

Original Article

A Pilot Study of the Experience of Family Caregivers of Patients With Advanced Pancreatic Cancer Using a Mixed Methods Approach

Deborah W. Sherman, PhD, CRNP, ANP-BC, ACHPN, FAAN,
Deborah B. McGuire, PhD, RN, FAAN, David Free, MS, NP-C, ACHPN, and
Joo Young Cheon, MS, RN

*University of Maryland School of Nursing (D.W.S., D.B.M., J.Y.C.), Baltimore, Maryland; and
Department of Pain Medicine and Palliative Care (D.F.), Beth Israel Medical Center, New York, New
York, USA*

Abstract

Context. Pancreatic cancer presents a wide spectrum of significant symptomatology. The high symptom burden, coupled with a rapidly fatal diagnosis, limits preparation or time for adjustment for both patients and their family caregivers. From the initial diagnosis and throughout the illness experience, the physical and emotional demands of caregiving can predispose caregivers themselves to illness and a greater risk of mortality. Understanding the negative and positive aspects of caregiving for patients with advanced pancreatic cancer will inform interventions that promote positive caregiver outcomes and support caregivers in their role.

Objectives. To provide feasibility data for a larger, mixed methods, longitudinal study focused on the experience of family caregivers of patients with advanced pancreatic cancer and preliminary qualitative data to substantiate the significance of studying this caregiver population.

Methods. This was a mixed methods study guided by the Stress Process Model. Eight family caregivers of patients with advanced pancreatic cancer from oncology practices of a university-affiliated medical center were surveyed.

Results. The pilot results supported the ability to recruit and retain participants and informed recruitment and data collection procedures. The qualitative results provided preliminary insights into caregiver experiences during the diagnosis and treatment phases. Key findings that substantiated the significance of studying these caregivers included the caregiving context of the history of sentinel symptoms, the crisis of diagnosis, the violation of assumptions about life and health, recognition of the circle of association, and contextual factors, as well as primary and secondary stressors, coping strategies, resources, discoveries, gains and growth, associated changes/transitions, and unmet caregiver needs.

Address correspondence to: Deborah W. Sherman, PhD, CRNP, ANP-BC, ACHPN, FAAN, College of Nursing and Health Sciences, Florida International

University, AHC-3 534A, 11200 SW 8th Street, Miami, FL 33199, USA. E-mail: desherma@fiu.edu

Accepted for publication: September 19, 2013.

Conclusion. Findings indicated caregivers' willingness to participate in research, highlighted the negative and positive aspects of the caregiver experience, and reinforced the significance of the future study and the need to develop interventions to support family caregivers in their roles. *J Pain Symptom Manage* 2014;48:385–399. © 2014 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Family caregivers, advanced pancreatic cancer, qualitative research, mixed methods

Introduction

Pancreatic cancer is the fourth leading cause of cancer deaths in the U.S.,¹ and 80% of patients present with advanced stage (i.e., III, IV) disease.^{2,3} Limited treatment options and resistance of the disease to chemotherapy result in a 95% mortality rate within one year of diagnosis and an estimated survival rate of only 4%.² The high symptom burden, coupled with a rapidly fatal diagnosis, does not allow preparation or time for adjustment for either patients or their family caregivers. During this compressed time frame, caregivers experience uncertainty, anger, depression, anxiety, exhaustion, and anticipatory grief⁴ and also may worry about their own genetic risk and that of other family members.²

Family caregivers provide a broad range of assistance to patients, which involves time and logistics, physical care, emotional burden, and financial costs that often lead caregivers to neglect their own needs.⁵ Throughout the illness experience, the physical demands of caregiving can predispose caregivers themselves to medical illness and a greater risk of mortality.⁶ Emotionally, caregivers often become demoralized and exhausted⁴ and may need to be treated for psychiatric problems.⁷ Family caregivers often abandon their own activities, which create stress on themselves, and the family as a unit.⁸ However, some researchers suggest a focus on the benefits of the caregiving experience and possible gains, which may act as a buffer against overwhelming burden and traumatic grief,⁹ and may motivate caregivers to maintain their roles.^{10–12}

Despite numerous studies focusing on caregivers in general and caregiving in the context of cancer,^{5,7,8,10,11,13–26} there is a dearth of literature regarding the experience of family caregivers of patients with advanced pancreatic

cancer. Petrin et al.²⁷ highlighted the distress of first-degree relatives of patients with pancreatic cancer, who articulated the stress they experience because of competing responsibilities, unfamiliar physical care demands, and the disruption of usual daily activities. In a longitudinal study that included patients with advanced pancreatic cancer and their family caregivers, Sherman et al.^{28,29} found that caregivers themselves had significant physical and emotional symptoms and lower quality of life as the patient's illness progressed.

