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Preliminary study of themes of meaning and psychosocial service use among informal cancer caregivers

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Abstract

Objective—The burden experienced by informal caregivers (ICs) of patients with advanced cancer is well documented. ICs are at risk for anxiety and depression, as well as existential concerns that arise when a loved one is facing a terminal illness. Few psychosocial interventions focus on existential concerns of ICs. However, a growing body of literature indicates that finding meaning in the experience of being an IC for a person with cancer has the potential to buffer against burden. The purpose of this study was to collect preliminary descriptive data regarding caregiver burden, meaning, and psychosocial service use to inform the adaptation of a meaning-centered intervention for ICs.

Method—Twenty-five caregivers and 32 patients completed brief, anonymous questionnaires that asked about their role as a caregiver or their perception of their loved one as a caregiver, caregiver burden, and psychosocial service use.

Results—Caregivers and patients identified anxiety and depression as top correlates of burden experienced by caregivers, whereas guilt, issues with role/sense of identity, and self-care were additional areas of concern. The majority of caregivers were not receiving psychosocial services, although they almost unanimously reported desiring services. A greater proportion of patients than caregivers believed that an intervention designed to enhance meaning would ameliorate burden, but, nevertheless, close to three quarters of caregivers reported interest in participating in such an intervention.

Significance of results—These study findings provide further support for, at a minimum, engaging ICs of persons with advanced cancer in interventions that address existential issues, mental health, self-care, and service use. Such interventions are likely to improve the quality of life of both patients with cancer and their ICs.

Keywords

Cancer caregiver; Caregiver burden; Meaning; Psychosocial service use

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INTRODUCTION

The 2009 Institute of Medicine (IOM) report “Retooling for an Aging America: Building the Health Care Workforce” highlighted the responsibility of health-care professionals to prepare informal caregivers (ICs) for their role, and the need to establish programs to assist them with managing their own stress that results from providing such care (Institute of Medicine, 2008). ICs are at risk for a range of psychological (e.g., anxiety, depression, hopelessness) (Kissane et al., 1994; Dumont et al., 2006) and physical (e.g., increased mortality, cardiovascular disease, poor immune functioning, sleep difficulties) (Christakis & Allison, 2006; Rohleder et al., 2009) complications. These symptoms are common elements of caregiver burden, which has been described as “a multidimensional biopsychosocial reaction resulting from an imbalance of care demands 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, p. 5). ICs are often unprepared to take on all of the aspects that this new role entails (Hinds, 1985; Morse & Fife, 1998; Northouse et al., 2000; Nijboer et al., 2001; Carlson et al., 2001; Given et al., 2001; Bishop et al., 2007) and often have a wide range of unmet needs (Northouse, 1984; Hileman et al., 1992; Laizner et al., 1993; Covinsky et al., 1994; Kissane et al., 1994; Hodgkinson et al., 2007; Kim & Given, 2008). Not only do ICs face the physical and emotional demands associated with caregiving, but, also, the patients for whom they provide care may no longer be able to provide them with the emotional support that they once did (Francis et al., 2010). Therefore, ICs are not only often unprepared to provide instrumental support, but they may also often be in great need of emotional support themselves.

Finding meaning in the experience of being an IC for a patient with cancer has the potential to buffer against these negative outcomes. Numerous studies have documented the experience of posttraumatic growth (Pinquart & Sorensen, 2003; Hudson et al., 2006) as a result of stressful experiences, and finding meaning has been proposed as one mechanism through which such positive outcomes are achieved (Pearlin et al., 1990; Farran et al., 1991; Park & Folkman, 1997; Rhoades & McFarland, 1999; Ayres, 2000; Manne et al., 2004; Bauer-Wu & Farran, 2005; Calhoun & Tedeschi, 2006; Pargament & Ano, 2006; Thornton & Perez, 2006). The addition of meaning-based coping (Folkman et al., 1994) to Lazarus and Folkman’s original model of stress and coping (Lazarus & Folkman, 1984) was based on the reports of caregivers of men with AIDS. 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 suffering. Although this suffering 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.

