (or may not) relate to mindfulness practices.

3.1. Physical activity

Many participants indicated that engaging in physical activity/exercise was a useful coping strategy, both while their patient was in the hospital and post-discharge. When the patient was in the hospital, caregivers commonly indicated that physical activity allowed them to feel "refreshed" and to "decompress."

> "You have to get out and get some fresh air – walk, go around the hospital, go around the campus. Just decompress." - Caregiver 1

> "When someone else was in the room with him or when the time was right, I would go walking on the campus. So when I was there I would go for half hour walks twice a day." - Caregiver 2

Post-discharge, caregivers tended to highlight how physical activity was an important self-care strategy, and sometimes indicated that they were able to be physically active (usually via walking) with the patient.

> "It's really important to eat properly and go walk, exercise, or whatever. That becomes much more important after discharge than even before, because your time becomes more limited – your options become limited." - Caregiver 2

> "It is as important for the caretaker to do their exercise and watch what they eat, or do as much as the patient does… You almost have to make the effort – like the doctors ask the patient to walk a certain amount each day. As a caregiver, you almost need to do that." - Caregiver 3

> "I was ecstatic because we were outside, we were able to go outside the building. We were just too happy we found a little park down the road where you could go and walk and see alligators and all the creatures. We found all of that stuff was just great. That was wonderful." - Caregiver 4

Many mindfulness-based programs include an element of physical activity, usually as a formal meditation practice that involves mindful movement and mindful walking [19,20]. Regarding mindful movement, individuals are asked to be fully present with whatever sensations are currently existing in their body (*e.g.*, tightness, tingling) as they move through various poses. For example, in mindful walking, the instructor asks participants to notice the sensations of walking – how it feels to put their foot on the ground, how the muscles engage in the legs during each step, *etc*. These movement practices encourage present-moment awareness of the physical body and participants are asked to move in a way that is comfortable for them. Caregivers in the current study clearly found benefit in physical activity, and mindfulness-based interventions would likely supplement existing physical activity regimens by encouraging a non-judgmental, present-moment focus on the specific activity. Further, participants would likely learn new movement exercises that are taught within the program itself.

3.2. *Spirituality*

Many participants indicated that their spirituality/religious beliefs allowed them to better cope with the patient's course of treatment. This theme was consistent throughout the inpatient and post-discharge period. Specifically, spirituality was often discussed in the context of managing emotions (*e.g.*, fear) and several individuals indicated that their faith allowed them to realize what they did and did not have control over regarding their patient's health status (suggesting that their spirituality may have enhanced acceptance of their current situation).

> "I'm a spiritual person so obviously I prayed and spent time in the chapel and just meditation; trying to center myself so that I wasn't spinning out in front of him." - Caregiver 5

> "…the old saying 'don't be afraid' in the Bible… Not that there weren't some days when on my way home, not out of fear, but of concern, there would be tears rolling down my cheeks. So you know, you can't just keep it bottled in, you have to accept the fact that there's some things out of your control, and there's so many things that you have to be humble about, Wherever that help comes from – friends or family, or medical staff, or that faith in a higher power." - Caregiver 6

Although mindfulness-based interventions are generally secular, for individuals who are religious/spiritual, mindfulness may complement these faith-based activities. For instance, mindfulness practices aim to cultivate non-judgment of the present moment, with the goal to be present with whatever is happening in that specific moment [19]. Consistent with previous research [21], participant responses suggested that spirituality may be related to a sense of acceptance of the current circumstance. Additionally, mindfulness practices train an individual to put their attention where they want it, which may enhance present-moment focus during prayer or other spiritual practices. In fact, a recent study found that participants reported mindfulness practices as supplementing their religion and spirituality [22].

3.3. *Hobbies*

Participants indicated that they would engage in certain hobbies as a caregiver. Although some indicated taking up new hobbies as a way to cope with caregiving, most reported engaging in activities that they already knew would be helpful for them. Although not explicitly stated, it is clear that caregivers felt limited in the type of hobbies they could engage in and the amount of time to devote to them, especially post-discharge of the patient. As such, most hobbies appeared self-contained and fairly simple. Physical activity overlaps somewhat with this theme, and we do not repeat those statements here.

> "You could say I was depressed because I wanted to be home so bad. That was the hardest part – being away from my family for months. But, I would watch TV and knit; I knitted hats for cancer patients." - Caregiver 7

> "I taught myself how to quilt. I just bought a lot of squares and started learning. I just kept doing that." - Caregiver 4

Inherent to mindfulness practices is the ability to put your attention on a specific experience (breath, physical sensation, emotion) and to intentionally shift your attention to another experience as wanted [10]. Caregivers can apply mindfulness when engaging in specific hobbies as a way to stay fully present with that activity. When the mind does wander to something else, an individual who practices mindfulness is likely to be aware that this is happening, and then are able to bring their attention back to the task at hand. Relatedly, the concept of flow is often discussed in the context of mindfulness, which is when a person is so focused on a specific activity, that they become fully immersed in that task, enjoying it without being distracted by other thoughts, emotions, *etc* [23–25]. Mindfulness practices may allow caregivers to be more engaged and present with whatever activity they are doing, which has the potential to increase enjoyment/pleasure with that activity.

