



Older Adult Caregivers' Experiences in an Online, Interactive Mindfulness Intervention

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Abstract

Background. While today's older adults experience longevity, they often manage several chronic conditions and increasingly serve as informal caregivers for aging parents, children with life-long disabilities, and spouses. Older adult caregivers managing personal chronic illness often experience significant psychosocial hardships. **Objective.** The primary purpose of this study was to explore the experiences of older adult caregivers in an online, interactive mindfulness intervention. **Methods.** Self-reported older caregivers who participated in an online-based mindfulness program (n = 20) were recruited for semi-structured interviews. Participants were asked to provide feedback about any previous experience with mindfulness and/or meditation, hopes or goals held prior to the start of the program, desired expectations, motivation for joining, impressions of sessions, most beneficial topics, potential application of content, and any perceived effects. Participants' responses were analyzed using qualitative content analysis. **Results.** Five themes emerged from the analysis: Managing the Comprehensive Effects of Caregiving, Openness to Meditation and Mindfulness, Course Engagement and Incremental Growth, Building Rapport through Shared Experiences, and Ongoing Application and Opportunities for Refinement. Participants reported both short-term post-exercise benefits such as increased calm, relaxation, and stress relief, as well as long-term positive outcomes. Notably, participants found the program's unique interactive feature to be particularly beneficial as a form of perceived social support. **Conclusions.** Caregivers for older adults may derive benefit and potentially experience reduced subjective caregiver burden as a result of participating in a Mindfulness-Based Stress Reduction (MBSR) program, particularly when the program is augmented with a self-compassion approach and perceived social support.

Keywords

mindfulness, meditation, interventions, older adults, MBSR

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Introduction

Shifting demographics in the United States have yielded an increasing population of older adults. In 2014, the population of individuals aged 65 or older was 14.5%, projected to increase to 23.5% by 2060.^{1,2} While today's older adults experience longevity, they often manage several chronic conditions³ and increasingly serve as informal caregivers for aging parents, children with life-long disabilities, and spouses.^{4,5} A report published by the AARP Public Policy Institute and the National Alliance for Caregiving in 2015 found that 34.2 million Americans provided unpaid care to an older adult in the previous year.⁶

Many older adults, particularly those with personal chronic illness, experience significant hardships while attempting to provide care for others. Caregiver burden refers to the physical, financial, and psychosocial hardships of caring for a loved one struggling with a medical condition.⁷ Objective burden results

from providing physical forms of assistance, while subjective burden is related to the psychological, social, and emotional impacts of objective burden.⁸ Caregiver burden affects emotional, social, financial, and physical domains and is estimated to affect up to 32% of caregivers.⁹ Adverse health outcomes associated with caregiver burden include social isolation and anxiety,^{10,11} higher rates of depression,^{12,13} mortality,¹⁴ poorer quality of life,¹⁵ and cardiovascular disease,¹⁶ with possibility

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of increased burden experienced over time.¹⁷ A study of caregivers found 36% were vulnerable older adults experiencing difficulty with providing care and poor personal health.¹⁸ Further, caregiver burden also adversely affects recipients of care, with reported outcomes including more frequent hospitalizations and higher levels of mortality.^{19,20} Caregivers often describe psychosocial contexts that include complicated emotional reactions to their caregiving responsibilities, such as struggles with stress, anxiety, exhaustion, loneliness and pain.^{21,22} Therefore, efforts to ameliorate caregiver burden potentially provide benefit for both caregivers and recipients.

Mindfulness refers to one's focused attention on the present moment and nonjudgmental awareness.²³ Bishop et al. proposed a 2-component model of mindfulness, with the first component consisting of the self-regulation of attention, allowing for increased recognition of mental events in the present moment. The second component involves adopting a particular orientation toward one's experiences in the present moment, an orientation that is characterized by curiosity, openness and acceptance.²⁴ Mindfulness meditation as a practice refers to focusing one's attention on the emergence of thoughts, emotions and body sensations while observing them as they arrive and pass.²⁵ Trait mindfulness and mindfulness interventions demonstrate changes in underlying biological mechanisms that contribute to mindfulness benefits,²⁶ such as reducing the connection between the amygdala and other regions of the brain that drive stress reactivity, decreasing respiratory rates and potentially normalizing diurnal cortisol secretion among those with high cortisol levels.^{27,28} Further, mindfulness interventions have been found to counteract the sympathetic fight or flight response by increasing parasympathetic nervous system activation.^{27,29} These biological changes potentially contribute to positive outcomes in other aspects of health and wellness.

