THE EXPERIENCE OF INFORMAL CAREGIVERS

FOR PERSONS WITH METASTATIC CANCER:

PERCEPTIONS OF SUPPORT

A

PROJECT

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By

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Abstract

Purpose/Objectives: To investigate the experience and perceptions of support of caregivers for persons with advanced cancer.

Research Approach: A qualitative descriptive approach using focus groups to explore the caregiver experience.

Setting: An outpatient oncology infusion center in southcentral Alaska.

Participants: 14 adult caregivers of persons with stage IV cancer.

Methodologic Approach: Participants attended one of two focus groups. They were asked to share their experiences as informal caregivers. Focus groups were digitally recorded and transcribed verbatim for analysis. Krueger's method for content coding and data analysis was used to identify themes (1998).

Findings: Key themes that emerged during data analysis included internal stressors such as emotional and psychological distress, and external stressors of needed financial support and nutritional information, suggesting the stated need of a more comprehensive care approach.

Conclusions: Participants recognized needs but did not feel they were supported in accessing resources. The experience of caregiving was often abrupt in onset in this population and the overwhelming amount of information they received did not include enough information on the act of caregiving or the resources available.

Implications for Nursing: Advanced practice nurses are instrumental in identifying and addressing caregiver needs. As patient educators and advocates, they provide education and resource support to both the patients and the caregivers in an effort to minimize caregiver exhaustion.

Knowledge Translation: Early identification of the primary caregiver of a person with complex care needs can facilitate information and use of available community resources. Knowledge of community resources can help decrease caregiver burden and ease the physical and emotional toll of caregiving.

Keywords: Caregiver burden, role strain, physical effects, community resources

Background and Problem Statement

In 2009, nearly 66 million Americans (three in ten households) had at least one person providing unpaid care as an informal caregiver (Collins & Swartz, 2011). Informal caregivers face multiple challenges that may affect their quality of life and psychological well-being. Living this role challenges the caregiver's ability to care for their loved one as well as maintain their health. Frequently, the caregivers are elderly (>65) and have significant health issues of their own that can be affected by the caregiver role (Girgis, Lambert, Johnson, Waller, & Currow, 2012). The impact of caregiving on a person's well-being is often overlooked or considered second to that of the one being cared for. Opportunities for caregiver support have been proposed as an important strategy to assist them in effectively functioning for the benefit of themselves and the patient (Fujinami, Otis-Green, Klein, Sidhu, & Ferrell, 2012).

The value of this unpaid labor force is estimated to be at least $306 billion annually, nearly double the combined costs of home health care ($43 billion) and nursing home care ($115 billion). To make matters worse, caregivers are more likely to lack health insurance coverage due to time out of the workforce. These burdens and health risks can hinder the caregivers' ability to provide care, lead to higher health care costs and affect the quality of life of both the caregiver and care receivers (Ho, Collins, Davis, & Doty, 2005).

Advanced cancer can be described as any cancer that has metastasized from the site of the original tumor through the lymphatic system to distant tissues and organs. Complications such as altered mental state, pain, dyspnea, obstruction, and anorexia/cachexia can cause additional physical and emotional stress to the person with cancer as well as the primary informal caregiver by increasing caregiving demands. The need for informal caregiver support has been recognized, however there is a lack of information regarding the specific needs of these caregivers, from their perspective.

The purpose of this project was to explore and describe the experience of adults who are the primary caregivers of persons with advanced cancer and to identify the perceptions of support. Exploration included: caregiver burden, role strain, and physical effects on the caregiver, as well as the community resources accessed.

Review of the Literature

A review of the literature revealed considerable research on the act of caregiving, caregiver burden, role strain, and the physical effects on the caregiver. There is clear documentation of the need for caregivers to have access to appropriate and effective social support, however, there is a lack of information of perceived needs of caregivers of seriously ill, metastatic cancer patients from their perspective. Literature reviewed will provide the backdrop for further exploration of this topic. Areas reviewed included: the role of an informal caregiver, caregiver burden, caregiver health outcomes, and perceptions of available resources in the community.

