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Lack of Communication and Control: Experiences of Distance Caregivers of Parents With Advanced Cancer

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Distance caregiving, the experience of providing instrumental and emotional support to an ill loved one who is geographically distant from the caregiver, is a new and relatively unexplored phenomenon in health care, although its prevalence is increasing in the United States. Unlike previous generations in which family members cared for each other in their own homes or communities, many of today's adult children caregivers of parents with chronic illnesses are struggling with the demands of caregiving from a distance by themselves.

More than seven million Americans were distance caregivers in 1997, and the number was expected to grow as baby boomers and their parents aged (Wagner, 1997). According to the National Caregiving Survey conducted by the National Alliance for Caregiving (NAC) and AARP (2004), about 15% of adult children are distance caregivers for parents. The National Council on the Aging (NCOA, 1997) projected that the number of distance caregivers will increase to 14 million by 2012. The literature on distance caregiving is very sparse and nursing research has been nonexistent, and trending data have not been evaluated nationally since the late 1990s. Although much is known about the effects of caregiving on local caregivers of patients with cancer, little is known about the impact of caregiving on adult children living at a distance. With the number of distance caregivers increasing, research is needed to understand the experience and develop interventions to include these caregivers in family-centered care (Mazanec, 2009; NCOA, 1997). This article presents the qualitative results of interviews with 14 distance caregivers of parents diagnosed with advanced lung, gastrointestinal, or gynecologic malignancies. The caregivers were part of a larger quantitative study exploring predictors of psychological outcomes of distance caregiving (Mazanec, 2009).

Purpose/Objectives: To explore the new and complex phenomenon of distance caregiving in the advanced cancer population.

Research Approach: Qualitative.

Setting: A large comprehensive cancer center in the mid-western region of the United States.

Participants: 14 distance caregivers of parents with advanced cancer.

Methodologic Approach: Patients with advanced lung, gastrointestinal, and gynecologic malignancies consented to have their distance caregiving adult children contacted to participate in the study. Responses to three open-ended questions guided the tape-recorded telephone interviews with the distance caregivers. Following transcription, content analysis with inductive coding was performed.

Findings: Two major themes, communication and control, and five subthemes, benefits and burdens of distance caregiving, dealing with uncertainty, direct action through information seeking, protecting, and staying connected, emerged from the data.

Conclusions: Distance caregivers experience some of the same stressors that local caregivers of patients with cancer experience. In addition, they have unique psychosocial needs related to the burden of geographic distance.

Interpretation: Distance caregivers could benefit from nursing interventions targeted at their unique needs. Innovative interventions using Web-based computer technology for improved communication, as well as supportive care interventions, may be helpful.

Background and Significance

Caregiving for a Family Member With Cancer

A diagnosis of cancer is a major life stressor for the patient and the family (Ferrell, Grant, Borneman, Juarez, & ter Veer, 1999; Given & Sherwood, 2006; Northouse, Kershaw, Mood, & Schafenacker, 2005). In the United

States, 1,529,560 new cases of cancer and 569,490 deaths from cancer were projected for 2010 (Jemal, Siegel, Xu, & Ward, 2010). The diagnosis poses a threat to the stability of the family system and the potential loss of a family member (Haley, LaMonde, Han, Burton, & Schonwetter, 2003; Northouse, 2005). Caregiving burdens not only have increased in intensity but also are being experienced over longer periods of time (Bull & McShane, 2002). With the advent of new cancer treatment options, patients with advanced cancer and their families are struggling with the prolonged and difficult course of the disease. Such burdens are known to negatively influence the physical and psychological well-being of the caregivers (Borneman et al., 2003; Matthews, Baker, & Spillers, 2003; Sherwood, Given, Given, & von Eye, 2005).

The benefits of caregiving have been explored, in addition to the costs, and many caregivers have reported finding meaning and purpose in providing care. Caregivers who derive benefit from the role have fewer depressive symptoms and better self-assessed health than caregivers who identify only the costs or burdens of caregiving (Cohen, Colantonio, & Vernich, 2002; Habermann & Davis, 2005; Hudson, Aranda, & Hayman-White, 2005). Helping caregivers to identify meaning and purpose in their role while providing support to minimize burden has been shown to improve caregiver well-being, which has been linked to overall patient well-being (Northouse, 2005).

