

Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C): Rationale and Overview

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ABSTRACT

Objective: The multidimensional burden that results from providing care to a patient with cancer is well documented and a growing number of psychosocial interventions have been developed to address this burden. None, however, target existential distress, a critical, common element — and potentially driving mechanism — of caregiver burden. Meaning-Centered Psychotherapy (MCP) is a structured psychotherapeutic intervention originally developed by our group to target existential distress and spiritual well-being among patients with advanced cancer. We are currently developing Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C). The objective of this qualitative study is to describe the application of MCP to the unique experience of caregivers of patients with advanced cancer.

Methods: A case study of a participant from an initial MCP-C group is presented, with a focus on the application of sources of meaning to the cancer caregiving experience.

Results: The exploration of critical sources of meaning in the participant's life generally, and related to caregiving specifically, highlighted significant areas of growth, including an increased understanding of the historical context shaping her experience of providing care, the recognition of the need for improved self-care and reconnecting with meaningful activities, and the possibility for continued connectedness to others and the world, despite the limitations resulting from her husband's terminal illness.

Significance of results: Existential distress is a critical and often overlooked element of burden among cancer caregivers. MCP-C is intended to target this component of burden and address this critical gap in the palliative care literature. Clinical trials are underway to evaluate the efficacy of MCP-C delivered over the Internet. Future studies are needed to evaluate the benefits of MCP-C for particularly burdened groups of caregivers, such as caregivers of patients with brain tumors and those undergoing hematopoietic stem cell transplantations, and to identify target points of delivery that will optimize the intervention's benefits.

KEYWORDS: Caregiver, cancer, meaning, therapy, existential

INTRODUCTION

There is growing recognition that comprehensive care for cancer patients involves attending to the psychosocial needs of their informal caregivers (Breitbart & Alici, 2009; Institute of Medicine, 2008). Informal caregivers (ICs) are defined as any relative, friend,

or partner who has a significant relationship with and provides assistance (i.e., physical, emotional) to a patient with a life-threatening, incurable illness (Hudson & Payne, 2009). In 2009, 65,700,000 people in the United States served as ICs for medically ill relatives, including 4,600,000 cancer patients (National Alliance for Caregiving, 2009).

The burden experienced by cancer caregivers is well documented. Caregiver burden has been described as “a multidimensional biopsychosocial reaction resulting from an imbalance of care demands

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relative to caregivers' personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill" (Given et al., 2001, 5). Caregiver burden includes both psychological (e.g., anxiety, depression, hopelessness (Dumont et al., 2006; Kissane et al., 1994) and physical (e.g., increased mortality, cardiovascular disease, poor immune functioning, and sleep difficulty) complications (Christakis & Allison, 2006; Rohleder et al., 2009)). Importantly, studies have reported rates of anxiety and depression among family caregivers that are comparable to (Baider & De-Nour, 1988; Baider et al., 1996; Cliff & Macdonagh, 2000; Given et al., 1993; Kornblith et al., 1994; Kris et al., 2006; Rivera, 2009) and even surpass (Baider & De-Nour, 1988; Cliff & Macdonagh, 2000; Ey et al., 1999; Gallagher et al., 2002; McLean et al., 2011) those of the patients for whom they provide care.

EXISTENTIAL DISTRESS AMONG CANCER CAREGIVERS

A critical, potential driving, element of caregiver burden is existential distress. While no one definition of existential distress exists, it has been described as including feelings of hopelessness, demoralization, loss of personal meaning and dignity, feelings of burden towards others, and the desire for death or the decreased will to continue living (Chochinov et al., 2006; Henery, 2003; Hensch & Danielson, 2009). Cherny et al. (1994) describe existential distress in terms of whether individuals are focused on past (e.g., unfulfilled aspirations, regret), present (e.g., loss of important occupational, social and familial role functions), and future (e.g., the death of/separation from a loved one) concerns. Included in their description of existential distress are issues related to identity, personal integrity, meaninglessness, hopelessness, death, futility, and religious/spiritual concerns.