Because there is ample evidence that family caregivers are neglected by the health care system and remain an at-risk and vulnerable population,⁶ a future mixed methods longitudinal study is planned to inform the development of interventions aimed at reducing negative consequences and promoting positive aspects of caregiving across the illness trajectory.^{30,31} The knowledge gained based on caregivers of patients with advanced pancreatic cancer may be applicable to caregivers of patients with other solid tumors; Salpeter et al.³² report the similarities in illness trajectories when these tumors are in the advanced stages.

Here, we report the results of a pilot study designed to 1) examine the feasibility of a larger, mixed methods, longitudinal study of family caregivers of patients with advanced pancreatic cancer, specifically the initial recruitment and retention of participants, ease of administration of selected instruments, evaluation of interview questions, and data collection procedures and 2) provide preliminary qualitative data obtained during the diagnosis/treatment phases to gain insights into the caregiver experience and further substantiate the significance of research for this specific caregiver population.

Methods

This was a mixed methods pilot study of the caregivers of patients newly diagnosed with advanced pancreatic cancer, from two oncology practices at a northeastern U.S. university-affiliated medical center and National Cancer Institute-designated cancer center. This feasibility study was conducted over a three-month period. Pilot data were collected only during the diagnosis and treatment phases because of time constraints and limited funding.

The Stress Process Model³³ (Fig. 1; Table 1, available at jpsmjjournal.com), which addresses the negative and positive aspects of caregiving, provided the theoretical framework that guided the selection of study variables and instruments. This model also informed the development of the interview guide (Table 2, available at jpsmjjournal.com), with open-ended questions that enabled participants to share their individual perspectives regarding the caregiving experience and reinforced the value of the model for use in the study.

The quantitative component involved the measurement of caregiver strain, mastery, symptoms, post-traumatic growth, and quality of life, using reliable and validated instruments. The qualitative component was

conducted immediately following administration of the questionnaires.

Informed consent was obtained from eligible patients (to access their medical data) and their family caregivers. The inclusion criteria for family caregivers were 1) men or women aged 18 years or older (no upper age limit) and identified by a patient newly diagnosed with Stage III or IV pancreatic cancer as a relative, partner, friend, or neighbor with whom they had a personal relationship and who provided physical, emotional, or practical assistance; 2) cognitively intact or had no more than mild intellectual impairment, according to the Short Portable Mental Status Examination;³⁴ and 3) spoke English. Exclusion criteria included caregivers 1) of patients who had Stage I or II pancreatic cancer, 2) of patients who were seeking a second opinion but were not treated at the institution, 3) who self-reported current treatment of a life-threatening or terminal illness, and 4) who self-reported untreated psychiatric illness or substance abuse. The institutional review board of the affiliated medical center approved the study.

Before data collection, the researchers described the goals and methods to the physician and nonphysician staff of the oncology practices, who then mentioned the study to eligible