Local Caregiving

Because little is known about the distance caregiving experience, literature on local caregiving may provide some insight about the experience. A caregiver is defined as an unpaid person who helps another with physical care or coping with disease (Hileman, Lackey, & Hassanein, 1992). The tasks associated with caregiving are complex and include helping with daily and weekly household chores, managing financial affairs, and providing emotional support (Pepin, 1992). Although caregivers have described the burdens associated with providing hands-on physical care or tangible assistance, many have reported that the provision of emotional support can be more burdensome than physical care (Borneman et al., 2003; Kurtz, Kurtz, Given, & Given, 2005). That would suggest that supportive interventions for caregivers need to address the psychological domain of caregiver quality of life as well as the physical domain.

Distance Caregiving

Although much is known about local caregiving, research on distance caregiving is very limited, and operational definitions are lacking. Schoonover, Brody, Hoffman, and Kleban (1988) studied 55 adult children living more than 50 miles from their ill parents. Mileage

was used to define distance. More than half of the 55 distance caregivers reported feeling helpless and anxious, and 80% reported at least some strain caused by living away from the patient (Schoonover et al., 1988).

In 1997, the NCOA did a telephone survey of 200 distance caregivers and found that they lived an average of 304 miles from their ill loved ones. These distance caregivers reported the difficulties and the rewards of providing care. Seventy-nine percent of participants reported stress related to the distance. In a secondary analysis of the National Alliance of Caregiving and AARP survey of family caregivers of older adults (1997), Koerin and Harrigan (2003) evaluated responses from 109 distance caregivers living more than two hours away and reported that distance caregivers experienced emotional stress because of the geographic distance.

No research has been conducted to identify appropriate interventions to support distance caregivers and to alleviate their distress. The mass media have recognized a need to help distance caregivers with their tasks. For example, *Better Homes and Gardens* published tips for distance caregivers, which emphasized the importance of knowing local resources for parents and establishing a relationship with healthcare providers (Levine & Rubiner, 2005). However, no standards or guidelines exist for healthcare professionals to support and prepare distance caregivers for their role. The purpose of the current study was to explore the experience of distance caregiving a parent with advanced cancer and to identify targets for caregiver-desired nursing interventions based on caregiver experiences.

Methods

Procedure

Distance caregivers of patients from a comprehensive cancer center in the midwestern region of the United States who recently were diagnosed with lung, gastrointestinal, or gynecologic malignancies participated in the qualitative cross-sectional survey (see Table 1). The sample consisted of distance caregivers from the United States and Mexico.

After study approval from the cancer center's institutional review board, patients who met eligibility criteria were approached by the primary investigator for consent and permission to contact the adult child whom each determined was their most involved distance caregiver. For purposes of the study, eligibility criteria for distance caregivers included living at least 300 miles from the loved one, which was based on the average mileage of distance caregivers in the NCOA (1997) telephone survey.

If the parents agreed to participate, they contacted the caregivers about the study. About two weeks after the initial contact, the primary investigator contacted the

Table 1. Characteristics of Distance Caregivers

Characteristic	\bar{X}	Range
Age (years)	39	23–58
Characteristic	n	
Gender		
Female	8	
Male	6	
Ethnicity		
Caucasian	13	
African American	1	
Relationship status		
Married	10	
Not married	4	
Employment status		
Employed	10	
Not employed	4	
Caregiving others	9	
Type of cancer		
Lung	6	
Gastrointestinal	5	
Gynecologic	3	
Location		
Ohio	5	
Alabama	1	
California	1	
Georgia	1	
Illinois	1	
Mexico	1	
Michigan	1	
South Carolina	1	
Virginia	1	
Washington	1	
N=14		

parent to determine whether the caregiver had given permission for telephone contact. After verbal consent for the study was obtained from the distance caregiver, the primary investigator conducted the caregiver interviews over the telephone at a time that was convenient for the participant. Some caregivers were available immediately following consent, whereas others preferred to schedule a follow-up date and time. Some preferred to conduct the interview from their homes, whereas others preferred to be called while at work, in the privacy of their offices. The principal investigator tape-recorded the telephone conversations, which were conducted from a private office. Participants were asked three open-ended questions that were developed in consultation with two of the authors. The questions were designed to explore the global experience of distance caregiving in this population and to identify targets for nursing interventions (see Figure 1).

Caregivers were informed that the primary investigator was available to them for as long as they wanted to talk, but that the questions most likely would take about 30 minutes. The telephone interviews lasted an average of 10 minutes (range = 4–33 minutes). Caregivers determined the length of the interview. They were

encouraged to talk about their experiences, but many caregivers were juggling careers and family and had limited uninterrupted time for the interviews. Following professional transcription, the principal investigator reviewed all interviews for accuracy by comparing the transcription with the audiotape. Saturation was achieved at 14 participants.