A recent systematic review of interventions for cancer caregivers conducted by our group (Applebaum & Breitbart, 2012) produced 49 interventions developed specifically for ICs of patients with cancer. This large number of studies reflects the field's growing recognition of the severity of burden experienced by ICs, and the subsequent need to provide care to ICs, in addition to cancer patients (Surbone et al., 2010). However, one domain that received limited attention was existential issues; only one intervention specifically targeted existential concerns of ICs (Duggleby et al., 2007), although several others acknowledged the importance of existential issues, including the importance of finding meaning through the cancer caregiving experience (Toseland et al., 1995; Scott et al., 2004; Northouse et al., 2005; Kozachik et al., 2006; McLean et al., 2008). To our knowledge, there are no empirically supported interventions that focus specifically on helping ICs find a sense of meaning and purpose in their caregiving. ICs face unique challenges in making meaning, and palliative care researchers have acknowledged that finding meaning in the caregiving experience leads to better mental health among caregivers and, in turn, the provision of better care for the patient (Park et al., 2010). Therefore, assisting caregivers to access sources of meaning in the caregiving experience should lead to improvements in their quality of life (QOL) and the quality of the care they provide.

Meaning-Centered Psychotherapy (MCP), an existential therapeutic model developed by our group (Breitbart et al., 2010; 2012), addresses 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., 2008; 2009) indicated that IMCP improved patients' sense of meaning and purpose in life, and led to their finding comfort and strength in spiritual beliefs, and to increases in life productivity. 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 patient with cancer. Additionally, MCP's impact on QOL makes it a promising approach to targeting caregiver burden.

Study Purpose

In order to develop a tailored, theory-driven existential intervention for cancer caregivers that is acceptable and effective, and that may be easily disseminated, information regarding caregiver burden, meaning, and intervention preferences is first needed. The purpose of the present study was to gather information about caregiver burden and themes of meaning making in order to shape the content of an existential intervention for ICs, and understand their intervention preferences, support needs, and barriers to psychosocial service use to determine an acceptable intervention format and mode of delivery.

METHOD

Participants and Procedures

Participants were recruited from the outpatient counseling center in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center (MSKCC) between July 6 and August 2, 2011. Patients and the caregivers who accompanied them to their visits in the Counseling Center were recruited during routine clinic visits. Participants were approached by the study PI (A.J.A.) or research assistant (A.P.) and asked if they were interested in completing an anonymous, brief questionnaire, that asked about their role as a caregiver or their perception of their loved one as a caregiver. No protected health information (PHI) was collected. The questionnaires (separate versions for patients and caregivers) took ~5 minutes to complete and were returned by participants anonymously via a dropoff box that was held at the Counseling Center Reception area. Importantly, although patients and their caregivers were often approached by study staff together, not all patients and/or caregivers completed the questionnaires, and therefore, the data collected are not representative of all patient/caregiver dyads.

Measures

The questionnaires used for the study from which these data were drawn were developed by the Psychotherapy Laboratory in the Department of Psychiatry and Behavioral Sciences and included both open- and closed-ended questions. Data presented here pertain to participants' responses to three domains assessed:

Caregiver Role—Caregivers were asked, “Do you consider yourself a caregiver to a cancer patient?” (yes/no); “If YES, what do you feel makes you a caregiver?” “If YES, what is your relationship to the patient (i.e., spouse, parent, child, friend)? Patients were asked, “Who has been closest to you during your cancer journey?” (and in order to maintain anonymity, identified the caregiver in terms of their relationship, such as “my mother,” “my spouse,” or “my best friend”); “Do you consider this person a caregiver?” (yes/no); “If YES, what makes them a caregiver?” “If YES, approximately what percent of this person's time each week is spent providing care?” and “How many other people in your life provide care for you?”

