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Addressing personal barriers to advance care planning: Qualitative investigation of a mindfulness-based intervention for adults with cancer and their family caregivers

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Abstract

Objective. Advance care planning (ACP) increases quality of life and satisfaction with care for those with cancer and their families, yet these important conversations often do not occur. Barriers include patients' and families' emotional responses to cancer, such as anxiety and sadness, which can lead to avoidance of discussing illness-related topics such as ACP. Interventions that address psychological barriers to ACP are needed. The purpose of this study was to explore the effects of a mindfulness intervention designed to cultivate patient and caregiver emotional and relational capacity to respond to the challenges of cancer with greater ease, potentially decreasing psychological barriers to ACP and enhancing ACP engagement.

Method. The Mindfully Optimizing Delivery of End-of-Life (MODEL) Care intervention provided 12 hours of experiential training to two cohorts of six to seven adults with advanced-stage cancer and their family caregivers ($n = 13$ dyads). Training included mindfulness practices, mindful communication skills development, and information about ACP. Patient and caregiver experiences of the MODEL Care program were assessed using semistructured interviews administered immediately postintervention and open-ended survey questions delivered immediately and at 4 weeks postintervention. Responses were analyzed using qualitative methods.

Result. Four salient themes were identified. Patients and caregivers reported the intervention (1) enhanced adaptive coping practices, (2) lowered emotional reactivity, (3) strengthened relationships, and (4) improved communication, including communication about their disease.

Significance of results. The MODEL Care intervention enhanced patient and caregiver capacity to respond to the emotional challenges that often accompany advanced cancer and decreased patient and caregiver psychological barriers to ACP.

Introduction

Advance care planning (ACP) has important benefits for patients with cancer and their caregivers. ACP improves alignment of the care a cancer patient receives with that patient's wishes (Brinkman-Stoppelenburg et al., 2014; Silveira et al., 2010), leads to earlier and increased referrals to hospice care (Tenoet al., 2007; Wright et al., 2008), reduces intensive treatment and hospitalizations at the end of life (EOL) (Brinkman-Stoppelenburg et al., 2014), increases patient and family quality of life (Detering et al., 2010; Silveira et al., 2010; Wright et al., 2008), and enhances satisfaction with care (Detering et al., 2010). Clinical guidelines recommend timely ACP and palliative care as vital components of person-centered cancer care (Ferrell et al., 2017; Institute of Medicine, 2014; Levy et al., 2016; Peppercorn et al., 2011), yet most patients with cancer do not have these important conversations (Nelson et al., 2011; Peppercorn et al., 2011; Wright et al., 2008). More than one-half of cancer patients report that their oncologists do not know their EOL care preferences (Miljkovic et al., 2015; Nelson et al., 2011). Despite ongoing efforts to increase ACP, a national longitudinal study found no increase in EOL discussions or use of living wills among those with cancer between 2000 and 2012 (Narang et al., 2015). As

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the global population continues to grow and age, the number of cancer deaths worldwide is expected to rise significantly to 13.2 million per year by 2030 (Weir et al., 2015), intensifying the urgency to find new, effective approaches to increase communication and documentation of patient EOL care preferences.

Effective ACP is a multistep process (Sudore et al., 2008) that occurs through a series of candid conversations between individuals, their family and/or surrogate decision-makers, and their healthcare providers (Brinkman-Stoppelenburg et al., 2014). Patients are given straightforward, clear information about their prognosis and options for care and treatment (Peppercorn et al., 2011) and are invited to consider their preferences for care within the context of their beliefs and values (Schwartz et al., 2003; Winter, 2013), life priorities (Dev et al., 2012), and practical concerns (Khan et al., 2014; Patlak et al., 2011).