Data Analysis

Content analysis with inductive coding was performed by the principal investigator using the Giorgi (1985) method. Transcripts were read multiple times to gain a sense of the whole caregiver experience. Themes emerged from the concrete language of the participants and were expanded and clarified by relating them to each other and to the overall distance caregiving experience. The researcher sought consensus on the themes with one of the authors, and discussions resulted in the refining and synthesizing of the themes until agreement existed. A thorough description of the experience was written. The researcher established the trustworthiness of the qualitative analysis with credibility and confirmability. Credibility was demonstrated through prolonged immersion in the data and subject manner, and confirmability was established by developing an audit trail that other researchers could follow. Transferability remains to be determined by potential users of the findings.

Results

The original eligibility criterion for distance was 300 miles or more, consistent with the NCOA (1997) survey. However, patients in the current study often identified the distance caregiver as the child who was perceived to live a long distance away, regardless of actual mileage. The eligibility criterion was changed midenrollment to those who lived at least 100 miles away to capture those who were identified as distance caregivers by their parents. Five themes evolved from the interviews.

Theme 1: Benefits and Burdens

Participants described the positive and negative aspects of distance caregiving but were quick to report the negative aspects of distance. They reported feeling guilty, helpless, and stressed because they lived so far away, and one participant described the experience as “frustrating, exhausting, and stressful.”

Many reported that not being able to get home quickly was very difficult. For example, one caregiver stated, “It’s scary to be this far away; if I needed to get home right away, if anything were to happen and there was bad weather . . . that part is kinda stressful.” Travel time was a clear source of worry. One distance caregiver noted, “It takes me three and a half to four hours to

- “What is it like to have a parent with advanced cancer and to live far away?”
 - This general question was posed to help understand the distance caregiving experience in the cancer population.
- “If a friend or colleague came and told you tomorrow that his or her parent was just diagnosed with advanced cancer and lives far away, what advice would you give?”
 - This question was intended to identify issues or concerns in an indirect way, giving caregivers an opportunity to project their feelings onto another person.
- “We hope to develop a program of support to help distant caregivers. What do you think would be most helpful to you?”
 - The purpose of this question was to identify potential areas of need for clinical intervention.

Figure 1. Telephone Interview Questions

get there, so I can't be there immediately in a crisis.” Another participant said “[In] an emergency, I can't just hop on a plane to help her right away; it would take some time and that's a concern.”

On the other hand, many participants identified positive aspects of being a distance caregiver. One participant stated that “the family . . . I think it's brought us even closer now.” Some reported that frequent phone conversations had strengthened their relationship with their parent. For example, one participant stated, “It's nice because I think she might say things to me she wouldn't say if I were closer . . . so that part is a mixed blessing.” Another caregiver indicated that not having to see how her mom was doing and not having to face the cancer every day were beneficial: “I think it'd be harder if I was around her every day when she went to treatments.” For some, being far away was seen as burdensome; for others, the distance protected them from the cancer experience.

Theme 2: Struggling With Uncertainty

Most participants talked about dealing with uncertainty. Some reported uncertainty regarding when to visit, especially after treatment. For example, one son spoke about not knowing which treatment, surgery, or chemotherapy would be the most difficult for his mother. He stated, “We didn't know if we needed to come down right away versus waiting ‘til later.” He waited to visit when she started chemotherapy, thinking she would need him more then; however, he found that she had more difficulty with surgery and wished he had gone at that time instead. Others noted they did not know when to call to check in, because they did not know what was happening at home. For example, one caregiver said, “It's hard being away and hard to know when you should call . . . if she's sleeping.”

Like local caregivers, many distance caregivers talked about the uncertainty of the cancer prognosis and disease trajectory. One daughter said she needed to know what the outcome was going to be: “Why is she going through all this if it's not gonna work? I would like a finite answer,

is it working or isn't it . . . it's just not knowing.” However, the uncertainty associated with cancer prognosis and disease trajectory is compounded by distance. Many participants spoke about the uncertainty of not knowing how the parent really is doing. One son said, “I don't know exactly what's going on with my dad and how he actually physically is doing.” Another stated, “It's just very stressful because you can't be there; you can't evaluate him.” Many participants wished that they could see what was happening firsthand; the distance made that impossible.

Theme 3: Direct Action Through Information Seeking

All participants wanted more information. They wanted to know more about the disease, treatments, and what their parents actually were experiencing. One participant was frustrated with having to rely on her mother and father to give her second-hand information: “I would like more information . . . we don't truly understand it . . . I'm not even sure my parents understand it, too, all the time.” Another stated a similar concern.