Caregiver Burden—Caregivers were asked, “Do you struggle with any of the following? (check all that apply)” and then were given the following list of caregiver concerns: issues related to his/her role or sense of identity; self-care; sense of purpose/meaning in life; depression; anxiety; medical problems; financial problems; close relationships; guilt; other____. They were also asked to rate on a four point Likert scale, from *very* to *not at all*, “How overwhelmed do you feel by your role as a caregiver?” Patients were asked, “In your opinion, does this person struggle with any of the following? (check all that apply)” in response to the same list of concerns presented to caregivers.

Psychosocial Service Use—Caregivers were asked, “Do you currently receive psychotherapy or counseling of any kind?” (yes/no), and then asked to respond to the following questions using a four point Likert scale (no/maybe/most likely/definitely): “If NO, how interested would you be in receiving counseling?” and “If NO, do you think that you would be able to make time for counseling?” Participants were then given a brief description of an eight session existential psychotherapeutic approach for cancer caregivers being developed by the authors. Caregivers were asked to respond to the following two questions using a five point Likert scale (ranging from *not at all interested* to *extremely interested*): “How interested would you be in participating in this type of psychotherapy program?" and "How helpful do you think a program like this would be for you?" Caregivers were also asked, "What are three things that would keep you from participating in a program like the one described above?" Patients were asked, "Does your caregiver currently receive any type of psychotherapy or counseling?" (yes/no). They were then asked to respond to the following two questions using a four point Likert scale (no/ maybe/most likely/definitely): "If this person does not currently receive any type of psychotherapy or counseling, do you think he/she would be interested in receiving counseling (this might be individual or group)?" and "Do you think this person would be able to make time for counseling?"

RESULTS

Caregiver Role

Twenty-five caregivers completed the questionnaire. In terms of relationship to the patient for whom they provided care, the majority of caregivers (56%) were spouses, 24% were children, and the remaining 12% were divided equally between parents, friends, and individuals in "other" relationships to the patient. On average, caregivers spent 45% of their week providing care (range 2–100%). In addition to the caregivers, 32 patients completed the questionnaires. Of these, ~34% identified their spouse as their primary caregiver, 18% their friend, 16% their child, 13% their parent, 9% their significant other, and 9% individuals in other relationships to the patient. On average, patients estimated that their caregivers devoted 46% of their week to provide care.

When asked what makes them a caregiver, caregiver responses yielded four themes: Role Reversal, Time Demands, Emotional Support, and Support for Activities of Daily Living (ADL). Three of these same themes (Time Demands, Emotional Support and Support for ADLs) emerged in the responses of patients. Caregiver and patient responses are summarized in Table 1.

Caregiver Burden

Sixty percent of caregivers reported that they felt overwhelmed by their caregiving role (20% very, moderately, and a little overwhelmed, each). This burden specifically manifested as the psychosocial concerns presented in Table 2. Perhaps not surprisingly, 40% of caregivers reported struggling with anxiety, and 36% reported struggling with depression. Additionally, 28% reported struggling with financial problems, 20% with guilt, and 16% with their own medical concerns. However, 68% concurrently reported that caregiving made them feel good that they were helping, helped them to learn new things about themselves, and made them stronger, better people. Sixty-four percent reported that the caregiving role helped them to understand the importance of love, and 32% reported that caregiving gave their life purpose and a sense of meaning. When caregivers were asked whether they would be interested in participating in an intervention designed to help them experience a greater sense of meaning, 40% were moderately to very interested, and the majority (56%) of caregivers believed this type of program would be moderately to very helpful.