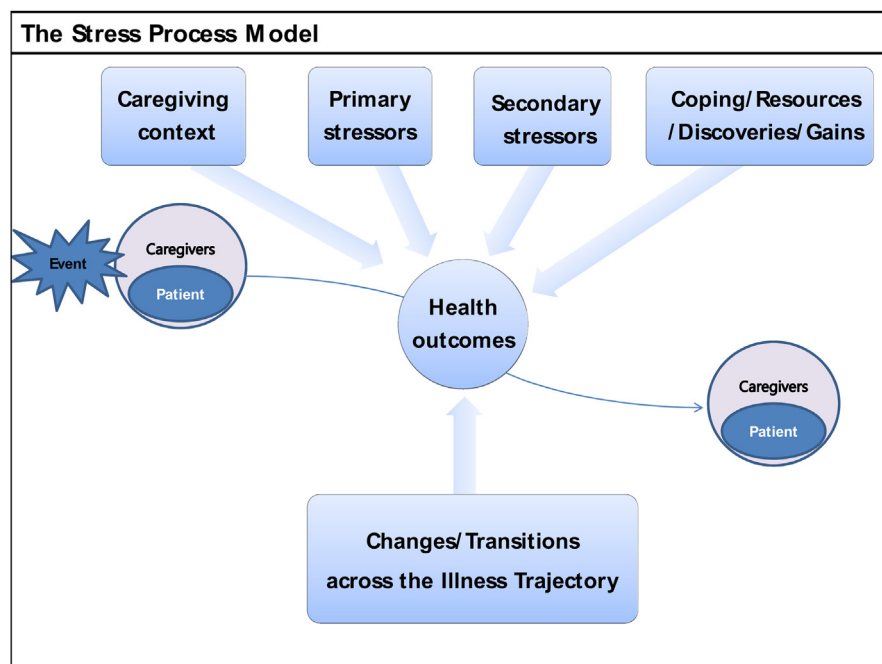


Fig. 1. The stress process model.

participants. If a caregiver expressed interest, an initial meeting was held with the principal investigator (PI), in a private setting in the clinic, to describe the purpose of the study and the time frame (diagnosis and treatment phases of the patient's illness). On obtaining informed consent, the PI administered the Demographic and Clinical Data Form. A first interview was then scheduled, which comprised the completion of the questionnaire booklet (quantitative component), followed by an audiorecorded conversation based on the interview guide (qualitative component). The questionnaire booklet was read to participants and took 20 minutes to complete; the qualitative interview lasted 60–90 minutes.

Analysis

Descriptive statistics were used to analyze demographic and clinical data. Qualitative data were analyzed and interpreted based on the principles set forth by Carini.³⁵ The steps of data analysis are outlined in Table 3 (available at jpsmjournal.com). To ensure the trustworthiness and scientific rigor of the qualitative data, the researchers discussed and compared the coding of the data and emerging themes and resolved any discrepancies by consensus; created an audit trail that documented analysis methods, decisions made, and interpretations; and used member checking, in which two caregivers reviewed the results and substantiated that they accurately represented the experience of family caregivers.

Results

Description of the Pilot Sample

The patient sample comprised three women and five men (age range 52–86 years). At the time of study enrollment, two patients had Stage III and six patients had Stage IV pancreatic cancer. The family caregiver sample comprised seven women who were wives or daughters and one husband (age range 34–74 years), all married, predominantly Caucasian (Table 4), and who were in the caregiver role from five to 48 months (Table 5).

Feasibility Data

The pilot study supported the feasibility of a larger study in terms of ability to identify and recruit eligible subjects. Over the first

Table 4
Caregiver Demographics (N = 8)

Variables	N	%
Age, yrs, mean (range)	64.6 (37–74)	
Gender		
Female	7	87.5
Male	1	12.5
Marital status		
Married	8	100
Race		
Black	2	25.0
Caucasian	6	75.0
Education level		
Less than high school education	1	12.5
High school education	1	12.5
Some college credits	1	12.5
Two years college degree	2	25.0
Four years college degree	2	25.0
Graduate degree	1	12.5
Employment status		
Retired	3	37.5
Full-time	3	37.5
Unemployed	1	12.5
Disabled	1	12.5
Religious affiliation		
Catholic	2	25.0
Jewish	1	12.5
Protestant	4	50.0
None	1	12.5
Income		
<\$30,000	1	12.5
\$41,000–\$60,000	1	12.5
\$61,000–\$75,000	3	37.5
\$76,000–\$90,000	1	12.5
>\$91,000	2	25.0

month of the study, 13 patients were diagnosed with advanced pancreatic cancer from the two oncology practices, and 10 caregivers met the study's inclusion criteria. Nine caregivers signed informed consent and completed the Demographic and Clinical Data Form at the time of enrollment; one potential participant declined as he did not want to discuss his experience. One patient died before the interview, thus his caregiver dropped out. The resulting sample of eight caregivers was deemed adequate to achieve the pilot study's objectives.