Mindfulness meditation positively influences several aspects of physical health, including increased immune functioning,³⁰⁻³³ increased telomere activity,³⁴ reduced blood pressure and cortisol levels.³³ Psychological benefits include reduced stress, anxiety, depression, medical symptoms and psychological distress.³⁵⁻⁴¹ Further, the practice of mindfulness promotes well-being, improves focus, reduces loneliness and related inflammatory responses to loneliness;³⁰⁻³² is inversely related to neuroticism and rumination, and positively related to body satisfaction.^{42,43} Research has shown that individuals with a higher degree of mindfulness are more empathetic toward others and themselves, compassionate, accepting and have stronger interpersonal skills.^{44,45} Therefore, the benefits of mindfulness-based interventions are particularly promising for older adult caregivers experiencing psychosocial issues related to their caregiving responsibilities. Mindfulness-Based Stress Reduction (MBSR) interventions have helped caregivers manage stress across a variety of care contexts, including recipients with chronic illness,²³ developmental disabilities,⁴⁶ and dementia,⁴⁷ and have demonstrated reduction in caregiver burden.^{23,48}

Historically, in-person attendance at mindfulness sessions has represented a key limitation for caregivers. However, recent interventions acknowledge the increased rates of technology usage among older adults⁴⁹ by offering online adaptations of MBSR program offerings. Research has established the feasibility of an online MBSR program for older adult caregivers⁵⁰ but greater insight is needed to understand these participants' experiences with engaging this material in an online format. Thus, the primary purpose of this study was to determine the effects of participation in an online, interactive MBSR intervention for older adult caregivers.

Methods

This study was part of a collaboration between (blinded) and (blinded). The overall goal of this collaboration was to explore the potential benefit of an online mindfulness intervention in improving mental and emotional health for older adult caregivers. This study was approved by the New England Institutional Review Board (NEIRB #12070334), an independent institution that reviews for protocols for nonacademic institutions.

Overview of the Intervention

The 7-week course was based upon MBSR and Mindful Self-Compassion approaches. Session topics over the course of the 7 weeks included the following: 1) Mindfulness and Healthy Aging, 2) Anchoring with the Breath, 3) Resiliency, Social Connectedness and Wellbeing, 4) Mindful Body Awareness, 5) Working with Thoughts, Challenging Emotions, 6) Challenging Body Sensations, and 7) Compassion, Kindness, and Action Planning. Participants were given the option of attending 1 of 2 weekly sessions led by a trained facilitator via WebEx. During the WebEx session, participants were able to engage in 2-way communication with the facilitator and other attendees using a chat function, and when the facilitator allowed individual feedback.

All sessions were 60 minutes except for the first session, which was scheduled for 90 minutes to accommodate orientation-related tasks, including introductions, an overview of the program, and initial troubleshooting of any technology-related issues. During the course of each weekly session, the facilitator led a brief discussion of the previous week's topic, presented didactics related to the chosen topic, and facilitated a guided meditation. The facilitator initiated open-ended questions related to module content and caregiving experiences, and also allowed time for participants to further discuss topics or questions related to the course topic or caregiving resources after the official close of the session.

Participants unable to attend a live session at the designated time were invited to attend previously recorded "drop-in sessions," which included review of didactics presented via PowerPoint presentation and a prerecorded guided meditation. Pre-recorded sessions presented didactics and the meditation exercise using a PowerPoint format, which did not allow users to interact with the facilitator or other attendees in real time. Additional program resources included a resource library with videos, additional tips, supplemental readings, and meditation exercises indexed according to topic.

Recruitment

This study was the second phase of a larger multi-phase research study intended to better understand the health-related issues of older adults covered by AARP® Medicare Supplement Plans from UnitedHealthcare (for New York residents, UnitedHealthcare Insurance Company of New York).

In this phase, a qualitative research study was conducted using standard qualitative procedures for conducting and analyzing semi-structured interviews. The purpose of these interviews was to elicit participants' experiences while participating in a mindfulness program. Participants who previously participated in the first phase of the study were recruited to participate in semi-structured interviews.