As seen in Table 2, 60% of patients reported that their caregiver suffered from anxiety, 28% reported that their caregiver suffered from depression, 19% reported that their caregiver experienced concerns over their sense of purpose/meaning in life, and 16% reported that their caregiver experienced guilt. When patients were asked whether an intervention that was designed to help informal caregivers experience a greater sense of meaning would help them to feel less burdened, only one patient said no. The responses of the remaining patients (outside of "yes" reported by 19 patients) are summarized in Table 3. The following four themes emerged in the responses: (1) increased meaning would reduce burden; (2) self-care; (3) guilt; and (4) benefits of group therapy. Several patients reported that finding a sense of meaning in the caregiving role would ameliorate their caregiver's depression and anxiety, and help them to feel good and proud of the job that they were doing.

Psychosocial Service Use

Sixty-four percent (*n* = 16) of caregivers reported not receiving any type of therapy or counseling, and of these, 92% reported being interested in receiving services. Of the caregivers not currently receiving therapy or counseling of any kind, the most common barriers (each reported by 48% of the sample) to service use were time and scheduling difficulties (i.e., coordinating with medical appointments for the patient). Other barriers included not wanting to leave the patient alone (guilt), limited financial resources, and a chaotic schedule that would not allow for regular, weekly appointments at a set time. Caregivers' responses also revealed their preference for interventions that could be delivered over the phone or the internet (which would allow them to remain at home with the patient and avoid the time and financial costs of traveling to and from the treatment center), and individual sessions that could be flexibly scheduled at convenient times for the caregiver.

Sixty-eight percent (*n* = 22) of patients reported that their caregiver was not receiving any type of therapy or counseling, and 50% (*n* = 16) believe that their caregiver would be interested in receiving services. Additionally, 53% (*n* = 17) believed that their caregiver would be able to find the time forcounseling.

DISCUSSION

This study collected descriptive information regarding caregiver burden, meaning, and psychosocial service use, as described by 25 ICs and 32 patients receiving care in the outpatient Counseling Center in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center.

Caregiver Role

The majority of caregivers self-identified or were identified by the patient as a spouse/ partner, which is in line with previous studies which have identified cancer caregivers as primarily female spouse/partners (Garlo et al., 2010; Tamayo et al., 2010; Van Houtven et al., 2010; Mezue et al., 2011; Parvataneni et al., 2011). The second largest group of caregivers was (adult) children. Although these data were not collected here (because of exclusion of PHI), it is likely that many of these female adult child caregivers had additional caregiving roles, such as caring for young children, in addition to working full-time paid jobs. These multiple caregiving roles place female caregivers at particular risk for burden (National Alliance for Caregiving in Collaboration with AARP, 2009). Additionally, both caregivers and patients reported that caregivers devoted approximately half of their entire week to that role. This agreement is a testament to the many descriptions of caregiving as a full-time job, albeit one that is unpaid and often conducted in addition to other forms of actual employment and caregiving duties (e.g., Rabow et al., 2004). Research suggests that the amount of time caregivers spend providing care varies (Hayman et al., 2001; Yabroff & Kim, 2009; Palos et al., 2011). Some studies show caregivers spend an average of 8.3 hours per day, whereas others suggest an average of 10 hours per week. Findings from our study fall midway between these extremes, showing that caregivers spend close to half of their entire week providing care.

The most common theme that emerged when caregivers and patients described the caregiving role was *Support for Activities of Daily Living*; seven caregivers and seven patients each described the caregiving role as one that is focused on tasks, such as accompanying the patient to medical appointments and helping with care needs, from the basic (i.e., cooking meals, attending to financial matters) to the medically oriented (i.e., helping with hydration infusions). The most common responsibility identified was the importance of having the caregiver physically take the patient (many of whom may not have been ambulatory) to physicians' appointments, and be present at these appointments to help the patient process information discussed and make medical decisions. *Emotional Support* also emerged as a common theme regarding the caregiving role. Indeed, one caregiver reported that it was emotional support alone that made him/her a caregiver.

