

Original Article

Cite this article: Applebaum AJ *et al.* (2022). A qualitative exploration of the feasibility and acceptability of Meaning-Centered Psychotherapy for Cancer Caregivers. *Palliative and Supportive Care* 20, 623–629. <https://doi.org/10.1017/S1478951521002030>

Received: 11 October 2021

Accepted: 23 December 2021




Key words:

Caregiver; Caregiver distress; Existential distress; Meaning-Centered Psychotherapy; Meaning-Centered Psychotherapy for Cancer Caregivers; Psychosocial intervention

Author for correspondence:

Allison J. Applebaum, Caregivers Clinic, Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th Floor, New York, NY 10022, USA. E-mail: applebaa@mskcc.org

A qualitative exploration of the feasibility and acceptability of Meaning-Centered Psychotherapy for Cancer Caregivers

A. J. Applebaum, PH.D.¹ , K. E. Roberts, PH.D.², K. Lynch, M.S., M.P.H.¹, R. Gebert, B.A.¹, M. Loschiavo, B.A.¹, M. Behrens, B.S.¹, L. E. Walsh, M.S.¹ , L. C. Polacek, M.A.¹ , E. L. Diamond, M.D.³ and W. S. Breitbart, M.D.¹

¹Department of Psychiatry and Behavioral Sciences, Memorial Sloan Kettering Cancer Center, New York, NY;

²Ferkauf Graduate School of Psychology, Yeshiva University, Bronx, NY and ³Department of Neurology, Memorial Sloan Kettering Cancer Center, New York, NY

Abstract

Objective. Caregivers of patients with cancer are at significant risk for existential distress. Such distress negatively impacts caregivers' quality of life and capacity to serve in their role as healthcare proxies, and ultimately, contributes to poor bereavement outcomes. Our team developed Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C), the first targeted psychosocial intervention that directly addresses existential distress in caregivers.

Method. Nine caregivers of patients with glioblastoma multiforme (GBM) enrolled in a pilot randomized controlled trial evaluating the feasibility, acceptability, and effects of MCP-C, and completed in-depth interviews about their experience in the therapy. One focus group with three MCP-C interventionists was also completed.

Results. Four key themes emerged from interviews: (1) MCP-C validated caregivers' experience of caregiving; (2) MCP-C helped participants reframe their "caregiving identity" as a facet of their larger self-identity, by placing caregiving in the context of their life's journey; (3) MCP-C enabled caregivers to find ways to assert their agency through caregiving; and (4) the structure and sequence of sessions made MCP-C accessible and feasible. Feedback from interventionists highlighted several potential manual changes and overall ways in which MCP-C can help facilitate caregivers' openness to discussing death and engaging in advanced care planning discussions with the patient.

Significance of results. The overarching goal of MCP-C is to allow caregivers to concurrently experience meaning and suffering; the intervention does not seek to deny the reality of challenges endured by caregivers, but instead to foster a connection to meaning and purpose alongside their suffering. Through in-depth interviews with caregivers and a focus group with MCP interventionists, we have refined and improved our MCP-C manual so that it can most effectively assist caregivers in experiencing meaning and purpose, despite inevitable suffering.

Introduction

The approximately 6 million Americans who serve as family and friend caregivers to patients with cancer are an essential extension of the healthcare team (Kent *et al.*, 2019). Caregivers perform tasks that may be emotionally, physically, existentially, socially, or financially demanding, and as a result, they are at increased risk for psychiatric morbidities, including anxiety and depression (Covinsky *et al.*, 1994; Cliff and MacDonagh, 2000; Braun *et al.*, 2007), and physical health conditions, including poor immune functioning, cardiovascular disease, and sleep difficulties (Carter, 2003; Hudson *et al.*, 2011; Buyck *et al.*, 2013; Kim *et al.*, 2014). This significantly impacts their capacity to provide high-quality care to patient loved ones and can lead to poor bereavement outcomes (Cho *et al.*, 2006).

A critical, potential driving element of these outcomes is existential distress, which has been described as including feelings of hopelessness, demoralization, loss of personal meaning and dignity, feelings of burden toward others, and the desire for death or the decreased will to continue living (Vitaliano *et al.*, 2002; Christakis and Allison, 2006; Hearson and McClement, 2007). For cancer caregivers, the competing demands of cancer caregiving, other caregiving responsibilities (*i.e.*, childcare), paid employment, and personal life goals have the potential to lead to psychological, spiritual, and existential distress. Indeed, our systematic review highlighted existential concerns as a significant area of unaddressed suffering among caregivers of patients with brain tumors (Applebaum *et al.*, 2016b) and patients undergoing hematopoietic stem cell transplantation (Applebaum *et al.*, 2016a). Together, these reviews indicated that caregivers commonly struggle with: (1) changes in their sense of identity; (2) guilt regarding their responsibility to care for themselves while also attending to the complex needs of the

patient; (3) changes in and loss of their relationship with the patient due to the impact of illness and treatment on patients; and (4) fears and anticipatory grief regarding the impending death and need to continue life after the patient has died.