Existential distress and suffering experienced by caregivers is common, and may lead to increased feelings of guilt and powerlessness (Chochinov et al., 2006). For ICs, 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. However, the caregiving experience is also an opportunity for meaning-making and growth (Folkman et al., 1994). Importantly, finding meaning in the experience of being an IC for a patient with cancer has the potential to buffer against caregiver burden. The addition of meaning-based coping (Folkman et al., 1994) to Lazarus and Folkman's original model of stress and coping was based on the reports of caregivers of men with AIDS (Lazarus & Folkman, 1984), which highlighted their concurrent experience of meaning

and suffering in the context of providing care to their terminally ill loved ones. Indeed, a growing number of studies have documented the experience of post-traumatic growth (Hudson et al., 2006; Pinquart & Sörensen, 2003) as a result of stressful experiences, and finding meaning has been proposed as one mechanism through which positive outcomes can be achieved (Ayers, 2000; Bauer-Wu & Farran, 2005; Calhoun & Tedeschi, 2006; Farran et al., 1991; Manne et al., 2004; Pargament & Ano, 2006; Park & Folkman, 1997; Pearlin et al., 1990; Rhoades & McFarland, 1999; Thornton & Perez, 2006).

Meaning-making is rooted in the existential concept of one's ability to find meaning or "making sense" out of suffering. Having a loved one diagnosed with cancer and experiencing the resultant challenges of becoming an IC is a potential source of great anguish. Although this distress may be a transformative experience that ultimately leads to more adaptive coping (Frankl, 1963), it is a process that may also result in feelings of guilt and powerlessness. Frankl (1963; 1967; 1973; 1978) suggested that we may find meaning through the choices we make (e.g., the attitude an IC takes toward this role), our creative endeavors (e.g., ICs may create new ways to provide 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 ICs may experience growth as opposed to distress.

In a descriptive study of the unmet needs and intervention preferences among cancer caregivers (Applebaum et al., 2014), we identified existential concerns — including guilt, issues with role changes, sense of identity, and responsibility to the self — as a critical area of distress. Qualitative analysis of caregiver responses to the study questions highlighted a common theme among participant responses: *an increased sense of meaning would decrease burden*. However, very few caregivers reported at the time of assessment naturally engaging in a process of meaning-making. This study included an assessment of both patients and caregivers, and almost unanimously, patients acknowledged the benefits to their caregivers of finding meaning in this role. These responses corroborated the need for an intervention focused on existential needs.

LIMITED INTERVENTIONS FOR EXISTENTIAL DISTRESS AMONG CANCER CAREGIVERS

While a growing number of psychosocial interventions have been developed to target caregiver burden, our review of this literature (Applebaum & Breitbart, 2013) highlighted the dearth of interventions that

attend to existential distress or meaning-making among caregivers. Indeed, of the 49 interventions reviewed, only one specifically targeted existential concerns of ICs (Duggleby et al., 2007), although others acknowledged the importance of existential issues, including the importance of finding meaning through the cancer caregiving experience (Kozachik et al., 2001; McLean et al., 2008; Northouse et al., 2005; Scott et al., 2004; Toseland et al., 1995).

Since the publication of our review in 2013, one additional intervention that attends to caregivers' existential concerns has been reported. Existential Behavioral Therapy (EBT; Hayes, 2003) was developed to provide support to ICs of palliative care patients (not limited to cancer) through a manualized, six-session group psychotherapy intervention that is described as a "third wave" behavioral therapy (Hayes, 2003), integrating traditional cognitive and behavioral therapeutic techniques with existential themes. Sessions focused equally upon existential concerns and mindfulness skills practice, and topics included mindfulness, death, bereavement, finding meaning, self-care, stress management, and personal values (Fegg et al., 2013). A randomized controlled trial comparing the impact of EBT to usual care among 160 caregivers of palliative care patients demonstrated efficacy of the intervention in improving anxiety and quality of life immediately after completion of the program, as well as depression and quality of life one year after completion (Fegg et al., 2013). Notably, participants were caregivers of patients with life expectancies of six months or less, and included both current and bereaved caregivers.