The interview guide consisted of 13 questions. Questions elicited feedback for a number of topics. The interview guide included questions that asked participants to describe the degree to which they were familiar with the concepts of mindfulness and meditation prior to learning about the program, any previous experience practicing mindfulness and/or meditation, whether any friends or family members practiced mindfulness and/or meditation, any hopes or goals held prior to the start of sessions, and any desired expectations as result of their participation in the program. Participants were asked to share their role as a caregiver, any support or help received in that capacity, current sources of emotional support, existing opportunities to connect with other caregivers, and existing coping mechanisms. Questions also asked participants to describe their initial impressions of the sessions, motivation for joining, comfort level with managing technology, potential areas of focus, details regarding the customary setting of their meditation practice, completion of "homework" assignments, and attendance at optional "drop-in" sessions. Additionally, interview guide questions asked participants to describe favorite, most helpful and least helpful topics, potential application of new learnings, and any observed effects in their lives (in general or caregiving specifically). In addition, they were asked to describe any changes to perspective or mental, emotional, or physical health. Several questions prompted participants to describe the degree to which they interacted with the instructor or other caregivers in the group, the nature and topic of those interactions, whether they requested advice or resources from others, and any potential benefit derived from those interactions. A few questions elicited participants' satisfaction with program administration, including reminder calls, clarity of instruction, and perceived accessibility of available support. Lastly, participants were invited to provide feedback of any nature.

Eligible participants from the first phase of the study were stratified according to age range and gender, with the aim of recruiting an equal proportion of participants from each segment. Given recommendations that indicate 12-20 participants as an adequate sample size for an interview study,⁵¹ investigators planned an initial goal of 20 interviews, after which they decided to assess whether data saturation had been achieved and recruit additional participants if necessary.⁵² Data saturation refers to the point at which no additional characteristics within categories emerge as significant in the process of analysis.⁵³

A marketing research company was provided with a list of the 56 eligible participants who completed T1 and T2 surveys (out of 135 who originally enrolled and only completed a T1). The marketing company was instructed to recruit participants with as even a distribution as possible among age range and gender, given the available sample. Recruiters contacted participants by telephone, verified identity, explained the study, and scheduled interviews with the first 20 participants successfully recruited according to the guidelines for stratification. Verbal consent was obtained prior to the start of the

interview. Interviews lasted approximately 1 hour. No personal identifiers were collected. All interviews were audio recorded and transcribed verbatim.

Overview of Intervention

The primary purpose of the intervention was to determine if participation in an online meditation intervention would improve the mental and emotional health of older adult caregivers. The first phase of the study consisted of a program evaluation in which a sample pool of AARP Medicare Supplement certificate holders, previously identified as caregivers, were recruited for participation in the study. Inclusion criteria for the study consisted of those who were previously identified as a caregiver using a screener administered via an interactive voice (IVR) survey in conjunction with AARP's Aging Strong initiative. Exclusion criteria included not being a current enrollee in an AARP Medicare Supplement plan, currently engaged in care coordination services, not currently enrolled in an AARP Medicare Supplement plan, younger than 65 years of age, on the "do not call" list, not having a valid phone number, not web-enabled, and not a caregiver. All other participants were considered eligible for participation. Potential participants received pre-mailer scripts prior to an invitation to participate via telephone. Participants were directed to the provider's website to review terms, conditions, privacy policies, and to provide consent if all terms were amenable.

Three surveys were administered: prior to the start of the program, after the conclusion of the 7-week program, and 30-60 days later to assess the effects of program participation. In addition, participants who registered to participate in the program but missed the first program session received an IVR phone call. Participants also received reminder emails encouraging completion of the surveys.

Analysis

Investigators analyzed participants' transcribed interviews using qualitative description. Qualitative description was an ideal methodology for this data as it draws from a naturalistic perspective, offers flexibility in commitment to a theory or framework, typically involves review of interview data, and allows for maximum variation sampling.⁵⁴

Two investigators (J.H. and R.U.) conducted a qualitative content analysis using an iterative, constant comparison process. During the coding process, both coders independently read transcripts, identified an initial code list, and developed operational definitions. Then coders returned to the transcripts and conducted line-by-line coding that included comparison and refinement of identified coding between both investigators. Coders subsequently discussed, reviewed, and reread interview data to develop final coding and to reach consensus about meaning.⁵⁵ One investigator coded all transcripts while the other coded 50% of the overlap. Both investigators reviewed coding on overlapping transcripts to reevaluate passages coded across researchers, and the codes applied based on the assigned definition in the codebook.⁵⁶ Any conflicts in assigned codes was settled through discussion until consensus was reached.

Next, both investigators examined the properties and categories of all codes to identify opportunities for categorization according to shared properties. Investigators subsequently used this categorization of codes to develop overarching themes that described patterns of usage and provided a narrative of participants' overall use. Throughout this process, investigators were mindful of the biases and existing

perspectives they brought to the analysis. Final coding was imported into Nvivo,⁵⁷ a qualitative software program.