Caregiver Burden

Both caregivers and patients reported that anxiety and depression were the top correlates of burden experienced by caregivers. These findings are in accord with the large body of literature documenting the high rates of anxiety and depression in cancer caregivers, rates that often exceed those experienced by patients themselves (Grunfeld et al., 2004; Hauser & Kramer, 2004). Additionally, the time caregivers devote to providing care often prevents them from working full-time paid jobs; caregiving activities (i.e., transportation, medical supplies) are often costly, and, therefore, it is not surprising that caregivers and patients both reported that financial concerns were the third most common correlate of burden among caregivers.

One fifth of caregivers reported concerns with guilt, issues with their role/sense of identity, and self-care, but very few reported concerns with their sense of purpose or meaning in life. More patients, on the other hand, reported that their caregivers struggled with a sense of purpose and meaning in their life. One possible explanation for this discrepancy is that a large proportion of caregivers reported that their caregiving role made them feel good about themselves, made them stronger and better people, and helped them to understand the importance of love. These caregivers may already be making meaning of this role and/or finding benefit in caregiving, despite their burden. However, only a small percentage reported that caregiving gave their life purpose and a sense of meaning. It is possible that these caregivers do not even entertain the possibility of making meaning, but may be more capable of doing so once the intensity of the stress of caregiving subsides. Indeed, Frankl suggests that finding meaning is a process and can occur during an experience of suffering, as well as retrospectively (Frankl, 1963). Concurrently, however, a large percentage of caregivers reported that an intervention designed to enhance their sense of meaning in caregiving would be helpful in ameliorating their burden, and might help them to begin the process of finding meaning while their family member was still living.

Patients, on the other hand, appeared to be more concerned about their caregivers' sense of meaning and purpose. Almost every patient interviewed reported that an increased sense of meaning would allow their caregiver to feel less burdened. The responses of patients (outlined in Table 3) highlight this belief among patients of the connectedness between meaning and burden; three patients directly referenced the potential benefit of meaning on symptoms of anxiety and depression, and one patient reported that increased meaning would facilitate the caregiver's sense of the importance of this role which, in turn, would allow him to develop a greater appreciation for himself. It is clear from patients' perspectives, therefore, that caregivers have the potential to make meaning of the suffering experienced as a caregiver, or to engage in what Lazarus and Folkman define as meaning-based coping (Folkman et al., 1994). It is also possible that if caregivers engaged in a meaning-making intervention, it would open up more possibilities for both the caregiver and patient to explore some of these issues together.

Psychosocial Service Use

There was close agreement with caregivers and patients that the majority of caregivers are not receiving therapy or counseling of any kind. However, caregivers almost unanimously reported wanting to receive such services, whereas only half of the patients reported that their caregiver would be interested in receiving services, and many patients felt that it would be difficult for their caregiver to find time to do so.

These results add to the growing body of literature that documents the underutilization of mental health services by ICs (Vanderwerker et al., 2005), which often continues into bereavement (Cherlin et al., 2007; Lichtenthal et al., 2011). For example, in their study of 86 bereaved caregivers of advanced cancer patients, Lichtenthal et al. (2011) found that 57% of bereaved caregivers who met criteria for a diagnosis of prolonged grief disorder did not access mental health services. This statistic is alarming given that, in this sample, a diagnosis of prolonged grief disorder was significantly associated with suicidality and poor quality of life. Therefore, it is clear that ICs of advanced cancer patients are neglecting their mental health needs, both while providing care and once bereaved.

Numerous consistent barriers to utilization of mental health services by ICs have emerged in the literature. These include: (1) ICs' lack of knowledge about the services available to them (Aoun et al., 2005); (2) the stigma associated with mental health service use (Levy & Derby, 1992; Vanderwerker et al., 2005; Cherlin et al., 2007; Lichtenthal et al., 2011); (3) caregivers' guilt and belief that utilization of mental health services would have harmful effects on the patients for whom they care (Hudson et al., 2004; Aoun et al., 2005; Janda et al., 2006); (4) practical issues of time (e.g., Vanderwerker et al., 2005; Keir, 2007; Lichtenthal et al., 2011); and (5) limited financial resources (Hayman et al., 2001).