Prior research has identified multiple patient barriers to ACP conversations. Some barriers, such as lack of access to providers willing to initiate ACP (Agledahl et al., 2011; Dev et al., 2012; Heyland et al., 2013; Keating et al., 2010; Nelson et al., 2011; Tulsky et al., 1998; Wagner et al., 2010) or lack of knowledge that ACP is an option (Tobler et al., 2012) with significant benefits (Levi et al., 2010) can be effectively addressed through systems changes that promote or require ACP as a standard part of patient care and education. Other barriers present a different kind of challenge. Evidence shows that many patients experience psychological challenges when participating in ACP conversations (Greutmann et al., 2013). These include emotional discomfort (i.e., anxiety, sadness, or fear) when thinking about cancer or EOL (Schickedanz et al., 2009; Simon et al., 2015) and awkwardness when talking about the disease or death with family or providers (Northouse & Northouse, 1988) who may not feel comfortable participating in these discussions (Foster et al., 2015). These psychological challenges can lead to avoidance of reflection and communication about EOL issues, including ACP. Interventions for patients with advanced cancer that address these psychological barriers are needed to enable patients and caregivers to realize the important benefits that ACP can provide.

Mindfulness is a moment-to-moment intentional awareness that facilitates acceptance of one's lived experience (Davis & Hayes, 2011; Kabat-Zinn, 2003). Mindfulness practices developed through training enable individuals to mobilize regulatory resources when presented with emotional challenges, minimizing negative consequences associated with intense emotional reactions (Tang et al., 2015; Teper et al., 2013) and maximizing appropriate, contextualized responsiveness. Evidence shows that mindfulness facilitates the regulation of emotion (Corcoran et al., 2009; Farb et al., 2010; Tang et al., 2015) and decreases the emotional reactivity (Cahn & Polich, 2009) that often inhibits timely communication about EOL and ACP (Generous & Keeley, 2017; Sorrell, 2018). Evidence also suggests that mindfulness is inversely correlated with psychological distress (Barnes et al., 2007; Carmody & Baer, 2008; Coffey & Hartman, 2008) and is linked with relationship satisfaction (Gambrel & Keeling, 2010; Jones et al., 2011). By cultivating mindfulness and mindful communication skills, patients and their caregivers may develop an adaptive alternative to emotional reactivity and avoidant coping that could facilitate healthy coping and openness to ACP.

The purpose of this study was to explore the effects of a novel mindfulness intervention, Mindfully Optimizing Delivery of End-of-Life (MODEL) Care on the lived experiences and ACP of a cohort of patients with advanced cancer and their caregivers. The intervention combined mindfulness practice, mindful dialog, and information about ACP to cultivate emotional and relational capacities that may enable patients and their caregivers to respond to the experience of living with advanced cancer and to talk about the disease and future care with greater ease.

Methods

Study population

The inclusion criteria for patients in the MODEL Care study were: (1) adults 18 years of age or older; (2) receiving care from a medical oncologist who had agreed to be involved in the study; (3) diagnosed with an incurable and advanced-stage solid malignancy (stage IIIB, IIIC, or IV); and (4) whose death within the next 12 months would not be a surprise for their attending medical oncologist (Moss et al., 2010; Robinson et al., 2008). Participants also (5) were willing and able to participate in the MODEL Care mindfulness classes, (6) had a family member or friend eligible and interested in participating in the study, (7) were willing and able to consent, (8) had not completed a *Physician Orders for Scope of Treatment* (POST) ACP form with their oncologist, and (9) were not receiving hospice care.

Inclusion criteria for caregivers were: (1) adults 18 years of age or older; (2) chosen by a family member or friend with cancer to join them in participating in the study; (3) willing and able to participate in the MODEL Care sessions; and (4) able and willing to consent.

Intervention

Two groups of six to seven dyads each participated in six weekly two-hour MODEL Care sessions, 12 total hours, over a six-week period. Participants were also provided instructions for recommended home practice between sessions. Table 1 outlines the core topics, mindfulness practices, didactic components, and home mindfulness practices for each MODEL Care session. The course combined methods from traditional Mindfulness-Based Stress Reduction programs (Santorelli & Kabat-Zinn, 2013) (i.e., body scan, sitting meditation, hatha yoga [modified as necessary for each participant], and compassion meditation) with mindful speaking and mindful listening practices (Kramer, 2007) to cultivate patient and caregiver capacity for self-regulation in response to emotional stimuli and to foster enhanced ease with communication about sensitive topics. Information on ACP was provided and discussed in session 4 and included the American Society of Clinical Oncology's *Advanced Cancer Care Planning: A Decision-Making Guide for Patients and Families Facing Serious Illness* booklet and the Indiana POST form. Sessions were led by a facilitator with extensive training in mindfulness teaching and practice methods (author K.B.-C.).