Informal caregivers are defined as those who provide care without a specific professional role. They can include spouses, children, family members, friends, and religious or social contacts. They are responsible for a multitude of tasks including but not limited to: management

and coordination of medical care, administration of medication and therapies, emotional support, transportation and personal care, (Navaie-Weiser, Feldmen & Gould, 2002), as well as organizing appointments, social services, managing money, and assisting with social activities (Schofield, Herman, & Block, 1997). Often the role of caregiver falls to family members or close friends, and they are often called upon to provide physical and emotional care. Many caregivers report caregiving as a rewarding experience, but the majority also experience physical, emotional, social, and financial difficulties (Harding et al., 2011). Caregivers report challenges such as uncertainty of competence, distress in witnessing patient deterioration, loss of time to focus on their own needs, lack of regular support, anxiety and frustration at not having proper training and preparation, as well as feeling invisible (Epiphaniou et al., 2012).

Caregiver roles have changed drastically over the last few decades due to multiple factors including but not limited to: increased complexity of cancer treatments, increased survival of chronically, terminally ill patients, fragmented healthcare services, and a lack of health care resources (Givens & Northouse, 2011). One needs assessment found that 70-80% of caregivers feel they are unprepared for the role, lack information to provide adequate care, and worry that the care they provide is less than optimal. Furthermore, the extent to which caregivers' psychosocial needs were not being met was a consistent and strong predictor of poor mental health across all phases of survivorship, beyond demographic characteristics (Kim, Kashy, Spiller, & Evans, 2010).

Caregivers have reported frustration, anger, guilt, loneliness and exhaustion. While most caregivers may not experience adverse physical health effects, the Family Caregivers Alliance (2012) reported that caregivers are more likely to have depression or anxiety disorders, long term medical problems such as diabetes and heart disease. They also have a higher level of stress

hormones, spend more days sick with infections, have increased incidence of flu, higher levels of obesity, and may also be at risk for mental decline such as problems with memory and attention.

Inclusion in support groups has been reported to be beneficial to caregivers. Snyder, Quayhagen, Shepherd, and Bower (1995) found that support groups reduced isolation, and that the sense of being a part of a group enabled more communication and the development of trust. Support groups validated feelings and experiences, helped with coping strategies, and provided both formal and informal education. Damen, Mortelmans, and Van Hove (2000) concluded that groups provide two complementary sources of support through information sharing that allows both educational and emotional support for participants.

Community support services, such as caregiver education or support programs, have been shown to reduce the effects of stress on primary caregivers. There are multiple methods available to educate and support caregivers. These include: community workshops, lectures, discussions, support groups, skills assessment groups, individual counseling and training, family counseling, case management/care coordination, and technology based interventions (Toseland, 2004).

The amount of time that caregivers devoted to caregiving was likely to decrease the amount of time available to caregivers for social interaction. Less time to spend with others, coupled with the progressive illness of a loved one, may result in worsened perceptions of social support. Less time to spend with others, combined with progressive loss of a loved one may result in decreased perceptions of social support. The lack of social support is one factor that contributed to negative psychological symptoms experienced by caregivers. Several studies in showed that lower ratings of social support are associated with greater symptoms of depression (Cannuscio, Colditz, Rimm, Berkman, Jones, & Kawachi, 2004; Schultz & Williamson, 1991).

In summary, a number of studies reported in this review have demonstrated the

importance of identifying the physical, practical, social, financial, psychological and spiritual

support needs of caregivers for metastatic cancer patients. The increased demand for care as the

disease progresses places increased stress on the caregiver and the caregivers support system.

Determining the needs of the caregiver so they can provide effective care is important.