To date, there are no empirically supported interventions that specifically target meaning-making among informal cancer caregivers. Importantly, the experience of providing care to a patient with cancer varies significantly from the experience of providing care for patients with neurological diseases, such as Alzheimer's or Parkinson's disease, and therefore interventions developed for this population must account for the unique experience of cancer caregiving. In light of previous research indicating that finding meaning in caregiving leads to more positive mental health outcomes among informal caregivers, including enhanced caregiving capacity and improved care for the patient (Park, 2010), interventions that foster meaning-making among caregivers have the potential to improve their quality of life and that of the patients for whom they provide care. While the benefits of such interventions will likely be vast across the caregiving trajectory, when delivered early — such as well in advance of a patient's transition to hospice care — they have the potential to serve a protective role against poor psychosocial outcomes.

MEANING-CENTERED PSYCHOTHERAPY (MCP)

Attention to spiritual and existential distress among patients with cancer and their caregivers is a critical component of palliative care, but to date, very few interventions focus specifically on these needs. Our group has developed Meaning-Centered Psychotherapy (Breitbart et al., 2010; 2012; 2015), an existential therapeutic model developed to address the existential issues of suffering, guilt, and death. MCP has demonstrated efficacy in improving spiritual well-being and a sense of meaning, and decreasing symptoms of anxiety in patients with advanced cancer. Secondary analyses from a trial of Individual Meaning-Centered Psychotherapy (IMCP; Lichtenthal et al., 2009; 2008) indicated that IMCP improved patients' sense of meaning and purpose in life, led to their finding comfort and strength in spiritual beliefs, and to increases in life productivity. Both individual and group formats of MCP have been developed and tested. Meaning-Centered Group Psychotherapy (MCGP) includes eight, 1.5 hour-long sessions, while Individual Meaning-Centered Psychotherapy (IMCP) involves seven, 1 hour-long session. As an established, efficacious intervention, MCP provides a solid foundation for a meaning-making intervention that is tailored toward the unique needs of individuals caring for a loved one with cancer. Importantly, given the underutilization of psychosocial services by this population (Hart et al., 2007; Lichtenthal et al., 2011; Shelby et al., 2002), it is hypothesized that attention to meaning will be congruent with IC's experience and thus offer an attractive intervention that promises to ameliorate a critical element of caregiver burden.

MEANING-CENTERED PSYCHOTHERAPY FOR INFORMAL CANCER CAREGIVERS (MCP-C)

The experience of providing care for a patient with cancer may be a source of great suffering. This suffering may be experienced in a variety of ways (e.g., psychological and existential distress, medical problems), as described previously. Such suffering may lead to caregivers becoming disconnected from elements of their identity that they once prioritized, disconnected from important activities and relationships, and experiencing a decrease in their sense of meaning and purpose generally, or as related to caregiving, specifically. Such loss of meaning ultimately increases suffering and burden of caregivers, and negatively impacts the quality of the care provided to patients. Such suffering, however, may exist concurrently with positive emotions, connectedness, and growth. Through an

exploration of the unique experience of providing care for a patient with cancer, including caregivers' previous experiences of illness, loss and care, the manner in which caregivers respond to the limitations of the caregiving role, how providing care for another may serve as a catalyst for improved self-care, and relationship with oneself and the care recipient, caregivers may find great meaning in the caregiving role, which ultimately will improve their quality of life and protect them from the burden commonly associated with the caregiving role. These outcomes serve as the impetus for the adaptation of Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C).

The goal of MCP-C is to help caregivers connect — or reconnect — to various sources of meaning in their lives. The four sources of meaning addressed in MCP-C are historical, attitudinal, creative, and experiential. Table 1 outlines these sources of meaning, and their relevance to the experience of providing care to a patient with cancer.