Study assessment

Interviews

Patients and caregivers completed separate audio-recorded semi-structured interviews exploring the impact of participation within one week of completing the six-week MODEL Care, intervention (Table 2). All interview recordings were transcribed and qualitatively analyzed.

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Table 1. MODEL Care intervention summary

	Session theme	Mindfulness practices	Didactics	Home practice
1	Awareness: Meeting ourselves where we are in honesty and kindness	• Mindful eating (raisin exercise) • Body scan (focusing on awareness of breathing and body sensations)	• Course introduction and guidelines. • Defining mindfulness as being present for our lives just as they are as a means for enhancing connection with those we love, what is important to us, and a way to enable choices to proceed from personal values rather than emotional reactions. • Introduction of interpersonal mindful dialog skills, including listening attentively with curiosity and nonjudgment, without needing to give advice or comment on others' sharing.	• Body scan daily (recorded guidance) • Eat one meal mindfully (handout provided) • Mindfulness of one daily activity (record on log)
2	Perception and creative responding: Struggle against "life as it is" as a source of suffering; wholeness no matter what is here	• Body scan • Introduction of gentle hatha yoga stretching • Awareness of breath sitting meditation	• Role of perception, habit-driven conditioning, and other mental factors in the self-appraisal of stress. • Recognizing with kindness, struggle as it is reflected in the body. • Use of mindfulness to enhance comfort in living with elements of life that are difficult or challenging, incorporating compassion and nonjudgment.	• Alternate body scan and yoga daily (recorded guidance) • Sit quietly 10 min daily with awareness of breath • Arriving for rest: recorded practice option for short body scan before sleep • Keep calendar of one pleasant event each day and how it is reflected in mind and body
3	Relational presence: Mindfulness in dialog with the body as an accurate place to learn. Offering hospitality to one's own experience	• Sitting meditation • Yoga practice • Mindful dialog	• Physiological and psychological bases of stress reactivity are reviewed along with relevant mindfulness research. • Guidelines for mindful dialog are introduced in greater depth and practiced: Pause, Relax, Open-Allow. • Compassion as both attitude and behavior relating to self and others is highlighted as integral to and an outcome of practice.	• Sitting meditation, yoga, or body scan daily • Keep daily Reactivity-Responsivity Calendar as relates to communication
4	Mindful dialog: Cultivating compassion and responsiveness in speech and action; communication on ACP as empowerment	• Sitting meditation • Yoga practice • Mindful dialog • Lovingkindness practice	• Expansion of mindful speaking and listening guidelines allowing previously learned mindfulness practices to support patients and their family caregivers in nonhabitual, nonreactive communication. • Mindful dialog about present moment challenges related to (1) being with change and uncertainty and (2) discussing goals of care with healthcare providers and family members. • Participants are invited to open dialog about what they value. • Participants are provided information about ACP, including the POST form (Sudore et al., 2017) (ACP tool) and palliative care programs in the area.	• Sitting meditation, yoga, body scan, or lovingkindness practice • Read ASCO Advanced Care Planning booklet (Hoerger et al., 2013) and review POST form together in mindful dialog
5	Mindful dialog associated with challenging thoughts and feelings:	• Sitting meditation • Yoga practice • Mindful dialog	• Using mindful dialog guidelines, deeper discussion of ACP as an ongoing process shared by patients, their family members, and	• Sitting meditation, yoga, or body scan with recorded guidance or self-guidance daily • Practicing mindful dialog

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Table 1. (*Continued.*)