Methods

Research design

A qualitative descriptive approach was used to explore the experience of informal

caregivers of persons with advanced cancer. Participants were recruited through flyers posted on

site at a large oncology practice in southcentral Alaska. An explanation of the study was

provided to each potential participant. Written information including informed consent was

provided. Perceptions were elicited through focus group interviews, conducted in a private

location and the interviews were audio recorded and then transcribed verbatim by the primary

researcher for analysis. Approval was secured through the University of Alaska Anchorage

Institutional Review Board (IRB) prior to recruiting participants.

Participants

Fourteen adults between the ages of 36 to 85 years participated in the study. There were 4

men (29%) and 10 women (71%) who participated. All participants were Caucasian. Eleven of

the participants (79%) were spouses to the person with cancer and the other three were the adult

daughters (21%) of the person with cancer. Seven of the caregivers (50%) reported working full

time or at least 40hours per week, while three were unemployed (21%) and four reported

working part time or less than 40hrs/week (29%). All participants had been the primary caregiver

for less than 2 years. Nine of the caregivers had been providing care for less than 6 months

(64%), three caregivers had been providing care for 6 months to 1 year (21%), and the remaining two had been a caregiver for greater than 1 year but not longer than 2 (14%). All participants were caring for someone with stage IV cancer. Diagnoses included: small cell lung cancer, non-small cell lung cancer, prostate cancer, colon cancer, breast cancer, multiple myeloma, and pancreatic cancer. Four participants reported spending greater than 26 hours per week providing care, five reported spending between 16 to 25 hours, and five reported spending between 5 to 15 hours.

Data Analysis

A conventional approach to content analysis suggested by Krueger (1998) was used to ensure rigor in the process of data analysis for qualitative research. Data for this study included focus group transcriptions and group meeting field notes. The primary researcher listened to the audio and transcribed it word for word. The transcribed data was then read and reread to identify ideas shared by group members. As the researcher came across an idea or phenomenon, a label or code was attached. If the idea or phenomenon reappeared in the data, the code was once again attached. Initial coding was done in the margins of the transcript as recommended by Krueger (1998). Relevant codes were then reassembled according to themes which were different than the original order. This process of axial coding allows rearrangement of the data according to themes, without changing the content.

Trustworthiness was maintained through adherence to Lincoln and Guba's model of trustworthiness of qualitative research: (a) credibility, (b) transferability, (c) dependability, and (d) confirmability (Lincoln & Guba, 1985).

To maintain credibility, all information was processed and reviewed in the same manner for each focus group. Another strategy used to establish credibility in this study was member

checking. The researcher tested credibility of themes by summarizing information and presenting

it at the end of the session. Additionally, the information was presented to the second group

during discussion for further verification. Participants could either affirm that the summaries

reflected their views, feelings, and experiences, or that they did not reflect these experiences

(Thomas & Magilvy, 2011).

Transferability was maintained by thorough documentation that described the research

context and the assumptions that were central to the study. The population, setting, and themes

were clearly outlined in the methods.

Dependability was achieved by maintaining an accurate audit trail including detailed

information and a clear description of the purpose of the study, the methods of participant

selection, data collection, data analysis, and interpretation (Lincoln & Guba, 1985).

And finally, confirmability occurred when credibility, transferability, and dependability

were established. Confirmability refers to the degree to which the results could be confirmed or

corroborated by others (Thomas & Magilvy, 2011).

Findings

Participants spoke openly about the internal and external stress they experienced in

relation to the caregiving role. Key themes that emerged during data analysis included internal

stressors describing emotional and psychological distress, and external stressors of needed

financial support and nutritional information, suggesting a more comprehensive care approach

would benefit caregivers. The voices of the study participants in describing caregiver perceptions

follow.

"It's difficult to be the only one doing everything."

There was agreement among the participants that they were not prepared for the amount of emotional stress that accompanied caregiving for a loved one. It was stated that "it is difficult to be the 'only' one doing everything". The participants had varying levels of independence, with some being able to work outside the home, and others needing to be with the person needing care 24 hours a day. "I've been doing this every day since November, I'm afraid to leave him with anyone else. What if something happens and I'm not there?"