3.4. *Social support*

There is strong evidence that high quality social support is a vital component to caregiver well-being and is also associated with better patient well-being [9,26–32]. However, isolation and the desire for social support was a commonly-reported theme among caregivers in the current study, especially while the patient was hospitalized and for those who traveled far from home for their patient's treatment. Furthermore, depending on the patient's health status, visitors to the hospital may be limited, which adds to the existing visitor restrictions in this population (*e.g.*, no children under the age of 12). For many of the caregivers in this sample, the patient was their spouse, and this person likely served as a strong source of social support pre-treatment [33]. Thus for some caregivers, they may have lost their primary source of support, as the patient is not typically focused on supporting the caregiver during treatment.

> "…because we live on the East coast, we didn't have too many people come visiting us. Actually that was a hard part for me. I felt very isolated." - Caregiver 8

> “Everyone’s situation may be different, but for us, we have some family support so we were able to do those things. And then when the doctors allowed, we were able to just take simple things and make a big thing about it, you know?” - Caregiver 2

This feeling of isolation made the high-quality types of support even more meaningful for caregivers:

> “They set up a class, a group meet, and said, hey, anybody want to join us? It is helpful to talk to people and you understand people’s situations and sometimes you end up getting a perspective of ‘okay you’re not alone or you’re not the only one going through it’ or whatever. You know what I mean?” - Caregiver 2

> “I have a ton of friends on Facebook that I would talk to about it, and I had so much support from them. That really helped.” - Caregiver 9

Caregivers of cancer patients, especially HCT patients, often experience isolation and the need for additional social support. In situations where social support can be obtained and likely beneficial, the medical team should encourage caregivers to seek it out. That said, there will be many instances where this simply isn’t possible. A primary component of mindfulness practices and mindfulness-based interventions is harnessing the ability to “sit with discomfort.” Mindfulness provides a unique opportunity for caregivers to experience discomfort that arises from isolation, without trying to avoid it. Additionally, through increased awareness that is cultivated via mindfulness, caregivers may more quickly identify their need for support and therefore seek out support sooner.

3.5. *Avoidance*

Another common coping strategy reported by caregivers was related to avoiding their own emotional or physical needs, in order to focus on the patient.

> “And when it involves my husband I absolutely put my own wants, or needs, or feelings, or emotions to the side as if they never existed because I told the medical team, I told them, ‘look if it takes the last breath I have in my body, this man is going to walk out of here.’ And that is the mindset that I kept for the entire time that he was in treatment and after he was discharged.” - Caregiver 10

Many reporting “just doing it” and not really processing what was happening for themselves in those moments. These strategies were more commonly reported when the patient was hospitalized.

> “Well I think after that it becomes your norm, right? …you just put yourself on autopilot, and it’s almost kind of like you forget about what you’re feeling…” - Caregiver 11

> “There wasn’t a lot I could do. I was just working and driving and trying to do… It was just that I was so busy I didn’t have time to think.” - Caregiver 12

Mindfulness practices encourage individuals to be with unpleasant experiences, whatever they may be, without trying to get rid or avoid them. This should ultimately cultivate the ability to sit with discomfort, which is particularly useful when a situation is out of one’s control. It is very possible that this general avoidant/“non-focus on the self” as a caregiver may be a beneficial coping strategy in the short-term. However, over time, this avoidant approach to difficult experiences is likely to cause additional stress and lower quality of life [34,35]. Mindfulness-based interventions specifically teach and encourage individuals to sit with unpleasant experiences through formal and informal practices (*e.g.*, sitting meditation, urge surfing). Examples include emotional discomfort (*e.g.*, sadness, frustration) or even physical discomfort (*e.g.*, aching feet or back). By staying with these experiences (even if only for a minute), the individual is able to become more aware of what is happening in their body and/or mind, in order to determine the most effective “next step.” Immediately engaging in avoidance strategies without allowing oneself time to notice what is happening could result in additional stress and decreased quality of life as discussed in the avoidance coping literature [34,35].

3.6. *Personal gains*

Caregivers were asked about what they might have personally gained through the experience of being a caregiver. Several common themes were voiced here, including a greater appreciation for their life and patient, greater empathy for other people, gaining strength as a person, and growing in their ability to show compassion for others.

> “I think it gave me a better understanding of what compassion is. Because in focusing on the one you love, it didn’t mean that there wasn’t enough left to focus on the other people around you.” - Caregiver 6

> “I have learned to become more tolerant. I have become a better listener. I am more in love with my husband than ever before.” - Caregiver 10

Many highlighted the importance of appreciating the current moment, and being grateful for what they did have.