Historical sources of meaning refer to critical elements of caregivers' past, present, and future legacies, many of which may be connected to the caregiving role. Past legacy refers to components of the caregiver's upbringing that they did not choose but which had a significant impact on who they are, including the family into which they were born, and the cultural, religious, and spiritual values of their family of origin. Critical elements of past legacy for caregivers include previous experiences of providing care or watching others (i.e., parents, grandparents) provide care to friends and family members, past experiences of illness or loss, and religious, spiritual, or familial traditions that promoted commitment to the family. Present legacy refers to the legacy the caregiver is currently living and creating, including engaging in the caregiving role. Future legacy refers to the impact the caregiver has on others, and includes how others view the caregiver in this role, and importantly, the ways in which this role sets an example for future generations, family members, and friends.

Attitudinal sources of meaning refer to the ways in which caregivers choose to face limitations and challenges. Reflecting on how one faces challenges can be an incredibly meaningful experience. Critically, becoming a caregiver is not generally perceived as a choice. However, helping caregivers to recognize how they came to decide to engage in this role — and specifically how and to what extent they engage in this role — may serve as a catalyst for improved self-efficacy. Additionally, highlighting how caregivers choose to face limitations due to the caregiving role, such as the inability to make advanced plans, interruptions to personal goals and employment, and often, a limited amount of time remaining with the

patient for whom they are providing care, can be a source of great meaning and strength and can foster the development of new skills, clarified values, and resilience.

Creative sources of meaning refer to the ways in which caregivers create and take responsibility for their lives, which includes how they engage in the caregiving role. Creating one's life requires courage and commitment, and engaging fully in the caregiving role with a loved one who is terminally ill is an example of an act that requires courage and commitment. Additionally, a critical area of creativity is responsibility to the self, and how one may continue to create one's life fully and attend to one's own needs, while providing care to a patient with cancer.

Table 1. Sources of meaning and caregiving

Source	Content
Historical	<i>Legacy given (past), lived (present), and to give (future).</i> Examples include previous experiences of providing or watching others provide care, of illness or loss, and family values associated with an ethic of care; taking pride in caregiving; and setting examples for future generations.
Attitudinal	<i>Choosing how one faces limitations associated with caregiving.</i> Reflection on challenges faced before caregiving and previous modes of facing such challenges, such as achievements in the face of adversity, rising above or transcending difficult circumstances. Discussion of choosing new ways to respond and taking pride in one's attitude. Examples include the choice one makes to provide care, how one faces the limitations that result from the caregiving role, and choosing to engage fully in the relationship with the patient despite the possibility of its ending.
Creative	<i>Engaging in life and taking responsibility for one's life through creative acts, such as through work, causes, family, artistic endeavors, and self-care.</i> Examples include courageously engaging fully in the caregiving role and taking responsibility for oneself through improved self-care, and discussion of existential and neurotic guilt as indicators of deficient self-care.
Experiential	<i>Connecting with life through love, relationships, nature, art, humor.</i> Examples include feeling and expressing love for the care recipient via a tight hug or handhold, finding humor in dark moments, and deriving hope for the future from a sense of belonging to something greater than oneself.

Finally, experiential sources of meaning include ways in which caregivers connect with the world through their five senses. This source of meaning, unlike those discussed previously, is derived in a more passive manner, through one's connecting with life through the five senses. For example, through a tight handhold or hug, caregivers may feel connected through love for the patient, may be transported from present suffering merely through listening to their favorite music or sharing a laugh at a difficult moment with the patient for whom they provide care, or may feel a sense of tranquility through experiencing the beauty of nature, which often serves as a reminder of the longevity of the world around them and the connectedness of humans and nature.

MCP-C is delivered in both group (8-sessions) and individual (7-sessions) formats. The outline for these sessions is presented in Table 2. The first two sessions are an introduction to the concept of meaning and meaning-making, and identity of the caregiver. The next five (or four, in the individual format) sessions are each focused on one of the four sources of meaning, and how the caregiver may connect or reconnect with each one of these so that they become resources at various points in the caregiving trajectory. The final session is an opportunity for caregivers

to reflect on goals for the future, which in some cases may include preparation for the loss of their loved one and the creation of a new life in the future. Each session includes didactics and experiential exercises through which caregivers begin to understand the relevance and importance of sustaining, re-connecting with, and creating meaning in their lives and caregiving through the sources of meaning previously described.