	Session theme	Mindfulness practices	Didactics	Home practice
	Meeting with practice what impedes open communication	• Lovingkindness practice	oncology providers grounded in the patient's values and preferences for goals of care. • Benefits of making decisions about desired scope of treatment in a timely fashion are highlighted, as well as consideration of surrogate decision-makers. • ACP tools, including the POST form, are further reviewed as a means of facilitating individual choices. • This dialog honors the wide variance of beliefs and values in the room within the themes of the shared human experience of coping with the unpredictable nature of life's changes and the preciousness of life.	guidelines in everyday life • Consider how to support ongoing practice and mindful dialog after the class
6	The rest of your life: Making the practice your own	• Body scan • Yoga • Sitting meditation • Lovingkindness practice	• Emphasis on the growing capacity of all participants to adapt more easily and effectively to everyday challenges and stressors, particularly those associated with advanced cancer. • Taking a mindful, open, conscious, and responsive—rather than reactive—approach is emphasized. • Using mindful communication skills, inviting each patient and family caregiver to share what has been learned in practice and any lingering questions concerning process and decisions about care preferences. • Invitation for patients to continue discussing care preferences with oncology team and sign POST form at next appointment with oncologist if ready to do so. • Review of core mindfulness skills and sharing of resources to support mindfulness practice after the class concludes.	• Mindfulness resources handout

All sessions were two hours and included provision of compact discs with audiorecordings of guided meditations of body scan, sitting meditation, gentle hatha yoga, and compassion (lovingkindness) meditation practices created by the facilitator for home practice.
ACP, advanced care planning.

Surveys

Patients and caregivers completed two postintervention surveys within one and four weeks postintervention that included both quantitative and qualitative questions. Each survey included one or more open-ended questions designed to elicit patient and caregiver feedback of what they gained from participation in the MODEL Care intervention (Table 2). Patient and caregiver written responses were included in the data set and qualitatively analyzed. Quantitative outcomes are reported elsewhere (Johns et al., 2014).

Data analysis

Interview transcripts were analyzed by two members of the research team (A.H.C. and J.K.B.) using immersion/crystallization methods described by Borkan (1999). Immersion/crystallization facilitates the development of new knowledge in areas previously underexplored with a focus on discovery. This method enabled the research team to gain a deeper appreciation and understanding of the possible associations between mindfulness practices, coping with advanced cancer, and communicating about the future (i.e., ACP)—all areas where there has been a paucity of research.

The researchers first engaged in deep immersion in the texts through separate iterative close readings and ongoing reflective "crystallization" of findings. Emergent themes were then used to guide the identification and organization of text exemplifying the impact of MODEL Care on patients' and caregivers' personal barriers to ACP. Next, codes were applied to these grouped passages using constant comparative methods to continuously review

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Table 2. Qualitative interview and open-ended survey questions

Within 1 week postintervention	
Patient and caregiver interview questions	
1. Once you started the mindfulness class, what kept you coming back each week?	
2. What impact has the mindfulness class or practices had on you?	
3. Does it seem that the experience has been helpful to your loved one?	
4. What did you find most helpful with the mindfulness class or practices?	
Patient and caregiver survey question	
1. Please describe what you gained from the MODEL Care program.	
4 weeks postintervention	
Follow-up survey questions	
Patient questions	Caregiver questions
1. What changes have you noticed in your interactions with your oncologist that you brought to the interactions?	1. What changes have you noticed in your interactions with your loved one's oncologist that you brought to the interactions?
2. What changes have you noticed in your interactions with your loved one who joined the study with you that either of you have brought to the interactions?	2. What changes have you noticed in your interactions with your loved one who joined the study with you that either of you have brought to the interactions?
3. What are you doing differently with regard to self-care as a result of this study?	3. What are you doing differently with regard to self-care as a result of this study?

and evaluate similarities and differences within and across coded categories (Glaser & Strauss, 1967). Negative cases were intentionally culled and carefully examined to avoid analytic bias (Taylor & Bogdan, 1998). The codebook evolved through the coding process, and codes were added, modified, or deleted as new data were analyzed. In the third phase, coded content was categorized into broader conceptual themes. Preliminary themes were continuously compared with the coded text to ensure the final themes were mutually exclusive and exhaustive.

Responses to one open-ended question collected 1 week postintervention and three open-ended questions collected 4 weeks postintervention (Table 2) were also analyzed using the same process of immersion/crystallization. Notably, the thematic categories identified in the open-ended survey responses were identical to the themes identified in the interview transcripts. No differences were found between the themes identified in the interview and survey responses collected 1 week postintervention and the survey responses collected 4 weeks postintervention.