In accordance with the previous statement, caregivers voiced the wish to be able to go to a movie, or the gym, or just out for a walk, without worrying about leaving their loved ones unattended. It is worthy to note that no participant was aware of respite services available in the community.

Another participant wondered about psychological support for the person she was providing care for, but also felt that she and other members of the family might benefit from individual or group counseling. Only one participant had used the onsite licensed counselor at the Cancer Center. There was concern that there would be resistance to formal counseling. "I'm not sure she wants to talk to anyone."

One participant stated, "Caring Bridge has been a life saver." Caring Bridge is an online forum where you can post information in blog format about anything pertaining to the caregiving experience. It is often used as a portal to put all information regarding the patient in one place. Current treatments, how they are feeling, needs you may have, etc. can be posted in one easy spot. This relieves the caregiver of the daunting task of multiple phone calls to update friends and family of the situation. Some of the participants had heard of Caring Bridge, but only four participants were actively using it. All participants in both groups stated that they were going to look into it as soon as they could.

"I just can't get over the cost"

The participants described in detail some of the financial difficulties they have experienced since the cancer diagnosis. The biggest hardships tended to focus on medication, diagnostic imaging, and travel expenses. There was extensive conversation between participants regarding resources available in the community. Living in Alaska creates a unique situation where often the person with cancer and the caregiver must travel for extended periods of time for treatment. Sometimes this includes relocating for months at a time. One participant described the hardship of travel for treatment outside.

> I have to pay for all of my travel expenses, including airfare and hotel, when we go to Seattle to see her primary oncologist. We make that trip every 3 months. I have spent at least $5000 so far. Not to mention I have to take time off work. I am pretty much out of paid leave.

Another participant described using a service through Angel Flight West, which provides free airfare for persons with extenuating health care needs who are traveling for health related needs. No other participants knew of this service. Another participant mentioned that Era (now Ravn Air) also donates up to three flights a year for patients in interior Alaska for travel to another city for treatment.

One participant balked at the cost of the medications, both chemotherapy and the take at home medications sometimes required to manage the disease, pain, or side effects. "I just can't get over the cost! It's absurd! I get a bill for $20,000 every time he has a chemo treatment. Where can I get help for that?" No participant was aware of medication reimbursement or assistance programs for which he/she might be eligible.

There was also discussion regarding the loss of work. One participant discussed the need to fill out "so much paper work that he did not think there was any way he could figure it all out."

All participants were aware of programs such as FMLA, Medicaid, and disability, but only seven participants were utilizing all three services. Most did not think they would qualify for services based on their income. "I always make just a little too much money to qualify for the programs."

"Eating is a struggle."

An unsuspected recurring theme was the need for nutritional counseling or support. Nutrition could be seen as an internal or external struggle. Caregivers perceived decreased appetite and intake as a failure on their part, but acknowledged that it was often the only thing the patient could control. All participants reported feeling overwhelmed by the "unwillingness" of the person receiving treatment to eat much of anything, much less anything healthy. The complications of therapy often include nausea, vomiting, anorexia, diarrhea, changes in taste, and mucositis. All of these complications influence the person's ability to maintain adequate nutrition and often the caregivers saw this as a failure on their part.

> I have searched the internet for ideas that would help my wife eat healthy foods. Her disease is complicated with renal insufficiency, so I spend a lot of time looking for information about nutritional needs of kidney patients and cancer patients, but I can't find much. I wish there was someone I could ask.

Another participant lamented that it did not matter what she prepared, her mother would not eat it. "It is a struggle to get her to drink a glass of water, much less have a nutritious meal." Discussion followed regarding different books and recipes that had been tried with success, but the overall consensus was that the person in treatment was only going to eat when and what

he/she want and the fight is often not worth it. "I feel like it is the only thing she thinks she still has control over, so she won't listen to me anyway."

"I don't even know what questions to ask."

An overwhelming, recurring theme during the interviews, was the desire for a more holistic or comprehensive care approach. All participants voiced a need to have one person they could go to with questions. Questions could pertain to any of the aforementioned topics, as well as a plethora of others. The group was quick to point out that they felt their loved one was getting excellent medical care but they wanted more information to be available to them.