At the time of caregiver enrollment, three of the eight patients were recently diagnosed with advanced pancreatic cancer but had been treated for early-stage pancreatic cancer within the last two years. Five patients received an initial diagnosis of advanced pancreatic cancer. Given the short timeline between diagnosis and treatment, all eight caregiver participants were interviewed for the pilot study just as patients were beginning treatment. Weekly follow-up with oncology staff revealed that one patient had died, but the other seven

Table 5
Caregiving Characteristics (N = 8)

Variables	N	%
Time in current caregiving role, months, range	5–48	
Average daily care, hours, mean	9	
Average hours of lost sleep per night, hours, mean	5.6	
Relationship to patient		
Wife	4	50.0
Husband	1	12.5
Mother	1	12.5
Daughter	2	25.0
Caregiver and children		
Some children at home	4	57.1
Some children not at home	5	71.4
Both of the above	2	28.6
Living arrangement		
Does not live with patient	2	25.0
Living with the patient	5	62.5
Lives with patient as needed	1	12.5
History of family caregiving		
No	5	62.5
Yes	3	37.5
Self-reported health status		
Good	4	50.0
Excellent	4	50.0
Amount of support from others		
No help	2	25.0
Some help	2	25.0
Adequate help	2	25.0
More than adequate help	2	25.0

patients remained in treatment during the three months of the pilot study. The need for immediate notification of the PI by the oncology staff when a patient was diagnosed was recognized as a key aspect to participant recruitment, enrollment, and data collection in the short period between diagnosis and treatment. Retention potential for the future was supported as all caregivers expressed willingness to continue participation in subsequent interviews and articulated the value of sharing their experiences and great appreciation that their feelings and concerns were being considered.

Based on the pilot results, other areas related to feasibility were addressed. The Demographic and Clinical Data Form was refined, ease of participants' comprehension of questionnaire items was confirmed, an appropriate time allocation for the quantitative and qualitative components of the interview was established as between 90 and 120 minutes, and the interview guide was refined to ensure clarity and avoid redundancy in the open-ended questions. Although interviews were originally to be conducted face-to-face in the clinic,

a decision was made to offer either in-person or telephonic interviews according to the participant's preference.

Qualitative Data

The qualitative results provide a composite picture of the caregiving experience. Representative comments are found in Table 6. Analysis of the interview data revealed that they were commensurate with the components of the Stress Process Model³³ (Fig. 1).

The Caregiving Context

1) *History of Illness: The Sentinel Event of Significant Symptoms.* The symptoms that most often heralded the diagnosis of advanced pancreatic cancer were pain, nausea/vomiting, weight loss, fatigue, and jaundice. Coupled with worry and uncertainty, the patient often tried to deny the symptoms and engage in self-treatment, whereas the family caregiver encouraged the patient to seek a medical evaluation. Symptoms were the sentinel event that initiated the caregiving context and engagement with the health care system, with the hope that symptoms were caused by anything other than cancer.

2) *The Crisis of Diagnosis.* The patient and family caregiver awaited the results of initial tests, many participants stating that they "kept calling the doctor for the test results." Some patients were "opened and closed" during surgery without having the cancer resected. As one caregiver said, "The word cancer was never mentioned until the doctor came to speak to us after the surgery—we were in total shock." Immediate decisions needed to be made regarding treatment. At this point, caregivers expressed feeling "lost in the health care system." Family caregivers searched for any information that could offer "a shred of hope" but "were quickly overwhelmed by the bleak and discouraging results." The health care system offered little help in navigating the system, "with no point person to serve as coordinator."