CASE EXAMPLE

Mrs. X was the 54-year-old wife and primary caregiver of her husband, a 66 year old retired New York City firefighter who was diagnosed with a glioblastoma multiforme (GBM) nine months before her engaging in Meaning-Centered Group Psychotherapy for Cancer Caregivers. She and her husband had two daughters in their early 20 s, both of whom lived outside of the New York metropolitan area, where the couple resided. Mrs. X had previously worked full-time in human resources for a large corporation. When her husband was initially diagnosed and underwent surgery and radiation, she worked part-time. But as the months passed and the disease progressed, she was forced to take an unpaid leave of absence from work in order to attend to his growing number of needs.

Table 2. Meaning-centered psychotherapy for cancer caregivers weekly topics

Session	Session Title	Content
1	Concepts and Sources of Meaning	Introductions; review of concepts and sources of meaning; <i>Meaningful Moments</i> experiential exercise; copies of <i>Man's Search for Meaning</i> distributed for optional reading.
2	Cancer Caregiving, Identity, and Meaning	Discussion of sense of identity before and after becoming a cancer caregiver; <i>Who am I?</i> experiential exercise; homework reflection on Session 3 experiential exercise.
3	Historical Sources of Meaning (Past Legacy)	Discussion of life as a legacy that has been given (past); <i>Historical Sources of Meaning-Past</i> experiential exercise; homework reflection on Session 4 experiential exercise.
4	Historical Sources of Meaning (Present and Future Legacy)	Discussion of life as a legacy that one lives (present) and gives (future); <i>Historical Sources of Meaning-Present and Future</i> experiential exercise; homework reflection on Session 5 experiential exercise and optional sharing of one's story.
5	Attitudinal Sources of Meaning: Encountering Life's Limitations	Discussion of confronting limitations associated with caregiving; <i>Encountering Life's Limitations</i> experiential exercise; introduction to Legacy Project; homework reflection on Session 6 experiential exercise.
6	Creative Sources of Meaning: Engaging in Life Fully	Discussion of creativity, courage and responsibility; <i>Creative Sources of Meaning</i> experiential exercise; homework reflection on Session 7 experiential exercise.
7	Experiential Sources of Meaning: Connecting with Life	Discussion of experiential sources of meaning, such as love, nature, art, and humor; <i>Love, Beauty, & Humor</i> experiential exercise; homework is planning/completion of Legacy Project for presentation in Session 8.
8	Transitions: Reflections, and Hopes for the Future	Review of sources of meaning, reflections on lessons learned; <i>Hopes for the Future</i> experiential exercise; goodbyes.

*Note. When delivered individually, the material from group sessions 3 and 4 are combined into one session on Legacy.

By the time she engaged in MCP-C, Mr. X was experiencing many of the neurocognitive and personality changes often associated with GBM, and was no longer able to complete all activities of daily living, such as dressing and feeding himself. Importantly, Mrs. X described her husband as someone who, for their 32 year marriage, was even tempered and gentle, but more recently, had become verbally aggressive, irritable, and forgetful. Mrs. X had no notable psychiatric history and had never before received professional psychological services. At the time that she enrolled in MCP-C, she was experiencing chronic worry about her husband and her future. This worry interfered with her sleep and ability to concentrate, and was associated with somatic symptoms, such as nausea and muscle tension. She also reported at times feeling hopeless about the future and fearful of living life without her husband, and abandoned by her daughters for not being present and helping to care for him.