Despite being a source of suffering, the caregiving experience is concurrently an opportunity for meaning-making and growth (Park et al., 1997). Meaning-making is rooted in the existential concept of one's ability to find meaning despite suffering. Having a loved one diagnosed with cancer and experiencing the resultant challenges may both engender suffering and be a transformative experience that ultimately leads to increased meaning, more adaptive coping, and growth (Park and Folkman, 1997; Bauer-Wu and Farran, 2005; Calhoun and Tedeschi, 2006; Pargament and Ano, 2006). Caregivers may find meaning through the choices they make (e.g., the attitude taken toward this role), creative endeavors (e.g., taking responsibility for one's life and goals while concurrently providing care), and experiences (e.g., gaining a new appreciation for their relationship with the patient). Making meaning of suffering, therefore, is one possible mechanism through which caregivers may experience growth as opposed to distress (Frankl, 1963, 1967, 1972, 1978), and finding meaning in caregiving has the potential to buffer against caregiver burden.

In response to the increasing recognition of existential distress among caregivers and to a lack of targeted psychosocial interventions (Applebaum and Breitbart, 2013; Applebaum, 2019b), we developed Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C) (Applebaum et al., 2015). Based on Meaning-Centered Psychotherapy (MCP), an approach proven to be highly effective in enhancing spiritual well-being and decreasing existential distress among patients with advanced cancer (Breitbart et al., 2012, 2015; Breitbart, 2017), MCP-C is a brief structured psychosocial intervention that seeks to assist caregivers to connect to a sense of meaning and purpose in life despite the challenges of caregiving (Applebaum et al., 2015). Through MCP-C, caregivers come to understand the benefits of connecting with meaning and how various sources of meaning may serve as resources, buffer common symptoms of burden, and diminish despair, especially as loved ones transition to end-of-life care (Applebaum et al., 2018).

The MCP-C manual was originally developed through five focus groups with caregivers of patients with various sites and stages of cancer and using a modified Delphi approach (Jandhyala, 2020; Niederberger et al., 2020; King et al., 2021) in which caregivers provided feedback on the original manual, their feedback was incorporated, and they subsequently provided another round of feedback (Sekayi and Kennedy, 2017). The resultant manual was then used in several pilot trials enrolling caregivers of patients with a wide range of cancers, cancer stages, and treatment types to explore the feasibility, acceptability, and preliminary effects of MCP-C (Applebaum et al., 2018; Applebaum, 2019a). The manual was most recently used in a pilot trial evaluating the feasibility, acceptability, and effects of MCP-C when delivered to the very vulnerable group of caregivers of patients with glioblastoma multiforme (GBM), a highly aggressive neurologic disease, with median survival of 12.1–14.6 months (Wen and Kesari, 2008). Personality changes, mood disturbances, and cognitive limitations are ubiquitous in the clinical course of GBM and make the provision of care particularly challenging (Salander, 1996), and the brief but intense period of caregiving combined with patients' poor prognosis produces significant existential distress in caregivers (Catt et al., 2008). Such caregivers may benefit significantly from MCP-C but may find engagement in psychosocial care burdensome.

In advance of a large-scale randomized controlled trial to more thoroughly examine the efficacy of MCP-C, we sought to refine the manual to ensure that the approach attends comprehensively to caregivers' existential needs. We focused on data from caregivers of patients with GBM as they represent one of the most burdened groups and, hence, are caregivers from whom we could derive rich data regarding how to best deliver MCP-C to meet caregivers' psychosocial needs without adding additional burden. As such, the purpose of the present study was to explore ways in which the approach achieves these goals and determine any recommendations for changes.

Method

Data presented here come from a subset of participants enrolled in a pilot randomized controlled trial among 60 caregivers of patients with GBM randomized to either seven sessions of MCP-C or Enhanced Usual Care (i.e., distress screening and targeted referrals). In addition to caregiver participants, feedback was provided by three MCP-C therapists who served as interventionists on prior MCP trials and on the current MCP-C trial.

Participants

Caregiver participants were recruited from Memorial Sloan Kettering Cancer Center (MSK) in-person at clinic appointments, via physician referral, and through informational flyers posted in clinic waiting rooms. Participants were: (1) at least 18 years of age; (2) a self-reported current caregiver to a patient with GBM; (3) able to read and understand English; (4) able to provide informed consent; and (5) had a score > 4 on the Distress Thermometer (DT) (Roth et al., 1998) and indication that this distress was related in some way to caregiving per self-report. Only one caregiver per patient was able to enroll. Participants were excluded if they had — in the judgment of the consenting professional, clinician, or PI — severe psychopathology or cognitive impairment likely to interfere with the participation or completion of the protocol or ability to provide meaningful information.