Table 6
Representative Caregiver Quotes

The Caregiving Context	<p>"He had stomach pains but thought it was because the stress of work—so he took antacids. But when his eyes started to become yellow, I knew it was something serious and begged him to go see the doctor."</p>
History of Illness: The Sentinel Event of Significant Symptoms	<p>"We had no idea it could be cancer—when we were told, we were like deer in headlights." "What should we do, who do we turn to, how do we proceed?" Patients and family caregivers were "emotionally unhinged," asking "How could this be happening?" Family caregivers spoke of the "marathon waiting times," "differing medical opinions," "inconsistent advice," or "information overload or underload."</p>
The Crisis of Diagnosis	<p>"An assumption that life will be long and that a person's state of health is within their control, dependent on their lifestyle and behaviors" was violated. "He ran every day, ate well, and we thought he would have a long healthy life and we would live into old age together—we were wrong."</p>
The Violation of Assumptions About Life and Health	<p>"Everyone in our family has their opinions and own experiences with doctors, so at times it was too much." "My sister drove us crazy, always calling our mom and stressing her out about what to do next." Several participants expressed the distress of their young children who "cried because they wanted to see grandma but she was too sick." Many participants spoke of how others within the circle were "significantly distressed, but we all came together, knowing how bad the diagnosis was."</p>
The Circle of Association	<p>"Dad takes care of her (mother) but I call every day and come over a couple of times of week to help with doctor's appointments or help when she is sick from the treatments. As the older sister, I have always felt it was my responsibility." "Above everyone else, mom knows that I have always been the one to help her—she can always count on me." "With everyone over, there is no private time and no place to retreat." "He is the focus of my life—I will take care of myself when it's over."</p>
Contextual Factors of Family Caregiving	<p>"Learning the health system was unreasonable given all that was happening." "Physicians are just making educated guesses and no one really has the answer." "You don't know what to expect or have the bigger picture. Information is important to understanding what to expect." The caregiver was concerned that "hope would be taken away if she knew it was cancer—but yet she knew something was really wrong." "I am most stressed now that the effect of <i>cancer is seen on the outside</i>—her color, her weight loss, and the falling out of her hair—and the worst is that I can't do anything to change it." "He is trying to protect me and still wants to be in charge so that I am not as stressed but I want to do things for him because he is the one who is sick." One caregiver stated "I am trying to stay strong—despite everything she is amazing—together we will fight this disease to the very end—whatever it takes."</p>
Primary Stressors Associated with Family Caregiving	<p>"I spend hours on the phone telling everyone what is happening." "Her whole family wants to visit when I just want to be alone with her."</p>
Secondary Stressors Associated with Family Caregiving	<p>Conduit of Medical Information</p>

(Continued)

Table 6
Continued

Social Life Became Limited	One caregiver remarked, "I used to enjoy going to church but now I don't want to leave him home alone so I am missing my church community."
	The circle of associations and connections shrank as "there is no time to spend with friends and who wants to be with Debbie Downer."
Losing Pleasure in Life	"Nothing matters anymore."
Caregiver Identity	"I will have no one to care for—I won't know what to do with myself."
Financial Stress	"I got enraged at the staff and it wasn't a pretty picture—I just couldn't have them add to her pain and insecurity."
Coping, Resources, Discoveries, Gains and Growth	"Sometimes you can't believe what happens and the only thing you can do is laugh."
	People were "more supportive than could ever be imagined."
	"In the face of death, you learn to not sweat the small stuff"
	"To let go of the negatives and focus on the positives in your life."
	Learned to "ask for help."
Changes or Transitions	"He loves me so much, he wants to make it easier for me—getting everything fixed in the house" and "teaching me how to take care of the bills."
	"She is telling me what she wants and as hard as it is to hear, it helps me understand what I need to do."

3) *The Violation of Assumptions about Life and Health.* Family caregivers were shocked by the "sudden and unexpected" diagnosis of advanced pancreatic cancer. If the patient had a healthy lifestyle, it was unfathomable to both patient and caregiver that the symptoms were from a life-limiting terminal disease. Caregivers quickly learned that lives can be "changed on a dime" and "that all bets are off."

4) *The Circle of Association.* Beyond the patient-caregiver relationship, participants described a "circle of association" that included family, friends, and the community. Several participants spoke about how others enhanced or interfered with interactions with health care professionals given their own expectations, fears, and degree of trust of the health care system. The relationship of patient and family caregiver was of a patient-child or patient-spouse; however, other family members were secondarily involved. Within the context of the patient/caregiver relationship, there were varying ages and degrees of emotional closeness dependent on the history of the relationship. For example, their mother was "their best friend" or the

illness brought about a sense of responsibility although "the relationship was not close before."

5) *Contextual Factors of Family Caregiving.* A number of contextual factors were illustrated by participants. The family caregiver may be the primary caregiver, who assumed total responsibility on a 24 hours basis. Alternatively, a caregiver may assume secondary responsibilities for caregiving, acting as support when the primary caregiver needs relief, or there was a sharing of responsibilities with other family members. Often, physical proximity to the patient resulted in expectations by patients, caregivers themselves, or extended family that the member in closest physical proximity would assume a direct caregiving role. Family members who lived farther away often were relieved that they did not have direct responsibility for caregiving but also expressed a sense of lack of control over the situation. Family caregivers discussed openly either a *willingness to care* born out a sense of responsibility or duty or (less often) a sense of "being forced" to assume caregiving responsibilities, with a perception of great personal sacrifice. In several families, a *sense of competition* existed between caregivers, with a need to

be viewed by the patient or other family members as the one who was most committed and supportive. Increased family interaction at a time of heightened anxiety exacerbated preexisting negative family dynamics and issues. As the patient's needs increased and the final days approached, with more family members in attendance, family caregivers felt an *invasion of their personal space and a lack of privacy*. Family caregivers also spoke of *competing priorities* when the patient's needs were primary; followed by the needs of children, spouses, and others; and compounded by the demands of work. Caregivers' self-care was not a priority.