Historical Sources of Meaning

Mrs. X identified being raised in the Catholic faith and in a big Italian family as key elements of her past legacy that had a significant impact on her sense of identity and values. As a young girl, spending time with her family was a priority, and each weekend her home was filled with many generations of relatives. The identification of this element of her past legacy helped Mrs. X to clarify why, in part, having her daughters live far away and not involved with helping her to care for her husband was so upsetting to her. She also described watching her mother take care of her widowed grandfather for 13 years at home through his progressive deterioration due to Alzheimer's disease, reporting that she never saw her mother "crumble" or complain about the burden of the caregiving role. Mrs. X identified a desire to be "strong like my mother" and emerging guilt as a result of her feeling worn out, burdened, angry, and resentful of her caregiving responsibilities. She described wanting to set the example of "strength" for her daughters that her mother had set for her. Through a discussion of current and future legacy, Mrs. X became open to the possibility that the legacy she was creating in that moment and the one she would give to others, including her daughters, could be accomplished in a manner different from her mother, though just as impactful. Specifically, Mrs. X recognized that her past legacy — including experiences in which women in her family were "strong but silent" — had significantly impacted the value she placed on limiting emotional expression and her discomfort with acknowledging her own pain. She recognized, however, that her current and future legacies were open to change and through her begin-

ning to honor her authentic feelings and speaking about them — in session, with her husband, daughters, and other family members — that she could create a different legacy, one which she hoped would impact how her daughters would face adversity in their lives in the future.

Attitudinal Sources of Meaning

Mrs. X felt strongly that she had no choice in becoming a caregiver. Her adult daughters lived in Michigan and California, and her parents were deceased, although she and her husband's extended family were all local. Despite this fact, she reported having a very hard time asking friends and extended family for help, or agreeing to receive help when it was offered to her. Instead she tended to take on all of the responsibilities of caregiving, in part, because she felt that she would "do things right" and there was a risk that others would not. Through an exploration of the ways in which Mrs. X responded to limitations and losses in the past, such as her parents' deaths and layoffs at a previous job, it became clear that she had a history of coping through "taking charge" and keeping busy, as well as through isolating herself and hiding her emotions. When her parents died, she organized both of their funerals and memorial services, continued to care for her two daughters (who at the time were children and then adolescents and still living at home), and worked full time. She rarely allowed herself to cry, and when she felt tears coming on, would quickly engage in a new task to keep busy and distract herself from the intensity of the emotions experienced.

The discussion of attitude allowed for the possibility of a more flexible view of the caregiving role to emerge. In many ways, Mrs. X had indeed chosen the extent to which she was engaging in this role, had chosen to be her husband's primary caregiver, and repeatedly refused offers of assistance from family members and friends. While she was proud of her ability to do everything for her husband — an element of attitude that she identified as a source of meaning and strength and one that would continue to be a resource for her throughout the caregiving trajectory — she also recognized her role within her current limitations, and her ability to respond to her caregiving position differently. For example, while previously she had accepted her daughters' lack of involvement in her husband's care, she recognized in session that her frustration with their limited involvement was an opportunity to address her desire to have them more engaged in his care and family life. She also recognized that she could choose to allow more extended family to be involved in caring for her husband, and that in so doing, she could

reflect on the caregiving role and her current distress as an opportunity for positive growth and change. Related to this was her recognition of the benefit of choosing to openly and authentically acknowledge her emotional distress. Her previous approach had left her chronically worried, and had contributed to her difficulty sleeping and suffering from frequent stomach pains and headaches. The session on legacy highlighted the origin of this approach, and the conversation about choosing one's attitude underscored new ways in which Mrs. X could respond to limitations she was currently facing, which would have a more positive impact on her mental health.

Creative Sources of Meaning

The session on creative sources of meaning was a particularly powerful one for Mrs. X. The discussion of creating and using one's life led to the emergence of several critical themes, with which Mrs. X had likely struggled for many years long before becoming a caregiver. First, she described feeling that she had not fulfilled her dreams or used her life to its fullest. As a young adult, she had aspirations to travel the world and pursue artistic endeavors, including photography and painting, areas in which she had great talent. However, the need to work from a young age to help contribute financially to her family prevented her from what Mrs. X described as "indulging" in these interests. She had dreams of traveling to Europe and through South America, but never had the financial means to do so. She and her husband married in their early 20s, and as soon as their first child arrived, the demands of working full-time and being a mother led to what she described as "shoving those dreams away." Through an exploration of creativity, Mrs. X was able to identify how critical these dreams had been for her, and recognize that she had the capacity to continue to create her life, despite her current challenges. This discussion helped Mrs. X to acknowledge that despite the pain and difficulties associated with her inevitable loss of her husband due to brain cancer, she would have a future that was open to new possibilities for growth and renewal, one which she could shape in a manner that would meet her own needs. Through this conversation, Mrs. X began to embrace the possibility of concurrently feeling intense pain and sadness, as well as hope.