The study was conducted at an academic medical center in the United States. Study procedures were approved by the Indiana University Institutional Review Board and Scientific Review Committee of the National Cancer Institute–designated cancer center where participants were enrolled. Written informed consent was obtained from all participants. The study is registered with ClinicalTrials.gov (NCT02367508).

Results

Sixty-eight patients were approached during the study enrollment period; 44 agreed to be assessed for eligibility and 22 were eligible to participate. In total, 13 patient/caregiver dyads were enrolled. Reasons for refusal included lack of interest ($n = 5$) and inability to attend the six MODEL Care sessions ($n = 4$). As shown in Table 3, a slight majority of enrolled patients (53.8%) were male and the majority of caregivers (76.9%) were female. The majority of patients (92.3%) and caregivers (69.2%) were Caucasian. Of the 13 enrolled patients, five had metastatic melanoma, three had lung cancer, two had leiomyosarcoma, and one each had pancreatic cancer, salivary ductal gland cancer, or anaplastic astrocytoma. Patients were diagnosed with metastatic cancer a mean of 20.9 months prior to enrollment ($SD = 21.4$ months; range, 1–76 months). Thirty percent of both patients and caregivers had a college degree, and 69% of patients and 62% of caregivers rated themselves as financially "comfortable" (Table 3).

Table 3. Participant demographics

	Patients (n = 13)	Caregivers (*n* = 13)
Age, mean (*SD*)	62.91 (10.6)	56.58 (15.6)
Race, *n* (%)		
American Indian/Alaska Native	0 (0)	1 (7.7)
Asian	0 (0)	1 (7.7)
Black/African American	1 (7.7)	2 (15.4)
White/Caucasian	12 (92.3)	9 (69.2)
Sex, *n* (%)		
Male	7 (53.8)	3 (23.1)
Female	6 (46.2)	10 (76.9)
Income, *n* (%)		
Comfortable	9 (69.2)	8 (61.5)
Enough to make ends meet	3 (23.1)	3 (23.1)
Not enough to make ends meet	1 (7.7)	2 (15.4)

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One of the 13 patient-caregiver dyads dropped out after the first session because of a lack of interest. A total of 12 patients and 12 caregivers completed the MODEL Care intervention. Patients attended an average of 4.3 of the six sessions; family caregivers attended an average of 4.2 sessions. The majority of those who missed completed a brief make-up session by phone with the mindfulness facilitator. One patient died shortly after the last intervention session. The majority of patients and caregivers responded to all of the open-ended survey questions; 20 participants completed qualitative interviews. As shown in Table 4, four salient themes were identified. Patients and caregivers reported that the intervention (1) enhanced adaptive coping practices, (2) lowered emotional reactivity, (3) strengthened their relationship with each other, and (4) improved their communication, including communication about their disease.

Theme 1: enhanced adaptive coping practices

The MODEL Care sessions provided instruction in multiple mindfulness practices designed to enhance the ability of patients and caregivers to cope with the challenges of living with advanced cancer. Practices included the body scan, breath awareness, sitting meditation, gentle yoga, and mindful dialog. These facilitated patient and caregiver mindful awareness of the present, self-compassion, nonjudgment, and the ability to acknowledge, reflect on, and discuss difficult experiences and topics with greater ease.

After completing the MODEL Care sessions, patients and caregivers reported that the mindfulness practices were effective in helping them to cope with the overall "trauma" of cancer (patient 4004). One patient shared, "I have an imaginary tool box of… things I can do, which help me to feel good despite the reality of…pain or negative emotion…" (patient 1001). Patients reported that the mindfulness practice of present-centered awareness enabled them to "live better in the moment rather than worrying about the future" (patient 1003), and to approach the challenges they faced with increased "relaxation" (patient 4004) and "appreciation" (patient 2002). Patients reported using the mindfulness practice of lovingkindness, which facilitates compassion for self and others (The Center for Contemplative Mind in Society; Zeng et al., 2015) to cope with their new and altered sense of self. One patient described embracing "the importance of loving yourself and generating acceptance for the new person I've become as my skills, stamina, and mental abilities diminish" (patient 4001). Patients also reported that mindfulness practices helped them to respond to the negative physical aspects of their disease and treatment (patient 2002). Patients shared that the practices enabled them to experience greater ease with the symptoms of their disease (patient 4005), allowing them to "meet the pain differently so it doesn't consume me" (patient 4001).