Procedure

Sixty caregivers met inclusion criteria, provided informed consent, and were enrolled in this trial. After completion of MCP-C, a random subset of participants ($N=10$) engaged in semi-structured interviews that explored how the intervention attended to their unique experience of caregiving-related distress. We aimed to limit interviews to 10 based on qualitative methodological standards for reaching data saturation (Guest et al., 2006); by the 10th interview, we reached data saturation of themes based on participant reported experiences.

Meaning-Centered Psychotherapy for Cancer Caregivers

MCP-C (Applebaum et al., 2015; Applebaum, 2019b) is a 7-session intervention that utilizes didactics, discussion, and experiential exercises that focus on themes related to meaning and caregiving as follows: Session 1 — Concepts and Sources of Meaning; Session 2 — Identity Before and After Becoming a Caregiver; Session 3 — Historical Sources of Meaning: Legacy (past, present, and future); Session 4 — Attitudinal Sources of Meaning: Encountering Life's Limitations; Session 5 — Creative Sources of Meaning: Creativity and Responsibility; Session 6 — Experiential Sources of Meaning: Connecting with Life via Love,

Beauty, and Humor; and Session 7 — Transitions: Reflection and Hopes for the Future. Caregivers are assigned readings and homework exercises specific to each session's theme which are utilized to guide discussion in subsequent sessions. MCP-C was delivered in person for 18 months before the COVID-19 pandemic, and then over a secure video conferencing virtual platform for the remainder of the trial.

MCP-C interventionists

MCP-C therapists were pre-doctoral clinical psychology graduate student externs and interns and post-doctoral clinical psychology fellows engaged in training placements at MSK. Therapists were extensively trained by the study PI (A.J.A.) in the rationale, principles, and implementation of MCP-C and received weekly supervision with prior review of audio-/video-recorded sessions. After the completion of the trial, the study PI conducted one focus group with three MCP-C therapists who had several years of experience in delivering MCP and MCP-C across several trials enrolling patients with advanced cancer and their caregivers, and who had served as the primary interventionists on the current trial. This discussion focused on therapists' perceptions of the MCP-C manual and suggestions for changes that would augment the intervention's capacity to enhance a sense of meaning and purpose among caregivers.

Qualitative analysis

Interviews with caregivers were audio-recorded and transcribed verbatim. Transcripts were analyzed using an inductive thematic analysis approach, involving two phases of "vertical" and "horizontal" coding (Kuckartz, 2014). In the vertical phase, each transcript was reviewed independently by the study's qualitative methodologist (K.L.) and the coding team (R.G., M.L., M.B.). For each interview, coders identified key participant feedback regarding each session and met to reach consensus on key conceptual findings. Once all transcripts were coded, the team sorted key findings into categories; in this horizontal phase, the team reviewed statements within each conceptual category to identify recurrent themes across the entire dataset. These themes were then discussed and refined in a consensus meeting with the study PI (A.J.A.).

The study was approved by the MSK Institutional Review Board #18-075 and listed on ClinicalTrials.gov with identifier NCT03454295.

Results

Caregiver interview results

Ten caregivers completed in-depth semi-structured interviews, though audio quality for one precluded transcription. Therefore, nine interviews were included for analysis. Five caregivers participated in MCP-C in-person, and four over telepsychiatry. Demographic information for these nine participants is presented in Table 1. All nine were female and, on average, 54 years old. The majority (78%) were married/partnered to the patient for whom they were providing care. At the time of the interview, caregivers had been providing care, on average, for 7.9 months and for a little over 7 h a day.

Four key themes emerged from the interviews (see Table 2), as well as session-specific feedback.

Table 1. Caregiver participant characteristics

Characteristic	N = 9
Gender, n (%)	
Female	9 (100%)
Age	
Mean (SD)	54.3 (15.9)
Median (IQR)	52 (49, 69)
Race, n (%)	
Asian/Pacific Islander	1 (11%)
Caucasian/White	8 (89%)
Relationship status, n (%)	
Single	1 (11%)
Married/Partnered	8 (89%)
Education, n (%)	
Vocational school or some college	1 (11%)
College degree	2 (22%)
Professional or graduate School	6 (67%)
Income, n (%)	
\$40,000–\$74,999	1 (11%)
\$75,000 or more	7 (78%)
Prefer not to answer	1 (11%)
Employment status, n (%)	
Paid full-time employment	5 (56%)
Paid part-time employment	1 (11%)
Homemaker	1 (11%)
Not employed — Retired	1 (11%)
Unemployed	1 (11%)
Patient's cancer stage, n (%)	
Stage IV	8 (89%)
Unstaged	1 (11%)
Months spent providing care	
Mean (SD)	7.89 (7.56)
Median (IQR)	6 (2, 10)
Hours/day spent providing care	
Mean (SD)	7.06 (8.34)
Median (IQR)	2 (1.5, 12)
Relationship to the patient, n (%)	
Spouse/Partner	7 (78%)
Child	1 (11%)
Sibling	1 (11%)
Caregiver/patient cohabitation, n (%)	
Yes, all of the time	7 (78%)
No	2 (22%)