A second important theme that emerged was Mrs. X's acknowledgment of the courage it had taken her to continue to engage fully in her marital relationship. She described her 32-year marriage as "solid" and "loving." She reported that, similar to herself, her husband rarely verbalized his emotions, the couple said "I love you" to one another on only rare occasions, and their manner of solving or resolving

arguments in the past was to "let things go" with time. Despite this, there was always a feeling of love and connectedness between them, a connectedness that became particularly important when their daughters moved away from home. Mrs. X reported that since her husband's diagnosis, she felt urgency to verbalize her emotions to her husband, to discuss important issues such as his wishes for end-of-life care and her fears about the future, and most importantly, capitalize on her realistic perception of her husband's limited capacity for clear communication. She also reported the conflict she felt regarding her desire to engage more than ever with her husband, but fear of doing so when their time together was becoming more limited and the inevitability of his passing a reality. The group members helped to highlight the courage Mrs. X possessed in acknowledging her desires to be more open, taking steps to do so, and engage more fully in her relationship, despite all of the challenges associated with doing so (including her husband's continued hesitancy to speak openly). This conversation also helped Mrs. X to recognize that her current courage and engagement would likely prevent future feelings of guilt and regret, after her husband's passing.

Finally, the session on creativity highlighted Mrs. X's general difficulty in taking responsibility for her own needs. Like other group members, she was a seasoned caregiver and had been for many years before her husband's illness to other extended family members and to her daughters, but had great difficulty in clearly identifying her own needs and asking others for help. This difficulty was particularly clear at the time of the group meeting, after a year of Mrs. X's intense caregiving, repeated rejection of others' help, and increasing burden. Discussion with group members helped Mrs. X recognize that she would be unable to continue to provide the level of care her husband required without beginning to neglect her basic needs for sleep, exercise, and engaging in activities that could bring brief moments of pleasure, and that over time as her husband's disease would progress and his needs increase, she would be required to involve others in his care. Additionally, Mrs. X recognized that her tendency to take full responsibility for her husband's care was, in part, a means of coping with the uncertainty of his illness and their future, similar to how she had coped with challenges and limitations in the past.

Experiential Sources of Meaning

The session on experiential sources of meaning highlighted this source of meaning as one that Mrs. X had engaged at various times throughout her life, and one which had the potential to become an even more

significant resource for her at the present time, when the demands of caregiving were great. Mrs. X identified that in the past, she had found peace and contentment through engaging in her artistic interests (photography, painting) and through prayer. Ever since her childhood, she experienced a sense of connectedness to something much greater than herself through prayer, in addition to a sense of awe, hope, and peace. Additionally, through painting and photography, she would often find the hours “flying by,” and would get lost in the present moment of the artistic creation. When asked about more recent experiences of connectedness through love, beauty, and humor, Mrs. X shared that before his illness, she and her husband often attended sporting events together, during which they would get “lost in the moment,” cheering for their favorite team and becoming energized by the crowds. Discussion with group leaders and members encouraged Mrs. X to think more flexibly about how to continue to engage in this type of activity, despite her husband’s limitations, such as through watching sports games together on the television. The discussion also highlighted the sense of peace Mrs. X felt at night when she fell asleep on her husband’s shoulder, something she had done almost every night of their marriage. Despite her husband’s limitations, in those moments, Mrs. X felt cared for, deeply loved, safe, and connected. She recognized that this connectedness was a gift, a feeling that she could experience despite how difficult the circumstances, and one which, though time limited, was very much present at the time of this session.