Caregivers noted changes in their loved one's ability to cope with their disease following the mindfulness sessions. One caregiver shared "My friend seems to be much calmer regarding his diagnosis and fear of death [following the MODEL Care sessions]" (caregiver 10030). Another caregiver observed a change in both the patient's attitude and ability to manage physical pain after participating in the mindfulness intervention: "[MODEL Care] really made her a much more positive person…it's helped her get through the pain issues she's had in her shoulder while she's had her radiation" (caregiver 40040).

Caregivers also shared their own experiences of suffering (caregiver 10010), stress (caregiver 40050) and the responsibility for making life-altering decisions (caregiver 30020) as they cared for loved ones facing cancer. As with patients, caregivers found the mindfulness practices helped promote their ability to cope with these ongoing challenges. Caregivers found "peace" (caregiver 30010) and an increased ability to "cope with the stress of cancer" (caregiver 40050) by using mindful sitting meditation to more fully "live in the moment" (caregiver 40020). Mindfulness practices such as present-centered awareness enabled caregivers to shift their perspective from future-oriented concerns to a focus on the present: "So, I'm now living in the present, I'm enjoying the present…I can think about the future, yes, but… I'm not going to dwell too much on it" (caregiver 10010). Patients commented on the changes that they noticed in their caregivers' ability to cope. For example, one patient observed, "I noticed that her attitude has been more positive since this course" (patient 1001). Another stated: "He's [caregiver] trying to be less impatient" (patient 2002).

Caregivers also used the mindfulness practices to help patients cope with their disease, noting in this context that mindfulness

Table 4. Interview and survey themes

Theme	Definition	Patient quotation	Caregiver quotation
1. Enhanced adaptive coping practices	Embodying resilience during experiences that incite stress	"My favorite part of all was the Body Scan. …by relaxing, it releases my mind from the trauma that it's in." (patient 4004)	"I think it has helped so much about not looking way down the road and dealing with today…coping with those changes that are happening today." (caregiver 40010)
1. Lowered emotional reactivity	Choosing an intentional response to emotional stimuli	"The 'pause'… allows you to not react in negative ways." (patient 4001)	"I just felt completely overwhelmed and it gave me a way to settle myself …before my emotions take over." (caregiver 40050)
3. Strengthened relationships	Enhancing relationships with loved ones	"My wife and I are closer than ever. I see that my way of handling my cancer before the (mindfulness) study we both participated in was driving us apart. Now we are together, mindful of our love for each other." (patient 1001)	"We definitely are aware of our precious time together and with our son." (caregiver 40050)
4. Improved communication	Improved communication skills and/or ability to communicate about sensitive topics	"I have talked to the doctor a little more. I've asked him some questions that I hadn't really broached before." (patient 2002)	"I think it kind of reminded us both that we need to make a conscious effort to ensure the communication occurs on important things and that we take time to do that and recognize it's important." (caregiver 20020)

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"gives me power in things that used to make me feel powerless" (caregiver 40050). For example, one caregiver reported, "That's probably…where I'm getting the rewards. My heightened awareness is helping [the patient] feel better…It may not heal him physically, but it can heal him emotionally" (caregiver 10010). Patients also noted changes in their caregivers' abilities to help them cope: "She's much more compassionate to what I'm feeling. Sometimes my emotions are right on top, and she deals with that a whole lot better than she used to" (patient 1003).

Theme 2: lowered emotional reactivity

Both patients and caregivers commented on the emotional challenge of living with the symptoms and circumstances of advanced cancer. In the words of one patient, "It's not easy to accept the fact that you're going to die soon" (patient 4004). Patients and caregivers each reported decreased reactivity to emotional stimuli following the MODEL Care mindfulness sessions.