Results

Twenty individuals participated in the study, with an even distribution of males (n = 10) and females (n = 10). Breakdown in age range was as follows: 65-69 (n = 8), 70-79 (n = 10), 80-89 (n = 2). The average participant age was 72.

Dosage data showed the mean number of sessions attended by participants was 6.25 with a median of 7 sessions. Participation among those in this study was higher than that of the overall population of 56 caregivers at a mean of 2.98 sessions attended and a median of 2 sessions.

Investigators ultimately developed 5 themes that reflected participants' experiences, feedback, and reported outcomes: Managing the Comprehensive Effects of Caregiving, Openness to Mindfulness and Meditation, Course Engagement and Incremental Growth, Building Rapport through Shared Experiences, and Ongoing Application and Opportunities for Refinement.

Managing the Comprehensive Effects of Caregiving

Participants' descriptions of their caregiving roles varied. Some described providing in-home support to aging parents, closely monitoring the care of parents residing in care centers, assuming increased responsibility for the care of a spouse who resided with them, or providing care or supervision of siblings. In addition to providing care, participants also described acquiring new duties on recipients' behalf, such as assuming responsibility for finances and medical decision-making.

While several participants were able to name supportive friends or family members, many with significant caregiving responsibilities, such as providing in-home care, expressed a desire for a greater degree of social support and often felt others might not want to hear about their difficulties. Participants reported utilizing a number of coping mechanisms, including exercise, spending time with friends, gardening, home improvement programs, and journaling.

I don't have anyone I can just vent to, but I keep a journal. Somebody told me a long time ago, if you get crazy, sit down and write a letter and then don't mail it—burn it. It's just letting off the steam that's good. But I do think it's my fault if I don't have somebody I can talk to. I think guys have a harder time finding friends like that than women do. (17)

Those with significant caregiving responsibilities were more likely to report difficulty in maintaining social connections, practicing self-care, and identifying consistent, regularly accessible coping mechanisms as a result of their caregiving responsibilities. As one caregiver explained,

Well, I was exercising, but [recipient]'s been in such bad shape, I haven't been able to get back to the gym and everything, and I enjoyed that. For a while I had a friend, and we rode our horses

together for an hour every day or once a week or something, and that helped me. But now I'm afraid to leave [recipient]. I'm afraid he'll fall and nobody will be there. (18)

In this way, participants' self-assessments of their caregiver burden often signaled the need for greater self-care and social support.

Openness to Mindfulness and Meditation

Almost all participants reported familiarity with the terms "mindfulness" and "meditation" and were able to distinguish between them. Slightly over half (n = 11) reported some degree of previous experience with mindfulness/meditation, including previous unsuccessful attempts at self-learning. Three participants described current mindfulness/meditation practices, and 2 others disclosed they had experience with other iterations of meditation, such as transcendental meditation, in previous years. Others were curious to learn more and recognized "mindfulness" as a "buzz word" that had gained increasing popularity in mainstream media. As one participant noted, *Everybody seems to be selling mindfulness one way or the other these days.*

Some participants related previous self-guided attempts at mindfulness or meditation that did not result in sustained effort due to uncertainty or need for further instruction. Many shared they already planned to seek additional information about mindfulness prior to learning about the program.

It was top of mind because my wife actually has Parkinson's disease. The doctor had been encouraging us to learn more about it. We heard more from friends and relatives who'd also done meditation or mindfulness, and so it seemed like something we should explore. (15)

I was excited, I thought it would be very helpful. I was familiar with mindfulness from my own experience, I have read a few books. I'm a librarian at the cancer center, so there's a book about mindfulness dealing with cancer. (6)

Upon learning of the opportunity to participate in the program, those with an existing practice of mindfulness and/or meditation expressed a desire to go "deeper" in their practice, curiosity about the feasibility of an online format, and interest in learning how these principles could apply to their role as a caregiver. Participants with less familiarity about mindfulness/meditation expressed an interest in learning more about these concepts, as well as determining whether these approaches could provide benefit to them as caregivers. Most participants were pleased to learn classes were offered online, increasing the likelihood they could attend.

For many participants, the program represented an opportunity to address caregiving-related challenges, including chronic stress, anxiety, depression, time constraints, and strained relationships.