Theme 1: MCP-C validated caregivers' experience of caregiving MCP-C provided a space for caregivers to step back from everyday challenges and reflect on their experiences, including their growth

Table 2. Key themes from qualitative interviews ($n = 9$)

Theme	Key quotes
MCP-C validated caregivers' experience of caregiving	"I think having a time when the caregiver can really just kind of think about themselves for a minute and just, someone is listening to them who actually wants to hear about them, not about the patient, I think that also is helpful. I think it's a good moment for people to just kind of regroup a little bit, recharge, and remember, you know, you're important too." (1012)
	"I originally felt like, 'oh are you guys sure that I'm a good candidate?' [...] but right from the get-go, I was made to feel like no, there's lots of different types of caregivers and [...] I think it was helpful just to, again, get that validation, of like, 'no you're allowed to be here because it's kind of hard for everyone involved.' And so, I think that was really helpful." (1008)
	"It felt good to focus on me as a person. When you're caring for another person, you put yourself on the back burner." (1004)
MCP-C helped participants reframe their "caregiving identity" as a facet of their larger self-identity, by placing caregiving in the context of their life's journey	"One of the things that we processed was to make this [caregiving] part of the continuum of my life, rather than a 'before' and 'after,' even though it is obviously. It's a huge change. I sort of, and I don't know if accept is the word, maybe it is accept, where we are now as part of my life and not aberrational." (1050)
	"I was certainly raised with particular messages from my mom [...] that] it's our job to make our corner of the world a better place. Just integrity, your family comes first [...] You know, it's how I've always sort of structured my life and I think that in some ways, you know, I take care in the way that I live. You know, it's not a different thing for me. It's all part of you, it's not like, 'this is who I am and I'm going to take care of him in a different way.' It's like, 'yeah this is what you do, right?'" (1023)
MCP-C enabled caregivers to find ways to assert their agency through caregiving	"I think what the sessions were helpful in doing is demonstrating that there were choices, that I made choices every day. And it wasn't just, I wasn't just being floated along like a leaf on the road, I actually jumped into the road and I could get out if I wanted to. So that was very helpful to me in considering my caregiver role and my attitude toward it [...] I was able to see various points in my life where I could identify agency, my own agency. That was helpful." (1050)
	"I define attitude as how you react in certain circumstances." (1004)
	"Usually [creativity] means to me, very artistic or whatever, out of the box. I think it was more just how you want something in your life to change or you want to feel a certain way. How do you take responsibility for creating that change or that new life or that new scenario? I think thinking of it [creativity] in that way, more just the responsibility of taking control of your life, I think that was really cool." (1008)
The structure and sequence of sessions made MCP-C accessible and feasible	"I don't take care of myself. And I did, since [the session], make appointments for certain things that have to do with my health and, so I learned from it [...] self-responsibility is something that the discussion helped me to look into." (1054)
	"[6 months post-diagnosis] felt like the right time because the first 6 months were so hard. There weren't too many cognitive and physical changes in my dad, they were less obvious. And then when things started to get kind of progressively bad, that's when I sought out the study, kind of as something to lean on in navigating these changes and deterioration." (1051)
	"I really liked the way it [MCP-C] contextualized things, and contextualized suffering [...] I thought it gave context to the journey and that you look for meaning in everything, not just the good stuff, but you look for meaning in the bad stuff. And when you find meaning in the bad stuff, it makes the bad stuff less, I'm not gonna say makes it less bad, but it makes it less difficult to tolerate." (1050)
	"I did one session over the phone. So, I did both. [pause] I think it's nice to have the option, but it's also...I was lucky in that when I did it over the phone there were no distractions, I was able to do it in a place where I wasn't distracted [...] but if you were just at home on the phone, it may be the possibility of a lot more distractions that would take away from it I think." (1012)

over time. Participants noted that they had put their own needs on the "back burner" while caring for their loved ones and appreciated having dedicated space to discuss their challenges. In fact, most felt that in the absence of MCP-C enrollment, they would not have given themselves the time or space to reflect.

Theme 2: MCP-C helped participants reframe their "caregiving identity" as a facet of their larger self-identity, by placing caregiving in the context of their life's journey

Throughout sessions, participants reflected on ways their experiences informed their caregiving identity, integrating caregiving into the "structure" and "journey" of their life. Discussions of *identity*, *history*, and *legacy* in Sessions 2 and 3 helped caregivers realize that their new "caregiver identity" was not necessarily separate from their "pre-caregiving" selves. Many noted that they "drew strength" from this perspective by recognizing how their past experiences informed their current role as caregivers.

Participants felt that by contextualizing caregiving within their life's journey, they were able to reframe caregiving as an important part of their life, without having the caregiver role subsume their entire identity.