Patients described experiencing fear (patient 1001) and anxiety (patient 4003) in response to their disease and treatments. The MODEL Care sessions included training in practices such as "pausing" and "taking a breath" that were specifically intended to enable participants to respond intentionally rather than automatically to emotional stimuli. Patients reported that these mindfulness practices supported them in responding to emotional provocations: "The pause…allows me to not react in negative ways, but to think about, 'How can I better deal with the negative circumstance?' when one comes up" (patient 4001). Another patient commented that the mindfulness practices learned during the MODEL Care sessions facilitated increased self-awareness of difficult emotions and promoted a positive response to these stimuli: "My oncologist felt that this brought emotions to the surface that I had repressed over the last 2 years, allowing me to address these issues in a more healthy and positive manner" (patient 4003).

Caregivers similarly noted that mindfulness practice helped them to respond thoughtfully rather than react impulsively to circumstances that incited uncomfortable emotions. For example, caregivers commented that the "pause" helped "keep my anxiety in check" (caregiver 10030), enabling them to notice and "set aside" (caregiver 20020) their impulse to react to negative experiences by "slowing down, taking time for the moment, and…not reacting as fast as maybe I would before" (caregiver 40010). Moreover, mindfulness practice enabled caregivers to regroup before responding to emotional triggers: "It gave me a way to settle myself more…before my emotions take over" (caregiver 40050).

Theme 3: strengthened relationships

Both patients and caregivers participating in the MODEL Care intervention reported a positive change in their relationship with each other postintervention. Patients reported that the shared experience brought them closer to their caregiver, who was frequently their spouse. For example, patients stated, "Now we are together, mindful of our love for each other" (patient 1001) or noted that they were "closer to each other" (patient 4004) or that "[we] feel a connection" (patient 2002). One patient reported that "we've gotten along better since we started this, it's really helped the relationship, especially dealing with the cancer" (patient 4005).

Patients credited the mindfulness sessions with helping to develop those stronger relationships. They commented on the benefits of spending time together practicing mindfulness: "We've been more in sync than we ever have been, and I think the class really helped a lot with that" (patient 1001). Patients also referenced specific techniques taught during the mindfulness sessions, such as the lovingkindness practice: "My husband and I did that together, and I think we could really feel a connection" (patient 2002). In commenting on the mindful dialog practices, another patient stated, "My way of handling cancer before the [mindfulness] study was driving us apart" (patient 1001).

Similar to patients, caregivers commented on the impact of the MODEL Care intervention on their relationship with the patient, remarking that it was "bringing us closer in these times of hardship" (caregiver 10010). Caregivers mentioned "spending more time together" with their loved one (caregiver 40040) as a positive benefit, along with an increased appreciation for the time they had together: "Let's say that [patient] is doing something that I normally would have considered trivial or not important. After the training, I realized how important it is to spend time with him, so I embrace whatever he is doing, and we started doing things together" (caregiver 10010). Caregivers also identified new abilities they had developed during the program, such as being "able to help each other in moments of stress" (caregiver 10010) and having "more of an understanding and consideration in what each of us is experiencing" (caregiver 10020). Caregivers described personal changes the program had facilitated that enabled improved relationships, such as being "more peaceful and easier to get along with" (caregiver 10020).

Theme 4: improved communication

Patients and caregivers both reported an improved ability to communicate with each other, clinicians, and others facing similar circumstances. Patients commented on their enhanced ability to "listen better" (patient 2002) and "listen more" (patient 4005) to their caregivers—abilities cultivated through the mindful dialogue practices. Patients and caregivers also found that the MODEL Care sessions improved their ability to communicate with others about their disease. For example, both patients and caregivers described an improved ability to communicate with the oncologist. Patients noted being able to ask their oncologist sensitive questions they had previously avoided: "I asked him about my life expectancy, and at a later time, he talked about it. It was never discussed before this study" (patient 2002). Caregivers also expressed greater ease when communicating with the oncologist about sensitive topics: "[I have a] sense… that I can ask difficult questions" (caregiver 10010). Patients and caregivers noted increased comfort talking about their disease postintervention and a heightened ability to be in touch with their experiences with cancer, including their fears and emotions.