‘Cause of my mother's age and because she has selective hearing, I don't always get the truth. . . . It would be nice if someone would call me up—you know, in the medical field . . . so I know . . . it's the not knowing that's scary.

The participants also asked about resources and support groups available to them and to their parents. One son wanted a manual that had “the top cancer institutions and top nutritionists in the area, the emergency rooms, and the homecare nurses.” He had to research that for himself and did not know the geographic area. One daughter suggested a fact sheet.

Your dad's been diagnosed with stage III colon cancer and this is what it means. . . . ‘Cause you know I go and look things up on the Internet and the Internet's only as good as whatever the source is.

Others wished a support group existed for distance caregivers. The distance did limit the ability to receive information firsthand, which increased uncertainty. However, distance caregivers, like local caregivers, seemed to be seeking information that would reassure them that their loved one had a good prognosis.

Theme 4: Protecting

Similar to the experience of local caregivers, many distance caregivers talked about their parents' need to protect them. Distance caregivers reported that their parents often withheld information so their adult children would not worry. One participant said about his mother, “Her personality is to constantly be concerned about other people; she is more worried about everybody else.” Another said when she asked her mother

how she was doing, “She reverts to the mother role and doesn’t want me to worry.” One daughter said, “Living far away, they won’t tell me over the phone; they feel like they’re burdening me.”

The need to protect was reciprocal. Distance caregivers wanted to protect their parents from worrying about them, and on a larger scale, from worrying about the cancer or dying. One caregiver and his siblings wanted to hide any upsetting information, such as job worries or problems with the children, from their mother, and he said, “We were all concerned about her, not taxing her with other things that are going on.” Another emphasized the importance of not giving up hope: “It doesn’t matter what they tell you, even the doctors are guessing at what’s going to happen. . . . The last thing you wanna do is give the patient the feeling that you’re panicking. . . . They shouldn’t be worried about you.” Specific to distance caregivers, she went on to say, “We all have a tendency to want to fly in—fly in and fix things—and cancer doesn’t work that way.” In the clinical setting, distance caregivers often fly in for a visit, try to change the plan of care, and attempt to fix everything before they return home.

Theme 5: Staying Connected

The importance of connectedness was apparent from the responses to question 2: “If a friend or colleague came and told you tomorrow that his or her parent was just diagnosed with advanced cancer and lives far away, what advice would you give?” Like local caregivers, distance caregivers reported the importance of staying connected with the ill parent, being in contact with the healthcare team, and, for some, being personally connected to God. Participants stressed maintaining connections with their parents, particularly because of the geographic distance. Many made daily calls, and some spoke to their parents numerous times throughout the day. One daughter gave advice for others, saying, “Continue to keep contact, be it phone or whatever you can, to have that constant contact just to check in—and then not to let the distance come between conversations and communication.” Others suggested, “Just because you’re not physically there doesn’t mean that you can’t be there emotionally and, you know, be there to talk . . . if they need to.”

Many wanted more communication with the physicians and nurses. One caregiver said, “It’d be nice to have contact with someone in the medical field.” She went on to say that she wanted to be able to ask questions because she didn’t think her parents understood the information given to them. Another said,

I would have really liked it if in the beginning I could have talked with one of the nurses about the treatment that my dad was gonna be going through . . . and the prognosis and side effects . . . that would have probably put my mind at ease a little more.

Some wanted the opportunity to communicate with other distance caregivers who were going through the same experience for support and validation of feelings. One daughter said,

There really ought to be some sort of Web site or blog or something that we the family members could send messages—to say, this is how I’m feeling and what I’m getting from my mom—can somebody just tell me this is normal?

A few caregivers spoke about the importance of their connection with a church community and with God. When asked how he was dealing with the situation, one participant said, “First of all, I’m a faithful person, so I have faith in God.” Another participant said, “I can’t be there right now and that’s tough, but I’ve put everything in God’s hands. . . . You have to put your faith in God . . . without a church family, I don’t know that I could’ve made it through.”

Discussion

The experience of distance caregiving centered on the five themes presented. The benefits and burdens experienced by distance caregivers are similar to those of local caregivers described in the literature but with some additional concerns. Local and distance caregivers struggle with the burden of the prognosis of cancer and treatment experiences; however, distance caregivers expressed those in addition to burdens unique to distance caregiving, such as traveling, worrying if they would be able to arrive in time during an emergency, the uncertainty of when the best time was to arrange a visit, and lack of control because of geographic distance.

The five themes described can be condensed into two main concepts: lack of control and communication. All participants were struggling with the unknown. They worried if they would be able to get home quickly in a crisis, something for which they could not control or plan. Most wanted more information and stronger communication with the healthcare team so that they had a better sense of what was happening. They seemed to be saying that they wanted to know that everything was going to be fine.