Theme 3: MCP-C enabled caregivers to find ways to assert their agency through caregiving

Session 4 discussions of *attitude* enabled caregivers to reflect on their agency as a caregiver. While many circumstances feel out of caregivers' control, in this session caregivers considered their *attitude* as something within their control and as a result, participants came to define *attitude* as the way one *chooses* to react to difficult circumstances. Similarly, participants noted that Session 5 allowed them to think about ways to assert control over their well-being; participants framed self-care as "responsibility towards yourself." Similarly, participants related the concept of *creativity* to agency in how one chooses to live one's life.

Theme 4: The structure and sequence of sessions made MCP-C accessible and feasible

Caregivers felt that the structure and sequence of sessions were appropriate. Most appreciated that sessions were structured around the central concept of meaning, facilitating connections between each session. Participants also appreciated the space to think about concepts of meaning and identity that they otherwise would not have discussed. Among participants who received care pre-pandemic, most preferred receiving care in-person, though all acknowledged that having a choice over the mode of delivery was helpful given their unpredictable schedules. Caregivers also shared that it would be most beneficial to participate in MCP-C early in the patient's illness journey.

Session feedback

Participants found each session uniquely beneficial and no essential changes to the manual were identified. Specific session-by-session feedback is summarized as follows: Session 1 was a "non-intimidating" introduction to *meaning*; Session 2 helped participants integrate the role of caregiver into their sense of identity; Session 3 helped participants draw strength from their past experience and reflect on how legacy could be created through caregiving; Session 4 assisted caregivers in cultivating a sense of acceptance and agency through caregiving; Session 5 facilitated a sense of responsibility to the self; Session 6 helped caregivers reflect on how they can connect to the "bigger picture" of their lives and to a sense of appreciation of caregiving, though several found the concept of "transcendence" difficult to define after the session; and Session 7 was described as an opportunity to reflect on progress in therapy and hopes for the future.

Therapist focus group results

Several suggestions for manual edits were made. First, interventionists shared conceptual perspectives that should be incorporated into therapist guidelines, including maintaining an awareness of the potential for the patient's death and the implication of the meaning-centered work for preparing caregivers for bereavement. Much of the work done in MCP-C can be drawn on as caregivers face future challenges, including end-of-life care and bereavement. Therapists discussed the application of the concept of *legacy* and the *Legacy Project* as opportunities to explore the caregiver's legacy and that of their loved one, and how caregivers can carry forward patient legacies into bereavement. More broadly, helping caregivers engage in advanced care planning was highlighted and emphasized as an important area for inclusion in the therapist guide.

Other feedback focused on additions to session questions and experiential exercises. First, as a compliment to exploring caregivers' definition of *meaning* in Session 1, the therapist team suggested the inclusion of caregivers' definition of *caregiver*, given the focus of this adaptation on caregiving and the impact of this role on all aspects of caregivers' lives. Second, the team suggested adjusting the third experiential exercise question in Session 4, the session that focuses on the *attitudinal* source of meaning (i.e., the meaning caregivers derive through facing limitations and losses and obstacles). This question focuses on facing death, and the original MCP-C manual asked caregivers to reflect on their own death. This was perceived as a missed opportunity to explore the topic of advance care planning and reflect on the death of the patient. As such, the question was changed to, "What would your loved one with cancer consider to be a good

or meaningful death? If you have discussed this with him/her, what can you do to help ensure that their wishes are carried out? If not, would you be open to discussing this with him/her before we finish MCP-C?" Therapists agreed that these additions would facilitate the caregiver exploring both their own and the patient's conceptualization of death, and also provide an opportunity to discuss challenges or conflicts in communication that may be occurring between the patient and caregiver around these difficult topics. Finally, the team suggested an additional (optional) homework assignment, the *Self-Care Project*, to be introduced in Session 5. The *Self-Care Project* involves caregivers responding to the following questions and making a commitment to integrating self-care into their lives: *What does it mean to you to take responsibility for your own needs? What aspect of your own life (or identity/sense of self) do you most want to nurture? What can you commit to doing regularly, starting today, that is in service of your well-being?*

Discussion

Participation in MCP-C provided caregivers with a space that felt like "their own," allowed them to focus on themselves, and validated the challenges of caregiving. Sessions helped contextualize the caregiving identity in the context of caregivers' larger life stories and assisted them in connecting to a sense of agency. For many, MCP-C also enhanced caregivers' sense of connectedness to patients and supported them in navigating anticipatory grief. Together, these themes highlight ways in which MCP-C helped to address suffering among caregivers that is universal: feeling isolated, unseen, and powerless, and a sense that they had no choice in becoming a caregiver. Session-by-session feedback confirmed that the material presented in the seven sessions was appropriate for caregivers of patients with GBM, and that GBM-specific tailoring was not needed to make the manual acceptable for this unique population. However, the construct of *transcendence* was identified as one potentially requiring greater explanation.