> “Now I learned life is short and you need to live each day like it could be your last. I learned that you need to tell people that you love them and that it’s critical to tell how you feel and make sure people know how you feel.” - Caregiver 5

> “You learn to appreciate the little things. I’m not bothered by what things used to bother me. It’s kind of like, ‘really’? So yeah, things don’t bother me as quickly anymore because I think when you go through something like this, that life-altering, changing, whatever… I think you start to really be thankful for what you have versus what you don’t have…” - Caregiver 11

These quotes highlight that although being a caregiver is stressful and difficult at times, many individuals report growing personally and/or in their relationship with the patient. This ability to find benefit from a stressful life experience is associated with increased resiliency and personal satisfaction [17,36]. Importantly, benefit finding/posttraumatic growth is associated with the ability to reappraise/reframe stressful situations [37,38], and nonjudgmental awareness that is taught via mindfulness has the ability to teach caregivers how reframe a given situation [39–41].

Inherent to mindfulness practice is a focus on the current moment, which has the ability to cultivate a greater appreciation for whatever that moment has to offer [10,42]. Caregivers reported having an appreciation for the present, along with more empathy for others. Recent research suggests a positive association among mindfulness and empathy, suggesting that mindfulness-based practices could cultivate empathy for others [43–45]. Thus, it is possible that practicing mindfulness could compliment, or even enhance, the personal gains reported here.

4. Conclusions

The current paper identified several coping strategies reported by caregivers of allogeneic HCT caregivers, falling into themes including physical activity, spirituality, hobbies, social support, and avoidance. Participants also voiced how they personally grew from the caregiving experience (*e.g.*, increased empathy, appreciation for life). Although caregivers report various coping strategies here, the larger HCT literature indicates that they continue to experience very high levels of stress at all stages of the caregiving process [1–3]. Thus, future researchers will want to determine how to provide support for these caregivers regarding stress management, and mindfulness-based interventions may be one promising avenue.

As outlined above in the results, we indicate how mindfulness may specifically relate to each theme reported by caregivers, suggesting the basis for this practice may already exist in ongoing activities. When considering the larger implications of these findings, mindfulness has the potential to aid caregivers in ultimately having more awareness of what they need in a given moment. This might be any number of things, including increased physical activity, social support, *etc*. When considering the theoretical underpinnings of mindfulness, enhanced attention might be one of the main underlying mechanisms that could aid caregivers in choosing appropriate coping strategies for a given situation. Through increasing general awareness via mindfulness, caregivers can possibly learn to take better care of themselves emotionally, cognitively, and physically. In addition to mindfulness increasing attention such that an already-useful coping strategy is implemented, mindfulness interventions may also teach new skills that allow a caregiver to better manage stress (*e.g.*, decentering, cognitive flexibility). Although these hypotheses are supported by the theoretical literature, empirical studies are needed to fully test whether these mechanisms actually underscore behavior change among HCT caregivers.

Future researchers will want to further explore whether mindfulness-based practices aid cancer caregivers in managing stress. Wood et al [15] summarize how Mindfulness-Based Cognitive Therapy (MBCT) may aid cancer caregivers in managing difficult thoughts and emotions by presenting how to tailor the MBCT session content for cancer caregivers. This paper does not actually test whether MBCT would aid in the management of stress, but instead proposes how that could be done. Our paper adds to this literature by presenting data on current coping strategies of HCT caregivers, and then outlining how mindfulness may relate to existing coping strategies. A few previous pilot studies have investigated mindfulness programs that target the patient/caregiver dyad with promising findings [46–48]. However, extrapolating how these findings would extend to HCT caregivers is difficult, primarily because of the small sample sizes, lack of comparison treatment conditions, and targeting the patient/caregiver dyad (*i.e.*, the programs were not specifically for caregivers). To our knowledge, no large-scale study has been conducted to determine whether a mindfulness intervention would result in the expected beneficial effects among cancer caregivers, much less among HCT allogeneic caregivers.

Although these findings provide unique information regarding the coping strategies of HCT caregivers, limitations of the present study should be noted. Our sample consisted of only HCT allogeneic caregivers, and therefore generalizing these findings to other cancer caregiving populations should be done with caution. Additionally, caregivers were interviewed 1–3 years post-transplant, which could result in memory recall bias. As discussed previously, findings from this study make sense in light of theoretical models of mindfulness; however, additional research is needed to demonstrate support for such hypotheses (*e.g.*, that learning mindfulness increases attention such that caregivers can skillfully choose which coping strategy to use in a given moment). Future research should also explore what barriers might exist to engaging in certain coping strategies (*e.g.*, logistical concerns), as well as what could augment such strategies (*e.g.*, reminders to practice new skills).

Overall, these findings highlight those coping strategies that are used by allogeneic HCT caregivers during the acute transplant period. Based on these findings, future research should explore whether a mindfulness-based program would augment and extend current coping strategies for stress management.

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Declaration of Competing Interest

The authors have no conflicts of interest to declare.

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