My time was so fragmented between caring for my wife's needs and my mother's needs, and there was very little time left for me. I'd

heard this expression before, that the caregiver oftentimes will die before the person receiving the care, and I thought, "You know, I'm finding myself in that position. I'm not happy with what's going on and I need to change it. (13)

I just wanted the patience to accept that we're both aging and we can't hear and see as well as we used to. Sometimes it's hard to, you know, be patient. (9)

Accordingly, almost all participants' pre-attendance goals centered on increasing their knowledge about mindfulness, advancing existing mindfulness practice, and reducing stress and distress related to caregiving. Participants also set goals related to reclaiming personal time to address their own needs, improving sleep quality, demonstrating more patience when delivering care, and managing emotions such as anger and impatience.

Sleeping definitely, being able to get to sleep, if I woke up in the middle of the night that I could get back to sleep without my mind taking over with all the negative thoughts. Then also to remember to sort of slow down, kind of mellow or relax a bit more. Like, if the doctor says, "You have to do this," I want my husband to do exactly what the doctor said instead of listening to what my husband says feels good to him. So kind of being present within the situation of what was happening. (12)

To help me not become frustrated and hopeless when certain situations arise, and help me to relax and be able to better work my way through. (5)

When asked to describe their comfort level with managing the technology required for an online-based program, many participants reported they previously used WebEx for work purposes and were familiar with its functioning. A few participants expressed concerns about unreliable internet service in rural areas, aging software or hardware, or less experience accessing the internet.

Course Engagement and Incremental Growth

Most participants reported they completed their sessions in a quiet area of their home, often in one's bedroom, office, or living room while in front of a computer. Participants prioritized locations they deemed the most comfortable, quiet, and private, with the ability to change the brightness of the room if needed. Several participants desired room to lay down during exercises, while others explained they remained seated in a chair even if the session's facilitator suggested lying down at the start of the lesson.

Several participants reported experiencing difficulty with managing the program's technology, including older, incompatible versions of software, and browser issues. However, affected participants reported most issues were addressed and resolved prior to the start of the second sessions. A few participants experienced a lag or buffering as a result of their internet service, and several participants preferred accessing the session via phone.

The majority of participants appreciated the format of the classes, with equal time allocated for didactics and meditation practice, and judged an hour was the perfect amount of time for the class. Favorite topics/concepts included self-compassion, self-care, resiliency, Pause/Breathe/Observe/Respond (PBOR), physical self-care through proper nutrition and sleep, as well as managing physical pain and discomfort.

One of the topics, about caring for yourself while being a caregiver, I thought that was really relevant. Like how a person manages to take care of themselves while they're giving all this attention to other people and energy to other people. How are you going to sustain that if you don't do some stuff for yourself emotionally and every other way? I think it's just vital. (8)

The lesson on gratitude mindfulness. The PBORs. That was the pause, breathe, observe, respond. It's a lot easier for people to receive a response rather than a reaction. And it puts mindfulness and determination into whatever there is. I can be quick with the tongue, and that can be hurtful to the people around me. So PBOR was a good move. (7)

Gratitude, being grateful for where you are and what you are. It's easy to get wrapped up in other people's concerns, other people's problems. Especially if you're a caregiver and feeling for yourself, regretting what you're doing. You're always thinking you could be better off somewhere else or in some other situation. (2)

Individual focus and objectives during meditation exercises varied among participants. While some participants reported close monitoring of the facilitator's voice and instructions, others gave particular focus or effort to various meditation-based components, such as the flow of the breath, relaxation of body parts, clearing the mind, regulating one's flow of thoughts, and setting intentions. Participants frequently reported their comfort with meditation increased with continued practice, and that focused concentration on the flow of breathing helped to corral wandering thoughts.

Usually I focused on my body, how I felt internally. Focusing on noticing my thoughts, noticing the sensations physically, just trying to slow things down. Sensory awareness of sounds and smells and pressures on my body as I was sitting in a chair. (19)

I was trying to focus on my breathing a lot, and I do think that's beneficial, at least for me. It kind of clears my mind a little bit because I am concentrating on my breathing, and so I kind of let some of the other thoughts go. So from that standpoint the mindfulness was probably good for me because I could just divorce myself from the other things that were going on, were going to be happening for the rest of the day. I forced myself to just be thinking about breathing. (4)

Several participants reported occasionally completing the "homework sessions" in which users were given the opportunity to revisit content topics and further practice with prerecorded meditation. However, many others reported insufficient time due to competing priorities, caregiving responsibilities, and a preference for attending the live sessions with other attendees.

Participants described several immediate post-exercise benefits, including improved calm, a relaxed state and improved energy. Some practiced meditation at their bedtime and observed they were able to fall asleep more easily at the end of the exercise.