In terms of timing and mode of delivery, several participants shared a desire to receive MCP-C earlier. A previous trial of a web-based MCP-C delivered to caregivers of patients with all sites and stages of cancer (Applebaum et al., 2018) indicated that caregivers who had been in the role for more than 2.5 years were less likely to drop from treatment compared to those who had been caregivers for shorter periods of time. We hypothesized that the capacity to engage in meaning-making was more accessible for caregivers whose loved ones were not recently diagnosed and who had moved through the crisis period of diagnosis. Here, given the rapidity with which GBM progresses and the swift emergence of caregiving-specific existential challenges (Applebaum et al., 2016b), this is a group for whom the delivery of MCP-C earlier in the caregiving trajectory — potentially soon after patients have completed an initial course of treatment post-diagnosis — would be optimal.

From the opening of the study through February 2020, MCP-C sessions were delivered in person, and we transitioned to delivery over telepsychiatry in March 2020 due to the COVID-19 pandemic. Participants who received sessions pre-pandemic in-person found participation feasible and they were appreciative of the flexibility of therapists to hold sessions at times that accommodated caregivers' schedules. There was no difference in attrition between caregivers who received MCP-C in-person versus over telepsychiatry, though recruitment efforts were aided by the ability to recruit and enroll participants without in-person

contact. As has been documented repeatedly over the past 18 months, the benefits of providing psychosocial care over telepsychiatry are vast and address many of the well-documented barriers to psychosocial care reported among caregivers (Hudson et al., 2006; Mosher et al., 2015; Devine et al., 2016). This study, like many others conducted in 2020, supports what is likely a shift in care delivery for caregivers to primarily web-based modalities.

Therapist feedback led to modifications centered around adding experiential exercise questions that reflect the unique needs and experiences associated with caregiving, and the importance of considering how elements of MCP-C may serve to prepare caregivers for advanced care planning discussions and bereavement. In the first session, paired with the standard MCP exploration of how one defines the construct of *meaning*, a question was added to elicit the caregiver's definition of *caregiver*. Just as the construct of *meaning* is unique to each of us, so too is the construct of *caregiver*. By explicitly exploring caregivers' definition and experience of this role without judgment, therapists can support caregivers in considering the meaning they may derive from the role. Moreover, this exploration serves as an important assessment point and responses can be used in future sessions to drive discussion about meaning and caregiving.

Another modification suggested was expanding questions in the fourth session that explore one's concept of a *good or meaningful death*. In the original version of MCP-C, this question was designed to understand what a meaningful end-of-life experience might look like for the patient. Questions added take this discussion a step further in prompting caregivers to share whether they have had conversations with the patient about death. These conversations about advanced care planning are understandably challenging for caregivers and patients, and the addition of a question about the patient's wishes and barriers to engaging in difficult conversations can facilitate such discussions. Indeed, simply acknowledging the possibility of death with caregivers in this trial prompted many to have profound and effective discussions with their loved ones that they otherwise had been avoiding. By explicitly exploring the topic of death, this also provides an opportunity to understand the complex emotions caregivers may have: concurrent anticipatory grief and a sense of anticipatory relief coinciding with patient death, as well as guilt about that anticipated reaction. Through these additional prompts, therapists may use meaning-centered perspectives, such as choosing one's attitude and living and giving a legacy, to gently guide caregivers in exploring these complexities.

The final change to the MCP-C manual was the addition of a *Self-Care Project* which can serve as marker to reinforce messages around responsibility to care for one's self and as a means to inspire continued integration of self-care long after completing MCP-C. In tandem with the *Self Care Project*, caregivers are also introduced to the idea of the *Legacy Project*, which similarly communicates that MCP-C is meant to provide caregivers with tools to support them in connecting with meaning despite the continued challenges they face in caregiving. Through the *Legacy Project*, caregivers may enhance their connectedness to their own legacy, as well as that of the patient, and explore ways in which they can carry forward that legacy after the patient's death. Pairing discussions of self-care and legacy can be powerful in enhancing a caregiver's sense of meaning while caregiving and into bereavement.

The overarching goal of MCP-C is to allow caregivers to concurrently experience meaning and suffering; the intervention does not seek to invalidate suffering and challenge, but instead to foster

a connection to meaning and purpose alongside this suffering. Through trials with various groups of caregivers, we have refined and improved our MCP-C manual so that it can most effectively assist caregivers in experiencing meaning and purpose, despite inevitable suffering.

Acknowledgments. We are grateful to Dr. Kailey Roberts, Dr. Rebecca Saracino, Laura Polacek, Leah Walsh, Sean Ryan, and Zeba Ahmad for their serving as interventionists on this trial

Funding. This study was funded by grant PEP-17-192-01-PCSM from the American Cancer Society and National Institutes of Health (P30CA008748, PI: Craig Thompson, MD; T32 CA009461, PI: Jamie Ostroff, PhD).