Primary Stressors Associated With Family Caregiving. Along with the contextual factors were the primary stressors that derive directly from the patient's illness and were sources of great angst for caregivers. The *lack of clear information and support* from health professionals was often an intense source of distress. Caregivers also expressed great distress about *revealing or concealing the diagnosis and the prognosis* to patients. This was particularly true when it was a parent-child relationship and the patient was elderly. Patients may have requested complete disclosure related to the diagnosis, but caregivers held steadfast to hope and asked the medical team to conceal information from the patient. As well, caregivers expressed a need to *understand the whole process*. Given the grim prognosis, another caregiver said "we dance around the edges" with death looming near but "having to put on a happy and positive face" to not further frighten the patient. As such, the caregiver served as *protector* of not only the patient but also other family members who could not accept and face the death of someone they love.

Although *the unknown and uncertainty* are constant, the patient, family caregiver, and extended family strived to *maintain a sense of normalcy*. However, the family caregiver and other family members experienced *reciprocal suffering*—"up when the patient is up and down when the patient is down." Just when caregivers seem to achieve some equilibrium, a new wave of bad news or unmanaged patient symptoms overcomes them. One caregiver said "his pain is my pain" and others said that

"watching hurts." As the disease progresses and the reality of the diagnosis and death takes hold, caregivers became extremely distressed by a sense of *lack of control* and often a *sense of failure*. They could not control the disease, were unsure about symptom management, and "felt frustrated" if the patient was "not eating and not helping herself."

Distress also stemmed from the *struggle of independence and dependence* of the patients themselves. In striving for normalcy, many patients wanted to remain independent in self-care and maintaining their roles at home. Caregivers, however, were "wanting to be helpful" and "take off the pressure," which created a sense of resentment on the part of the patient. Both the issues of protection and the level of assistance create a "push-pull" dynamic between caregivers and patients. Caregivers understand the patient's need for control but also the "tension it creates in the relationship." Caregiver *guilt* was experienced, for example, when "I pressure her to eat" or "get angry and frustrated" when the patient "doesn't have the energy to do things." Caregivers' guilt also came from "pressuring her to continue treatment" despite the symptom side effects and patient's feelings that "enough is enough." *Anticipatory grief* was manifested as caregivers want to maintain hope when the patient was "ready to let go." Maintaining hope also involved *believing in miracles*. One caregiver stated "if we stay positive, positive things will happen." However, for many caregivers, the "fear of being alone" was a driving force for "holding on." The comments "I can't let her go" and "I don't know what I'll do without him" were reflective of their anticipatory grief. Caregivers also realized that the *losses* were incremental—loss of companionship, normalcy, physical intimacy, etc. Many caregivers throughout the illness experience hoped or believed that perhaps they could *will them (the patient) into wellness* by making sure that the patient ate well, got rest, and maintained a positive attitude. The mutuality of the illness experience also mandated that caregivers *mirror the courage* of the patient when they are really "falling apart inside."

Secondary Stressors Associated With Family Caregiving. Family caregivers were the *conduit of medical information* to other family members and

friends, taking phone calls, and having their lives disrupted by multiple visitors to the home or trips to the hospital, which created additional tension and conflict. The caregiver's own *social life became limited* as he or she was consumed by the demands of caregiving. Caregivers related that "friends don't know what to say" or even worse "just don't ask" and that really hurts as "my mother is now the center of my life." Yet, caregivers cannot find the *time to de-stress* and take time out to care for their own physical, emotional, or spiritual needs. Caregivers also spoke about *losing pleasure in life* and expressed concern that their work suffered. On a philosophical level, caregivers began to question "Who am I?" and "What will become of me when she is gone?" Caregivers' identity and meaning and purpose in life were intimately tied to the relationship with the patient and, for the period of illness, their identity is defined by the caregiving role. Part of the angst expressed by caregivers was in *second guessing* themselves as to whether they had made the right decision. For some, anger surfaced as they "have been dealt a bad hand," and resent the *injustices of life*, for example, patients being asked to pay before they receive treatment or fighting with insurance companies for coverage of medical bills. The *financial stress* of the patient became the caregiver's responsibility.