DISCUSSION

A large and growing body of literature identifies existential distress as a critical, but often overlooked, component of caregiver burden. Existential distress may underlie many related psychological elements of caregiver burden and frame unique opportunities for intervention at their causal origin through an exploration of meaning. Indeed, meaning-making has been described as a potential mechanism for positive growth and buffering against such burden. Despite these facts, the state of the science of intervention development for cancer caregivers remains in its infancy, and only a limited number of investigations have explored interventions that attend to various elements of existential well-being (Duggleby et al., 2007; Hayes, 2003). Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C) is a novel, therapeutic approach intended to address the existential concerns commonly experienced by cancer caregivers. Based upon an empirically supported intervention that has demonstrated efficacy in improving the quality of life of patients with advanced

cancer, breast cancer survivors, and bereaved parents (Breitbart et al., 2012, in press; Lichtenthal & Breitbart, in press; Lichtenthal et al., 2014, 2015), MCP serves as robust basis upon which to develop a targeted psychotherapy to address the existential needs of cancer caregivers. Critically, the delivery of such an intervention early in the caregiving trajectory has the potential to mitigate caregiver burden and eventually, to protect against poor bereavement outcomes, including prolonged grief disorder.

The case example provided highlights various ways in which the exploration of four sources of meaning in life — legacy, attitude, creativity, and connectedness — may serve as resources for caregivers who feel burdened by the caregiving role and are struggling to attend to their own needs. The exploration of legacy gives context to caregivers’ experience of caregiving and helps them to recognize the historical factors that contributed to their engaging in and experience of this role, as well as how their caregiving work will form a key element of the legacy they will give to others in their lives. The discussion of attitude — and specifically, the ability of caregivers to choose their attitude in the face of the suffering they experience in their caregiving role — can be an incredibly transformative experience for those who feel that they have no choice in their role and little efficacy in their daily life. Responsibility to care for oneself and the desire to continue to create one’s life, despite the limitations of caregiving, are common themes that emerge when discussing creative sources of meaning. Through an exploration of creativity, courage, responsibility, and guilt, caregivers are afforded the opportunity to reflect on ways in which they are taking responsibility for their own lives, in addition to the life of their loved one with cancer, and how within the limitations of the caregiving role they may continue to create their lives. While the experiential source of meaning can serve as a resource throughout the caregiving trajectory, it is particularly salient for caregivers who are overwhelmed by the demands of caregiving, and for those whose loved ones are no longer eligible for curative treatment. Indeed, helping caregivers to recognize that through experiencing the world through their five senses and through love, beauty, and humor, they can enjoy moments of peace and transcendence, has the potential to be a transformative process.

While psychiatric diagnoses, such as anxiety and depression, are not discussed directly in the course of MCP-C, such symptoms are conceptualized in the context of caregivers becoming disconnected from various sources of meaning in their life. Helping caregivers to derive a new understanding of, or reconnection with, various sources of meaning has the potential to mitigate depressive and anxious

symptomatology often associated with caregiver burden. MCP-C leaders help caregivers to understand the benefits of connecting with meaning in their lives and how these 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.

CONCLUSIONS AND FUTURE DIRECTIONS

Randomized controlled trials are currently underway to evaluate the preliminary efficacy of MCP-C in enhancing spiritual well-being and meaning, and decreasing burden, anxiety and depression among cancer caregivers. Previous studies have documented the many challenges of enrolling and maintaining cancer caregivers in in-person psychotherapy trials (Applebaum & Breitbart, 2013). Highlighted in the literature are the benefits that may be derived from interventions delivered in alternate modalities, such as over the telephone or Internet. In addition to the in-person intervention, our group is currently investigating the efficacy of MCP-C delivered over the Internet. If successful, the web-based version of MCP-C will have the potential to reach caregivers across the country and world, who for a variety of reasons are unable to access high quality face-to-face mental health care. Our hope is that through the development and dissemination of MCP-C, an intervention developed specifically to address the existential distress experienced by cancer caregivers, the unique needs of this underserved and highly vulnerable group can be better met by the psycho-oncology and palliative care communities.

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