Conflict of interest. A.J.A. receives support from Blue Note Therapeutics. E.L.D. receives editorial support from Pfizer, Inc. outside the submitted work and serves on an advisory board for Day One Therapeutics. W.S.B. receives support from Blue Note Therapeutics and Adventis Healthcare.

References

- Applebaum A (2019a). Improving palliative care for caregivers of patients with glioblastoma multiforme (GBM). In: *Annual Kathleen Foley Palliative Care Retreat and Research Symposium, Jackson, Wyoming*.
- Applebaum A (2019b) Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C). In Applebaum A (ed.), *Cancer Caregivers*. New York, NY: Oxford University Press, pp. 237–253.
- Applebaum AJ and Breitbart W (2013) Care for the cancer caregiver: A systematic review. *Palliative and Supportive Care* **11**(3), 231–252. doi:10.1017/s1478951512000594
- Applebaum AJ, Kulikowski JR and Breitbart W (2015) Meaning-Centered psychotherapy for Cancer Caregivers (MCP-C): Rationale and overview. *Palliative and Supportive Care* **13**(6), 1631–1641. doi:10.1017/s1478951515000450
- Applebaum AJ, Bevans M, Son T, et al. (2016a) A scoping review of caregiver burden during allogeneic HSCT: Lessons learned and future directions. *Bone Marrow Transplantation* **51**(11), 1416–1422. doi:10.1038/bmt.2016.164
- Applebaum AJ, Kryza-Lacombe M, Buthorn J, et al. (2016b) Existential distress among caregivers of patients with brain tumors: A review of the literature. *Neuro-Oncology Practice* **3**(4), 232–244. doi:10.1093/nop/npv060
- Applebaum AJ, Buda KL, Schofield E, et al. (2018) Exploring the cancer caregiver's journey through web-based meaning-centered psychotherapy. *Psychooncology* **27**(3), 847–856. doi:10.1002/pon.4583
- Bauer-Wu S and Farran CJ (2005) Meaning in life and psycho-spiritual functioning: A comparison of breast cancer survivors and healthy women. *Journal of Holistic Nursing* **23**(2), 172–190. doi:10.1177/0898010105275927
- Braun M, Mikulincer M, Rydall A, et al. (2007) Hidden morbidity in cancer: Spouse caregivers. *Journal of Clinical Oncology* **25**(30), 4829–4834. doi:10.1200/jco.2006.10.0909
- Breitbart WS (2017) *Meaning-Centered Psychotherapy in the Cancer Setting Finding Meaning and Hope in the Face of Suffering: Finding Meaning and Hope in the Face of Suffering*. Oxford University Press. doi:10.1093/med/9780199837229.001.0001
- Breitbart W, Poppito S, Rosenfeld B, et al. (2012) Pilot randomized controlled trial of individual meaning-centered psychotherapy for patients with advanced cancer. *Journal of Clinical Oncology* **30**(12), 1304–1309. doi:10.1200/jco.2011.36.2517
- Breitbart W, Rosenfeld B, Pessin H, et al. (2015) Meaning-centered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. *Journal of Clinical Oncology* **33**(7), 749–754. doi:10.1200/jco.2014.57.2198
- Buycck JF, Ankri J, Dugravot A, et al. (2013) Informal caregiving and the risk for coronary heart disease: The Whitehall II study. *Journals of Gerontology* **68**(10), 1316–1323. doi:10.1093/gerona/ght025
- Callhoun LG and Tedeschi RG (2006) *Handbook of Posttraumatic Growth: Research & Practice*. Mahwah, NJ: Lawrence Erlbaum Associates Publishers.