Coping, Resources, Discoveries, Gains, and Growth.

With respect to *coping* with the illness experience, some commented "I have support from the family," "I have faith in God," or "I get praise for doing a good job." Several participants cited laughter and humor as ways of coping. Despite little time to care for themselves, participants spoke of "trying to exercise," "going away for a day or two with the children," and "going to the nail salon or window shopping," which provided a brief respite from their worries and the demands of caregiving.

On a cognitive level, participants coped by, for example, "getting good news," "denial," "choosing not to think about it," and "choosing what to hear." Participants also compared their experience with other patients and caregivers with advanced pancreatic cancer, particularly those "who were sicker or who died." This engendered a "sense of gratitude" that "things could be worse." What was important to all

participants was "living in the present" and "looking for the good in every situation." Speaking to "positive people" gave them strength and offered a supportive perspective. What was striking about the responses of participants was that the idea of coping was not an active process but something "you just have to do—what other choice do you have." A common response was that coping involved stifling emotions and maintaining their composure, particularly in the presence of the patient.

Despite many comments about positive ways of coping, three of the participants were not coping well. Their distress was apparent in their words and voices. One participant expressed concern about the amount of alcohol she was drinking with the stress from her mother's dying and having a sick husband and teenage children. Another noted how withdrawn she had become, focusing her entire life on her mother's needs to the neglect of her work and family. She realized that she was extremely depressed and would ask her physician for an antidepressant. One wife said that she had lost 30 lbs as she had no appetite and was chain smoking. Similarly, a husband said that he was smoking more as his way of reducing his stress. To deal with the circumstances they faced, family caregivers had to "adjust expectations" and "accept a new normal," understanding that life would never be the same but "you have to make the best of a bad situation."

In terms of *resources*, participants discovered their own strength, experienced the support of others, appreciated time together, were strengthened by the patients themselves, and had a different perspective on life. For most, the response was that they "were stronger than they realized," reflecting an increased self-efficacy. To their surprise, not only did immediate family and friends offer support but also individuals from the general community and church offered words of concern and encouragement. By sharing their personal stories, people tried to connect and acknowledge the distress of illness for both the patient and the family. Participants captured a central idea of "just appreciating being together" for whatever time was left. A wife stated "I have never spent this amount of time with him and I am grateful because we have actually become closer."

When questioned about the discoveries, gains, or growth experienced during the process

of caregiving, participants quietly reflected—having to think about the answer. Discoveries, gains, or growth were secondary outcomes which could only be appreciated based on prior lived experiences and losses. A remarkable *discovery* was that patients were “amazingly brave” and demonstrated “courage” which helped the family caregiver to remain strong. Reciprocal strengthening was revealed as one participant said “my mother has always been the backbone of our family—her strength has strengthened me.”

When asked about the *gains* in caregiving, the overwhelming response by family caregivers was that there were no gains. However, one participant said “I have faced a lot of death in my career to know that in hindsight, there will be recognition of something gained even in the face of death.” Personal growth was expressed as caregivers experienced new perspectives about life. One participant found an answer to the question “why me” as her mother said “no, why not me?” Another aspect of growth was that although in the past they took charge or managed on their own, now they learned that although self-reliance is important, allowing others to help was necessary.

Changes or Transitions. When participants were asked about the changes or transitions related to the illness that they were experiencing, they did not seem to connect with the question immediately. However, as they spoke of the changes they were experiencing, the sentinel transition was the diagnosis with pancreatic cancer, which led to an instantaneous *transition from a state of health to a state of illness*. Transitions were, for the most part, *not specific events but more gradual changes over time* and were more readily identified retrospectively. The nature of transitions was as an insidious evolutionary process of change in terms of lifestyle, relationships, intimacy, and loss with a shift toward an increasing internal focus of thought and external locus of control. The greatest transition was when it was clear that the patient’s symptoms resulted from the disease rather than the treatment. This transition involved the *realization that there was no cure for the disease*, and with the “cancer showing on the outside,” death would happen in the near rather than distant future.