The need to gain control over the cancer experience is not new to family members of patients with cancer. Unique to this population, however, is the added distress of living far away and not being able to see for oneself, on a frequent basis, how things really are. Having to rely on secondhand information or updates that may have been censored seemed to result in more distress than receiving that information in person. Many of the participants expressed the need for more information to gain control over the situation. More knowledge about disease process, treatments, side effects, and prognosis would have been helpful;

however, because the sample was so highly educated and participants most likely had the skills and resources to access information, the researchers were surprised that more information was wanted. The caregivers may have been seeking what they wanted to hear, rather than the known prognosis and associated statistics.

Like the need for control, the importance of communication is not unique to distance caregivers. However, because of the distance, the study participants identified that communication was particularly important, but they experienced challenges in staying connected with the parent throughout the experience. Because they were unable to visit in person, caregivers worked hard to maintain frequent contact by calling, sending cards, and keeping the lines of communication open. In response to the third question about designing a program of support in the future, a few participants noted that using computer technology, which would allow them to be present via webcam at physician visits, might make them feel more connected to the parent's cancer experience and to the healthcare team.

Most of the participants identified a need to have better communication with the physicians and nurses. They wanted more information and wished that they had been able to talk directly to a member of the healthcare team. Although the need for better communication often is described by local caregivers (Northouse et al., 2005), living far away makes this challenge even more complicated. Distance caregivers are unable to attend physician and treatment visits, do not have the opportunity to hear the news firsthand, and do not have the opportunities local caregivers have for patient and family education.

Clinical Implications

The study findings suggest that distance caregivers would benefit from nursing interventions that are targeted at their specific needs. The nurse is the healthcare team member most likely to have an impact on distance caregiver distress by providing education tools and support. Teaching distance caregivers about the disease process, treatment experience, and side effects by providing information via telephone or computer may be an easy way to help caregivers gain control as they struggle to understand the cancer experience. Materials addressing chemotherapy or radiation therapy and Web sites with virtual tours could be developed so that distance caregivers could see where their loved one was receiving treatment, decreasing uncertainty, and increasing control. Written tips and information on high-quality resources (e.g., home care, meal delivery, housekeeping) located in the patient's geographic community could provide the distance caregiver with tools for supporting their ill loved one.

Distance caregivers' responses indicate that a need exists to provide emotional support and help them cope

with uncertainty and lack of control. Interventions such as online support groups for distance caregivers to share their experiences could be designed to address concerns. System changes that assist in establishing relationships with the distance caregivers and increasing the availability of ongoing, open physician, nurse, and caregiver communication, with parent permission, may improve family-centered care by supporting the whole family.

More technologically complex interventions, such as the computer-based technology of webcams, might provide the opportunity for distance caregivers to be present at physician visits, possibly improving communication and decreasing fears of not knowing. The technology is available and familiar to many middle-aged adult distance caregivers and could be used with little financial burden (Mazanec, 2009).

Limitations

The findings of the current study should be interpreted with caution. The distance caregiver sample was largely Caucasian, relatively young in age, and highly educated. However, if those who are young, highly educated, and most likely computer literate are struggling to find resources, those who are older and less educated may have even greater difficulty in accessing support. Information should be provided in Web-based and written formats.

The caregiver interviews were surprisingly brief. That may reflect the impersonal nature of a telephone conversation rather than an in-person interview or may be the result of caregivers' busy schedules. In future studies, researchers should consider requesting that caregivers schedule the interview when they can have an hour of uninterrupted time. Although caregivers were encouraged to talk as long as they wanted, the study's credibility would have been strengthened by more in-depth data collection, possibly by conducting additional interviews with the caregivers across the disease trajectory. The lack of depth limits the transferability of the study.

Finally, the lack of member checking may have influenced the credibility and trustworthiness of the findings of the current study. Because of the short life expectancy of many of the patient participants, many died before the tapes were transcribed and reviewed. The principal investigator chose not to contact grieving distance caregivers for member checking. However, future studies would benefit from including consent for member checking and follow-up interviews after the death of a loved one, giving the participants the opportunity to reflect on their experience over the disease trajectory.

Conclusion

Distance caregiving is a new and complex phenomenon in the literature, and findings from the current study confirm that complexity. Distance caregivers experience

some of the same fears and concerns as local caregivers but have additional issues related to the geographic distance that increase burden. Interventions that address the loss of control and the communication issues associated with distance caregiving have the potential to provide opportunities for growth while minimizing burden.

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