If I couldn't fall asleep right away, then I would remember that maybe I should think of things that I was grateful for. If was worried about something, after I thought about what I was grateful for, it would redirect my mind to something more positive. (10)

Participants also explained that completion of meditation exercises prompted an attitudinal shift that better prepared them to face the rigors of the day and helped them reflect on the day's events with more gratitude. Several participants also found themselves applying mindfulness and meditation principles during potentially stressful moments. Many described making deliberate efforts to take care of themselves by finding interrupted quiet time, taking a break, or otherwise finding opportunities to rest and recover from their caregiving responsibilities. Others described improved social encounters in which they applied the learned frameworks of compassion and nonjudgement.

I was ready to take on the day. I was ready to take on whatever challenge presented itself. And I felt like I had taken care of myself. I had done an hour of self-care, so I was ready to go back to taking care of everybody around here. (7)

It improved my compassion. I wasn't so quick to judge or quick to want to move things along. I was more in tune with the idea that things are going to happen at their pace; and if you recognize and work with it, then your life is a lot simpler and a lot easier. (17)

Building Rapport Through Shared Experiences

While participants perceived many components of the program's meditation and mindfulness curriculum to be beneficial, they were especially appreciative of the interactive nature of sessions. More specifically, participants cited the ability to submit comments and questions directly to the instructor for response via a chat function, as well as the ability to confer with other attendees, among their favorite features of the program.

While several participants appreciated the flexibility offered by drop-in sessions, most caregivers expressed a strong preference for live meditation sessions hosted by the facilitator, as compared to optional pre-recorded drop-in sessions that were offered throughout the week. Pre-recorded sessions presented didactics and the meditation exercise using a PowerPoint format, which did not allow users to interact with the facilitator or other attendees in real time. Participants explained the live interactive exchange provided a more fulfilling experience, allowing feedback from themselves and fellow attendees, as well as the opportunity to learn more about others' personal contexts of caregiving. Further, participants described live sessions as being more "real," even if the content of both the live and prerecorded sessions was similar.

Having a live person there instead of just finding a time to listen to a recording really made a difference as to whether I was going to do it or not. I guess it would be similar to if I was sitting across the table from you and talking, or talking to you on the telephone. There just seemed to be a better connection. Don't ask me why. That's just how it is. (1)

What made it valuable was the fact that it was a live course. I think the social element where you know other people are doing the same thing probably made a difference. It was interesting to have people with their own problems and personalities chime in. Kind of livened it up, so I think it was important, a big part of the program. (10)

The live sessions, I really enjoyed them. I don't know if I could do eight weeks of prerecorded sessions. (15)

Similarly, participants described deriving comfort and support from other caregivers. Participants enjoyed hearing others' accounts of caregiving, and often used time at the end of class to consult other attendees about resources or approaches. Hearing others' caregiving experiences helped many caregivers to feel less alone, fostered a sense of connection to a larger community, and also provided perspective about their personal circumstances, as compared to others' situations. Caregivers with fewer responsibilities or lesser subjective burden expressed empathy for attendees whose accounts revealed ongoing struggles and loneliness, and expressed new gratitude for their own circumstances. Those more heavily burdened found comfort and solace when identifying shared struggles in others' accounts.

It's a support group atmosphere. They're also caregivers. You can related to them, you appreciate the random comments. I think it makes me a better caregiver because you know you're not the only one having these problems. Even if they don't have the solutions, it just feels good. (16)

I learned I'm not alone in the struggle, and that it's hard work. Some people, I'm not sure how they survive with what they have to do to care for their loved one. Most of us didn't decide to be a nurse. People would share something they did that particular week or that day or an idea which would make me think, "Oh, hey. I can do that". (12)

Ongoing Application of Mindfulness and Meditation, and Opportunities for Refinement

Participants reported many long-term, post-program gains as a result of their participation in the program. Reported benefits varied and ranged from descriptions of changed perspectives, altered relationship dynamics, greater confidence, implementation of new schedules and/or habits, and integration of meditation and mindfulness practices in daily life.

Many reported that their perspectives about existing relationships and appreciation for others was improved by greater empathy and compassion.

I have family members that live down here and I didn't appreciate what they do. Even though I disagree with some of the things, I

could look at it from a different perspective. I thought, “Ok, I need to have that compassion and understanding”. (20)

Others reported that, while their circumstances may not have changed, they gained new tools and coping mechanisms that significantly lessened their stress and anxiety.