Strengths and Limitations

The short completion time (~5 minutes) of the measures was a strength of this study, as it decreased the potential for additional burden on patients and caregivers who provided information. Combined with the anonymity of participants' responses, this brevity of assessment allowed for rapid data collection and few refusals to participate.

Our inability to collect PHI prevented us from examining mediators and moderators of burden among participants, and describing variations in preferences for psychosocial services among specifics groups of participants (i.e., according to gender or age). Additionally, our sample size was small and limited to patients who were receiving targeted psychiatric care in the Counseling Center in the Department of Psychiatry and Behavioral Sciences at MSKCC, and the caregivers who were accompanying them to their appointments. These patients were under the care of psychiatrists and/or psychologists and, therefore, may have been more accepting of psychosocial care (or the idea of care, in the case of caregivers) than a sample drawn from an outpatient medical oncology clinic. Additional information regarding patients' concurrent appointments (i.e., Did they travel to MSKCC just for psychotherapy? Or was the appointment scheduled on the same day as radiation therapy?) would have allowed us to understand the extent that psychosocial care was a priority for them, and the barriers that they faced in attending such appointments. Moreover, we did not collect data from patient/caregiver dyads and therefore were unable to comment specifically on variations in caregivers' and patients' perceptions of each caregiver's burden and psychosocial needs.

Future Directions

Although very preliminary, these data confirm the multidimensional nature of the cancer caregiving role, the complexity of the burden experienced, and the underutilization of – and hence need for – psychosocial services among caregivers. The reports of caregivers and patients highlight this population's risk for psychopathology, including anxiety and depression, as well as other correlates of burden.

In addition to targeted interventions for anxiety and depression, these data point to the need for interventions that attend to caregivers existential needs. The perception among both caregivers and patients that an intervention designed to increase meaning in the caregiving role would ameliorate the burden they experience highlights the need for interventions – such as MCP – that help caregivers reflect on the challenges and limitations of the caregiving role, as well as the potential for growth and benefit as a result of these challenges. Additionally, the majority of caregivers reported concerns with guilt, issues with their role/ sense of identity, and self-care, themes which are all attended to in the current MCP manual for patients with advanced cancer. Tailored toward cancer caregivers, MCP would attend to the potential ways in which caregivers' identities have changed or remained the same since becoming a caregiver, responsibility to care for oneself in addition to the patient, and existential and neurotic guilt, and would highlight the guilt experienced by caregivers as an opportunity to refocus attention upon one's own needs. Moreover, MCP may be particularly well suited to help caregivers connect with patients through the experiences of love, beauty, and humor, all of which are not contingent on patients' physical well-being. Indeed, one patient reported “I think it would be good to find some form for humor in the caregiving experience. . .caregiving is a unique and frustrating role, but sometimes we just have to laugh at the absurdity of it all!” Helping caregivers to engage in humor would allow them to transcend – even if momentarily – the burden that they are experiencing as a result of this role.

The results presented here also highlight the need for individualized, tailored interventions that attend to the temporal and financial demands experienced by caregivers. The challenges of enrolling patients in an in-person regularly scheduled therapy group are clear (e.g., Applebaum et al., 2011), and therefore future studies are needed to examine the flexible application of traditional psychotherapeutic interventions and modalities. Our group has already demonstrated the benefits of psychotherapy delivered over the telephone among hematopoietic stem cell transplant survivors (Applebaum et al., 2012), and additional studies are needed to establish the benefits of similar interventions delivered over the telephone, Internet, and Skype, for cancer caregivers. Future intervention options might also consider consumer-oriented support or lay-led groups that provide support not only during the experience of cancer but also after the death of their family member with cancer. When caregivers connect, they may share their experiences of suffering, as well as what allowed them to survive and even make meaning of and experience growth from their experiences. Such validation of the caregivers’ experience by other “experts” can go far in helping them to make sense of and move forward in their meaning-making journey.