Discussion

Patients with advanced cancer face challenging physical and psychological experiences as they navigate a terminal disease and accompanying treatments. Emotional responses to these threatening conditions (Mesters et al., 1997; Schickedanz et al., 2009; Simon et al., 2015) can prevent patients from making important decisions about care that could affect both their quality of life and quality of death, as well as their caregiver's experience of life and bereavement (Tschirhart et al., 2014; Wright et al., 2008). ACP empowers patients to approach current and future care and treatment decisions with informed and thoughtful

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deliberation grounded in their personal values, life priorities, and preferences while they are still able to speak for themselves and before urgent crises arise. Existing ACP interventions (Gundersen Health System, 2016; Regents of the University of California, 2012; The Conversation Project, 2016) support individuals in considering and clarifying their wishes for care; however, these approaches lack the inclusion of components that substantially modify patient or caregiver emotional discomfort and avoidance. Current interventions designed to support the psychological, spiritual, or existential wellbeing of patients with advanced cancer, such as Managing Cancer And Living Meaningfully (An et al., 2017; Lo et al., 2014, 2015, 2016; Nissim et al., 2012) and meaning-centered group psychotherapy (Breitbart, 2002; Breitbart et al., 2010, 2015), include neither mindful meditation or mindfulness communication practices as intervention components nor focus specifically on ACP. One of the innovative features of MODEL Care is the focus on cultivating adaptive coping through mindfulness to support openness to EOL conversations and ACP. The MODEL Care intervention brought together patients and their caregivers for shared experiential training in mindfulness and mindful communication practices, both presented within an explicit context of fostering contemplation and discussion about ACP. The sessions were designed to facilitate a common understanding of mindfulness practices and benefits within each patient/caregiver dyad and to enhance participant capacity to incorporate mindfulness and mindful communication practices into their everyday lives. Daily practice supported emotional self-regulation and fostered effective communication about sensitive topics, including future care. Patients and caregivers reported improved capacity to cope with the psychological discomfort of their disease, enhanced ability to respond intentionally and adaptively to emotional stimuli, strengthened relationships with each other, and improved skills and comfort with communicating about difficult topics—all important capacities for fostering engagement in ACP. Although mediator analysis was not conducted in this pilot study, there is emerging evidence that mindfulness meditation causes neuroplastic changes in brain regions that regulate attention (prefrontal cortex), emotion (amygdala), and self-awareness (posterior cingulate cortex) (Tang et al., 2015). Mindfulness meditation facilitates self-regulation of attention, emotion, and self-awareness by fostering attention to the present moment, coupled with acceptance and nonreactive awareness of internal and external experiences (Baer, 2003; Bishop et al, 2004). Therefore, mindfulness practice may reduce maladaptive reactions to the emotional and physical triggers that may lead to cancer-related avoidant coping, such as avoidance of ACP.

Our study is not without limitations. The nonrandomized, single-arm design with no control condition limits our ability to conclude that improvements noted for patients and their family caregivers were due to the MODEL Care intervention. We cannot rule out that the benefits participants reported receiving could be due to the attention received from a skilled facilitator and from peers in their MODEL Care group. The small sample size of 13 patient and family caregiver dyads also limits the strength of our conclusions. Participants were all English speaking, most were Caucasian, and most reported having a comfortable income, limiting generalizability of findings to other groups. Finally, all patients were referred to the study by their oncology team and were willing to enroll in a mindfulness-based intervention, creating the possibility of selection bias.

Future research could build on the findings of this pilot to explore the relationship among mindfulness practice, ability to communicate mindfully about advanced disease care preferences, ease with which patients and caregivers engage in these sensitive conversations, and concordance between expressed care preferences and treatments received at the EOL. Assessing the efficacy of MODEL Care in a randomized controlled trial compared with usual care, wait-list control, or an active intervention such as ACP decision support would answer a variety of research questions depending on the design chosen. Moreover, a randomized trial would ensure greater internal validity than was possible in the quasi-experimental pilot from which these qualitative data were drawn. Future quantitative research should include mediator analysis to test theoretically based constructs, such as self-regulation as a hypothesized mediator of the effects of MODEL Care on ACP. Despite limitations, the results of this pilot suggest that mindfulness-based interventions such as MODEL Care could play an important role in improving and expanding ACP uptake by enhancing the ability of patients and families to consider and discuss emotionally challenging topics, such as EOL preparations.

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