It's not like I don't get worried or scared and stressed, especially about my husband. About what's going to happen to him and then what's going to happen to us as result of this. It's not that I don't. But I'm working at accepting the situation and trying to abide with it rather than trying to push it away and say, "Oh, this isn't right. This is ruining my life". (8)

You figure out what the discomfort is and realize that very few things are as bad as we think they are. Get to the core of the issue, it's usually manageable one way or the other. That was what I got out of it, that you discover the source of your discomfort. If you can be a little rational about this stuff, it's a lot easier to deal with. (17)

Participants also described adopting a new mindfulness approach to daily tasks with renewed focus.

I really enjoyed the “slow down and savor your food.” And the theory of “Don't Multitask.” If I sit down and watch TV, I sit down and watch TV. I don't do both. (9)

I drive with more awareness, I try and put my problems in a pocket and I just concentrate on what needs to be concentrated. I'm a happier person. (3)

Many participants also described gaining a new understanding of the importance of self-care:

I think it was allowing me to consider my own life to be the most important of any consideration rather than putting my own needs and wants last on my plate. I put them first now, and then my mother and wife come second and third. So I kind of reordered my priorities, if you will. (13)

One of the big things I took away was that you have to focus on yourself, you've got to understand that you've got to take care of yourself too, and that was a huge thing I took away from that. (20)

Almost all participants planned to continue to practice mindfulness and meditation going forward, and for the long term. Several participants shared they planned to use the year-long access to library resources offered to all attendees. The majority indicated they were highly likely to recommend the program to others, and not just to caregivers.

Many participants pointed out that, while the program was helpful for developing coping skills and a renewed perspective, it could be improved by supplemental services such as therapy. Other suggestions included recommendations to address related topics during class exercises, such as depression and mental health, dealing with life's challenges and grief, managing chronic illness, and utilizing mindfulness and/or meditation to achieve happiness and maintain brain health.

A counselor that would enable them to diffuse their angst and unwind a bit, and find a way to enjoy all the colors of life besides this one thing, because I think these people demonstrated to me that they could become so overwhelmed by all that they didn't see anything else but a dark future. (19)

Participants also recommended additional social support, both in the form of strengthening the program's existing features, and adding new avenues of interaction. Many participants valued moments when the facilitator prompted them to share aspects of their caregiving experiences, as well as opportunities when attendees connected at the end of the exercise. Several individuals desired an expansion of those moments, as explained by the following participant:

I realize this was not group therapy. But some people provided thoughtful responses. I remember one woman said that instead of getting enraged at her husband, that she was able to soften her voice and not be angry. And so what [the facilitator] might have done with that is say something like, “Has anyone else had that experience of being able to modify their response to their partner?” So it'd get other people to say, “Well, yeah, I did.” And then he could say, “Well, what's that like for you people that had that experience, or ‘Can you imagine what that might be like if you do.’ It would just help expand it a bit”. (8)

Others requested opportunities to communicate more directly with other attendees, preferably in smaller groups to facilitate rapport building and allow additional time for sharing about caregiving struggles.

Additional suggestions included providing recommended readings of helpful caregiving sources, offering region-specific referrals for caregiving resources, integrating yoga with mindfulness, and providing transitional “phase 2” classes to further develop newly acquired skills.

Discussion

The purpose of this study was to explore the experiences of older adult caregivers in an interactive, online MBSR-based intervention. Participants described both short-term post-exercise benefits, as well as long-term outcomes. Notably, participants found the program's unique interactive feature, which provided accessibility for users' collaboration with facilitator guidance, to be of particular benefit and a form of perceived social support. Feedback indicates older adult caregivers derived benefit and potentially reduced subjective caregiver burden as a result of participating in an MSRB program, particularly because the program was augmented with a self-compassion approach and perceived social support.

Participants reported a number of benefits resulting from the program, including subjective improvement in sleep, reduction in stress and anxiety, and increased calm. Additionally, participants described acquiring a more positive perspective as it related to their caregiving responsibilities. This participant feedback suggests mindfulness/meditation may foster effective coping mechanisms for older adults struggling to manage age-

related transitions while also providing care for others. Specifically, older adult caregivers may use mindfulness/meditation to acquire tools that facilitate acceptance of the gradually changing roles and responsibilities between themselves and individuals for whom they provide care. Further, mindfulness/meditation practice may also help to alleviate cumulative stress, anxiety and emotional burnout resulting from providing daily care, while allowing caregivers to identify new pathways for reaching shared understanding with those who rely on their support. As many older adult caregivers often contend with personal health challenges while functioning in a caregiving capacity, meditation/mindfulness potentially emerges as a vital resource for maintaining self-care.