- Carter PA** (2003) Family caregivers' sleep loss and depression over time. *Cancer Nursing* **26**(4), 253–259. doi:10.1097/00002820-200308000-00001
- Catt S, Chalmers A and Fallowfield L** (2008) Psychosocial and supportive-care needs in high-grade glioma. *The Lancet Oncology* **9**(9), 884–891. doi:10.1016/S1470-2045(08)70230-4
- Cho MH, Dodd MJ, Lee KA, et al.** (2006) Self-reported sleep quality in family caregivers of gastric cancer patients who are receiving chemotherapy in Korea. *Journal of Cancer Education* **21**(1 Suppl), S37–S41. doi:10.1207/s15430154jce2101s_8
- Christakis NA and Allison PD** (2006) Mortality after the hospitalization of a spouse. *New England Journal of Medicine* **354**(7), 719–730. doi:10.1056/NEJMsa050196
- Cliff AM and MacDonagh RP** (2000) Psychosocial morbidity in prostate cancer: II. A comparison of patients and partners. *BJU International* **86**(7), 834–839. doi:10.1046/j.1464-410x.2000.00914.x
- Covinsky KE, Goldman L, Cook EF, et al.** (1994) The impact of serious illness on patients' families. SUPPORT investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. *Journal of the American Medical Association* **272**(23), 1839–1844. doi:10.1001/jama.272.23.1839
- Devine KA, Manne SL, Mee L, et al.** (2016) Barriers to psychological care among primary caregivers of children undergoing hematopoietic stem cell transplantation. *Supportive Care in Cancer* **24**(5), 2235–2242. doi:10.1007/s00520-015-3010-4
- Frankl VE** (1963) *Man's Search for Meaning: Revised and Updated*. New York: WW Publisher.
- Frankl VE** (1967) *Psychotherapy and Existentialism: Selected Papers on Logotherapy. With Contributions by James C. Crumbaugh [Et AL]* New York: Washington Square Press.
- Frankl VE** (1972) The feeling of meaninglessness: A challenge to psychotherapy. *American Journal of Psychoanalysis* **32**(1), 85–89. doi:10.1007/bf01872487
- Frankl VE** (1978) *The Unheard cry for Meaing*. New York: Simon and Schuster.
- Guest G, Bunce A and Johnson L** (2006) How many interviews are enough?: An experiment with data saturation and variability. *Field Methods* **18**(1), 59–82. doi:10.1177/15258222(05279903
- Hearson B and McClement S** (2007) Sleep disturbance in family caregivers of patients with advanced cancer. *International Journal of Palliative Nursing* **13**(10), 495–501. doi:10.12968/ijpn.2007.13.10.27493
- Hudson PL, Hayman-White K, Aranda S** (2006) Predicting family caregiver psychosocial functioning in palliative care. *Journal of Palliative Care* **22**(3), 133–140.
- Hudson PL, Thomas K, Trauer T, et al.** (2011) Psychological and social profile of family caregivers on commencement of palliative care. *Journal of Pain and Symptom Management* **41**(3), 522–534. doi:10.1016/j.jpainsymman.2010.05.006
- Jandhyala R** (2020) Delphi, non-RAND modified Delphi, RAND/UCLA appropriateness method and a novel group awareness and consensus methodology for consensus measurement: A systematic literature review. *Current Medical Research and Opinion* **36**(11), 1873–1887. doi:10.1080/03007995.2020.1816946
- Kent EE, Mollica MA, Buckenmaier S, et al.** (2019) The characteristics of informal cancer caregivers in the United States. *Seminars in Oncology Nursing* **35**(4), 328–332. doi:10.1016/j.soncn.2019.06.002
- Kim Y, Shaffer KM, Carver CS, et al.** (2014) Prevalence and predictors of depressive symptoms among cancer caregivers 5 years after the relative's cancer diagnosis. *Journal of Consulting and Clinical Psychology* **82**(1), 1–8. doi:10.1037/a0035116
- King Jr PR, Beehler GP, Donnelly K, et al.** (2021) A practical guide to applying the Delphi technique in mental health treatment adaptation: The example of enhanced problem-solving training (E-PST). *Professional Psychology: Research and Practice* **52**(4), 376–386. doi:10.1037/pro0000371
- Kuckartz U** (2014). *Qualitative Text Analysis: A Guide to Methods, Practice & Using Software*. Available at: <https://doi.org/10.4135/9781446288719>.
- Mosher CE, Given BA and Ostroff JS** (2015) Barriers to mental health service use among distressed family caregivers of lung cancer patients. *European Journal of Cancer Care* **24**(1), 50–59. doi:10.1111/ecc.12203
- Niederberger M and Spranger J** (2020) Delphi technique in health sciences: A map. *Frontiers in Public Health* **8**, 457–457. doi:10.3389/fpubh.2020.00457
- Pargament KI and Ano GG** (2006) Spiritual resources and struggles in coping with medical illness. *Southern Medical Journal* **99**(10), 1161–1162. doi:10.1097/01.smj.0000242847.40214.b6
- Park CL and Folkman S** (1997) Stability and change in psychosocial resources during caregiving and bereavement in partners of Men with AIDS. *Journal of Personality* **65**(2), 421–447. doi:10.1111/j.1467-6494.1997.tb00960.x
- Roth AJ, Kornblith AB, Batel-Copel L, et al.** (1998) Rapid screening for psychologic distress in men with prostate carcinoma. *Cancer* **82**(10), 1904–1908. doi:10.1002/(SICI)1097-0142(19980515)82:10
- Salander P** (1996) Brain tumor as a threat to life and personality. *Journal of Psychosocial Oncology* **14**(3), 1–18. doi:10.1300/J077v14n03_01
- Sekayi D and Kennedy A** (2017) Qualitative Delphi method: A four round process with a worked example. *The Qualitative Report* **22**(10), 2755–2763. doi:10.46743/2160-3715/2017.2974
- Vitaliano PP, Scanlan JM, Zhang J, et al.** (2002) A path model of chronic stress, the metabolic syndrome, and coronary heart disease. *Psychosomatic Medicine* **64**(3), 418–435. doi:10.1097/00006842-200205000-00006
- Wen PY and Kesari S** (2008) Malignant gliomas in adults. *New England Journal of Medicine* **359**(5), 492–507. doi:10.1056/NEJMra0708126