I can't complain about her medical care, her doctor has been honest to a fault sometimes. He told me I was going to get beat up, but he didn't really tell me how to make things a little easier for myself. It would be nice to have one person I could call to sort through some things. Heck, I would pay extra for that service.

The participants discussed that the doctors and nurses are not expected to be the source of this information. Often the information they need assistance with is outside the scope of medical expertise. Participants felt they needed help with financial information, disability, travel and lodging accommodations, respite, PCAs, emotional support, and so many other things that one participant stated, "I don't even know what questions I need to be asking." This comment received broad agreement from the group. "Don't get me wrong, my husband gets excellent care from his oncologist and the nurses, and I don't expect them to have all of the answers. As a matter of fact, I prefer they focus on my husband and let someone non-medical help me navigate the rest of it."

Other concerns included the delay from diagnosis to meeting the oncologist. It was discussed that this might be the appropriate time for a navigator, or social worker make the initial

contact, to discuss some immediate concerns, such as travel, lodging, or insurance needs. The American Cancer Society (ACS) was often referenced by participants when discussing needs that had been met.

> Sure there are tons of resources out there, but you never know what you are going to qualify for. It would be nice if there was one person that you could contact that could help you sort out the information. I have so much going on, I can't sit on the computer for hours trying to fill out these exhaustive applications only to be denied for one reason or another.

Discussion

Findings from this study suggested participants recognize and can describe their needs, based on internal and external stressors, but feel under-supported in accessing resources. The experience of caregiving is often abrupt in onset in this population and the overwhelming amount of information they receive is not felt to include information pertinent to the act of caregiving itself. Participants recognized that doctors and nurses are focused on the health of the person with cancer, but felt there is a need to have an outside resource who could support the caregiver by providing information about financial support, travel arrangements, disability or insurance questions, nutrition support and respite care. This finding was consistent with a needs assessment showing that 70%-80% of caregivers report that they need additional information to provide care, and that they feel unprepared to for the role, as well as concern that the care they provide is suboptimal (Kim, Kashy, Spillers, & Evans, 2010). Findings were also corroborated by Chambers et al. (2012), who stated the majority of caregivers reported that most of the unmet needs were related to information about health care services and information related to the person diagnosed with cancer. The same study noted that a majority of the information requested

by caregivers was related to accessing information, and addressing the impact caregiving was having on the caregiver's everyday life, instead of medical questions regarding the disease and its progression.

Consistent with the existing literature, a need for financial support was highlighted as a prominent stressor. Girgis et al., (2012), described the financial burden for caregivers, both in outright expenses, and in lost income and benefits. They also found that caregiving appears to reduce caregivers' ability to work, forces them to take leave without pay, and work fewer hours to accommodate the caregiver role. Despite this, many caregivers do not avail themselves of financial support (Fairclough & Slutsman, 2000). A study by the World Health Organization (WHO) highlighted the severity of this problem. WHO found that many caregivers suffer from long-term financial strain. This appears to be related to the time-consuming nature of the caregiving role. Difficulties accessing health care, wage losses, and transportation costs to and from the hospital, leaves the individual caregiver with limited earning opportunities while meeting ongoing expenses from the patient's illness experience (WHO, 2000).

Challenges with nutritional support were also supported in the literature. Participants in this study requested information on what their loved ones should eat, as well as how to stimulate their appetite. Bee, Barnes, & Luker, (2008), found that information on how to perform non-medical elements of caregiving, such as patient nutrition, positioning, and bathing was frequently requested and essential to the person receiving care. Existing literature supports the idea that reduced dietary intake contributes to caregiver/patient conflict. Caregivers tended to see weight loss as an indicator of failure on their part, resulting in the creation of an environment focused on food (Reid, McKenna, Fitzsimmons, & McCance, 2009). In reality, cancer cachexia is a common symptom of disease progression and no matter what food patients consume, they will continue to

lose weight. Information about healthy food choices is important, however, providers need to educate the caregivers on the trajectory of the disease, and acknowledge that the patient's progressive and involuntary weight loss confirms the poor prognosis and movement toward death. As a result, family members may be able to shift their focus from food, thus reducing tension in the final months of life.