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Table 1

Caregiver and patient role themes

Themes	Caregiver responses	Patient responses
Role reversal	"It's like a role reversal. . ..she is my mother, yet I am taking care of her."	
Time demands	"I devote more time to her than ever before. . . I'm around her all day and night." "Constant, constant caregiving."	"She is there for me. . .24/7."
Emotional support	"I give her emotional support, more than I ever have before." "When my father isn't feeling 100%, I feel as though I have to be there for him. Both to help with daily tasks or just emotional support." "My devotion and understanding make me a caregiver." "I feel that I am a caregiver because I emotionally support the cancer patient."	"She gives me moral support and anything else she can give." "My daughter is around to talk to me, to listen to me when I need to talk. She's a confidant." "My son is loving, supportive and understanding." "She checks in with me all the time. She visits me, offers advice, and brings food." "She is the person who is helping me through my cancer journey." "She is concerned with my health."
ADL support	"I take her everywhere. All places she needs to go, for medical appointments or for personal reasons." "I drive him to the hospital, to chemo, and to home." "I am a nurse, so I help with daily care, meds and driving. I also help with my sister's children." "He is my spouse of 30 years. Now that he is sick, I have to support my husband financially, drive him to his appointments and help him at home." "I drive her to appointments, advocate for her during treatments. I provide at home-care including hydration infusions, cook meals, tend to her needs, do the laundry, cleaning etc." "I am the primary company for the person and am there 24/7 as needed to help and do errands and make medical visits." "I take care of all my wife's needs"	"They managed every aspect of my well-being during the course of treatment." "They are involved in every aspect of my care, with the doctors, with asking questions, etc." "He is the one who has to assist me, take care of my financial issues and help me face my illness." "My son accompanies me to all my appointments. It's good to have a second pair of eyes and ears and he helps me to understand what the doctors are saying." "He makes sure I eat properly, that I'm comfortable, and he has come with me to all of my appointments from the beginning." "She stays with me in the hospital and cooks for me when I'm home." "I can't walk, so he drives me to doctors' appointments and anywhere else I need to be."

ADL, activities of daily living.

Table 2

Caregiver burden

Burden dimensions	Caregiver report (*n*/%)	Patient report (*n*/%)
Anxiety	10/40%	19/59%
Depression	9/36%	9/28%
Financial problems	7/28%	8/25%
Close relationships	6/24%	4/13%
Guilt	5/20%	5/16%
Issues with role/sense of identity	5/20%	3/9%
Self-care	5/20%	2/6%
Their own medical problems	4/16%	7/22%
Sense of purpose/meaning in life	3/12%	6/19%

Table 3

Patients' perceptions of caregiver meaning and burden

Increased meaning would reduce IC burden	"I believe having an understanding of purpose would definitely help my caregiver with anxiety and guilt." "Understanding their role and importance would definitely help any depression." "It will help her come out of the depression and relieve the anxiety she's experiencing." "It would deepen his sense of understanding and further develop his sense of the importance of being a caregiver. I think he would better appreciate himself." "Often a cancer diagnosis is harder on the caregiver than the patients. If they can make meaning of the experience, and get support around the experience, that would certainly help!" "My mother seems so disconnected these days, from me, from the family, even though she spends so much time. . .I wonder if finding meaning would help with this."
IC self-care	"Yes, it's very burdensome taking care of a person with cancer. It consumes almost all of the person's time. The caregiver needs space and time for themselves."
IC guilt	"My daughter has her own family and she does as much as she can. If she could share with others, she could alleviate some of the guilt she feels that she does not do enough." "I feel like she would feel guilty for going. . .she usually feels badly when she leaves me alone, even though I'm fine alone."
IC benefits of group therapy	"Being in a therapy group would help her to not feel alone." "The group would give him experience with people who are in his position. . .They could talk, share ideas, help find ways to cope with the situation they're in." "It would make them feel acknowledged and not always in the background or shadows of the patient."