Unlike mindfulness programs primarily based on MBSR, programmatic offerings for this study included a mindful self-compassion approach. The self-compassionate response, which encourages self-soothing or comfort during times of stress, as opposed to attempting to fix or control a problem, is related to improved well-being.⁵⁸ Such an approach may be ideal for caregivers, who often sacrifice their own needs in an effort to fulfill their caregiving responsibilities. Participants' descriptions of their renewed commitment to self-care and adaptations to caregiving demands may be a result of this unique blend of the MBSR and self-compassion approaches. This is a promising finding, especially in light of the well-documented association between older adult caregivers' decreased self-care and negative behavior changes.⁵⁹

The majority of participants reported subjective benefit they attributed to the practice of meditation or accompanying didactics. Yet participant feedback also showed the interactive nature of the program, which allowed attendees to share about their experiences and exchange resources, created the benefit of rapport and a form of social support. Even though the program emphasized didactics and practice, with less time allocated for the exchange of caregiver accounts, many participants described these opportunities as significant. Further, this exchange of experiences, and the resulting sense of identification, made attending live sessions preferable to prerecorded sessions and allowed participants to feel better connected. Given research that shows perceived social support may be a better predictor of subjective burden as compared to received support,⁶⁰ this intervention potentially demonstrates how older adult caregivers may derive meaningful social support from an intervention with an online format, while participating from remote locations. Highly accessible social support in this format may be especially beneficial for older adult caregivers with fewer options for received support during a pandemic such as COVID-19.

While participants found it helpful to hear other attendees' experiences with providing care, they also benefitted from learning about new approaches, tips and resources they were previously unaware of. This finding confirms that subjective and objective burden are inextricably linked and may require dual treatment. When asked for suggestions to further refine this program, participants desired greater opportunity and time to continue shared discussions of caregiving as well as leads for additional, regional resources. Given that perceived social

support mediates the association between resilience and caregiver burden,⁶¹ caregivers may be best served by mindfulness interventions that address both dimensions for caregiver burden by providing an element of social support.

Our findings support previous research that indicates caregivers' endorsement of the MBSR curriculum, as well as the desire for active, ongoing participation after the initial 8-week training.⁶² The majority of participants reported a desire to continue and grow their existing mindfulness practice with the benefit of 1 year's access to program resources. While these findings point to the intention to implement mindfulness as an ongoing habit, future studies should examine the degree to which participants adhere to consistent practice, especially as the trajectory for caregiving and related burden changes over time. Further research should determine if the demonstrated benefits of participation persist beyond a standardized 8-week program, and whether long-term mindfulness practice provides the same benefit and longitudinal mitigation of caregiver burden and related depressive symptoms.⁶²

Limitations of this study include recruitment of participants according to self-identification as caregivers, rather than assessment of caregiver burden. Thus, participants represented diverse contexts of caregiving and may have derived varying benefit from their participation. Additionally, this study's cross-sectional design does not allow for investigation of long-term intervention effects along the caregiving continuum. A larger, longer pilot study beyond 8 weeks should examine how the needs of caregivers may evolve over time and the extent to which mindfulness remains efficacious. Finally, social support emerged as a distinct benefit for participants. Though this program afforded the opportunity for participants to interact with a larger community of caregivers, it may not be ideal for all older adults, particularly those who are lonely and may benefit from interactions outside the home.

Conclusions

Older adult caregivers experience significant subjective and objective burden, often while managing their own chronic illnesses. The online adaptation of a mindfulness program provides improved accessibility for caregivers otherwise unable to attend face-to-face sessions. The addition of a self-compassion approach may help caregivers identify constructive strategies for adapting to caregiving responsibilities and a renewed commitment to self-care. Likewise, allowing participants to interact with a larger community of caregivers may provide perceived social support and positively influence both subjective and objective dimensions of caregiver burden. The sample used in this study was drawn from those who completed the program, and included participants with higher dosage than the overall study population of completers, which may represent a potential sample bias. Subsequent studies may examine patterns of use and perceived outcome among a wider range of older adult caregivers with more varied experiences. This study's qualitative approach provides a nuanced, contextual account of older adult caregivers' experiences while

participating in a mindfulness program. Future studies may employ a randomized control design to objectively measure participant outcomes to yield generalizable findings. Finally, future research should extend current findings with larger, longitudinal studies.

Authors' Note

LA developed the study proposal; JH and RU conducted and interpreted the analyses; JH, RU, RT, JS and ERW wrote and reviewed the manuscript. An independent review board reviewed and approved all study activities. All authors are employed or contracted by United-Health Group or ASI Services, Inc. However, their compensation was not dependent upon the results obtained in this research, and the investigators retained full independence in the conduct of this research.

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