The need for psychological support is well documented in the literature. Price, Butow & Costa, (2012) report that there is a significantly higher prevalence of borderline or clinical anxiety and depression among caregivers compared with community norms. A large study showed that caregivers who accessed mental health resources, reported reduced levels of bereavement, anxiety, depression, and an increased level of viewing the caregiving role positively (Fakhoury, McCarthy, & Addington-Hall, 1996). It is worthy to note that several participants discussed the decreased social interaction secondary to caregiving responsibilities. However, participants in this study did not acknowledge the correlation between decreased social interaction with decreased perceptions of support as found in the literature review.

Support for a more comprehensive care approach or the use of case management is also found in the literature. Cancer treatment, as a multidisciplinary approach requires complex coordination of care. Case management provides the coordination of services on behalf of an individual. Strusowski (2006) described how cancer care management by nurse navigators, integrates all aspects of patient care, including counseling, development and coordination of a plan of care, education, and symptom management. Navigation of complex care becomes necessary when treatment recommendations may include chemotherapy, radiation, and surgery. By interacting with patients and families in a variety of roles, the nurse case manager facilitates

quality, cost-effective outcomes by decreasing fragmentation and duplication of care (American Nurses Credentialing Center, 2009).

Limitations

A limitation recognized in this study was the presence of a researcher who was also involved in the direct patient care of the person with cancer. This may have prevented participants from sharing information that they thought might "hurt the researchers feelings" or less likely to discuss shortcomings of caregiver support that was or was not provided. Additionally, the small sample used in this study was recruited from one clinic and may reflect a shortcoming of that clinic alone, not a wider representation of cancer caregivers as a whole.

Nursing Implications and Recommendations

Advance practice nurses are instrumental in identifying and addressing caregiver needs. Providing education and support to the patient and the caregiver about resources available in the community can reduce caregiver exhaustion. Further research, including different methods of education dissemination is recommended. This study provides direction for further clinical studies in this area by highlighting needs as perceived by the caregivers. Further examination could provide insight to inform future nursing strategies the needed information to develop appropriate nursing strategies to assist patients and caregivers in coping with the situation for the duration of the disease process.

Another recommendation is the development of a patient and caregiver education leaflet or pamphlet. The information that should be included in the handout should include a list of resources available and a brief, simple description of each. This pamphlet should focus mainly on the needs of caregivers and resources that are generalized and not focusing on one cancer type. This information should include written material, audiotapes, and videotapes to assist

dissemination to those that may not function at a high literacy level. Most educational materials are written for the patients. Caregivers need educational material that incorporates problem solving strategies; such as how to care for their loved one, how to maintain health, and how to deal with bereavement (Payne, Large, Jarrett, & Turner, 2000).

Finally, the use of a nurse navigator or social worker is recommended for all newly diagnosed cancer patients as well as those with perceived need. While not a reimbursable service, the availability of a navigator to any oncology practice would greatly benefit the patients, caregivers, and also relieve the staff nurses of additional administrative duties. Nurse navigators function in a variety of roles to ease some of the external and internal stressors of the patient and caregiver. They can function in the role of skilled listener, coordinator, and counselor,   as well as providing educational and psychosocial benefits that lead to increased patient satisfaction, decreased patient anxiety, decreased lengths of stay, and reduced treatment delays (Korber, Padula, Gray, & Powell 2011).

In conclusion, the need for a more holistic care approach is evident from this study. Caregivers face both internal and external stressors that can impair their ability to provide effective care to their loved ones, and themselves. Advanced practice nurses can assist caregivers and provide the needed support described in this study by providing education, access to written, oral, and visual resources, as well as promoting use of nurse navigators in individual practices.

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