Psychologically and spiritually, another major transition was a shift of focus from society, the community, and family to a laser-like focus on the patient and relationship. This turning inward was because of a lack of psychic “energy to focus on anything else” and a desire to put “every ounce of energy into sustaining the relationship.” In the quiet moments of the day, caregivers had fleeting thoughts about the patient’s death, and what this would mean in terms of their own identity and life. Thoughts about death surfaced when any hope for cure was lost and the patients themselves had started preparations for death. Caregivers continued the fight as long as the patient was engaged in the battle; a major transition was coming to a point of *acceptance that death was near* and patients were ready themselves to “let go.” The transition was a shift from the hope for a cure to the hope for a comfortable death on one’s own terms.

Unmet Caregiver Needs. Caregivers could not readily identify their own unmet needs, perhaps because their focus was not on themselves. However, in listening to their stories and the stressors associated with caregiving, it was evident that caregivers’ unmet needs were to have someone to address their feelings and acknowledge the physical, emotional, social, and spiritual impacts associated with illness, loss, and the anticipated death of someone they loved. The needs of the caregivers were closely tied to the needs of patients and others in their circle of association; yet, for themselves, there was no true acknowledgment of their suffering. The opportunity to share their experiences and feelings was not a focus of health professionals; no one asked about what they felt and how they were coping with the situation. In fact, all participants welcomed the opportunity to share their true feelings, one going so far as to say that participating in the study “was a blessing.”

Discussion and Implications

The results of the pilot study supported the feasibility of a larger proposed study regarding recruitment and retention of participants and appropriateness of the selected instruments

and interview guide and informed the data collection processes. Results also reinforced the rapid illness trajectory of patients with pancreatic cancer, given that most patients were initially diagnosed with advanced disease. The time from diagnosis until treatment is extremely short, making it important for the oncology staff to immediately refer eligible patient/caregivers to the research team. The administration of the quantitative component of the study before the qualitative interviews allowed participants to develop a sense of comfort with the researcher. Although an interview guide was developed to address the components of the Stress Process Model,³³ the open-ended questions and reflective interviewing skills of the researcher encouraged communication; the researcher was able to further prompt the caregivers regarding the negative or positive feelings associated with caregiving, and participants appeared relaxed telling their stories.

In the interviews, the researcher brought the conversation back to the perceptions and needs of the caregiver rather than the patient. As similarly reported by Edwards et al.,¹⁵ the patient's health governed the experience. Pusa et al.³⁶ and Petrin et al.²⁷ also found that caregivers were ambivalent about their own needs as they believed that health professionals should focus on the needs of the patient rather than themselves. Stajduhar et al.²⁴ described the "legitimacy of need" and recognized that caregivers' views of their roles and needs would be important in understanding the interventions that caregivers would accept for themselves. The results of this pilot study indicated that when asked to focus on their experience, caregivers felt a sense of care and concern for themselves, which was not communicated to family or health professionals. Prior studies conducted by the first author have identified the physical, emotional, and social needs of family caregivers^{28,29,37} and their willingness to participate in palliative care research.^{38,39}

The pilot study also provided qualitative data regarding family caregiver experiences during the treatment phase of illness and reinforced the similarities to and differences from other cancer caregiving populations. Similarities relate to the primary stressors of direct care demands—physical care, maintaining nutrition, and management of symptoms.¹⁸

Given et al.¹⁸ and Petrin et al.²⁷ also reported competing demands, the disruption of the caregiver's usual daily activities, and assuming other household responsibilities as sources of caregiver stress. Other studies have documented the secondary stressors of being the conduit of information for the family and the need to reduce work-time and deal with the financial consequences of illness.^{18,21,40} As in the pilot study, Edwards et al.¹⁵ indicated that caregivers expressed concern if what they were doing was right for the patient and if they were second guessing the medical decisions. Reciprocal suffering has been substantiated by several caregiving articles,^{23,41,42} indicating that caregiver well-being decreases as patient well-being decreases.

As reported in the caregiving literature,^{18,23} the caregivers in our study also often coped using cognitive strategies, drawing from internal strengths, remaining positive, adjusting expectations, and suppressing their own emotions. Strang and Koop²⁵ documented that caregivers' beliefs and commitment to caring were important aspects of effective coping and that the patients themselves assisted caregivers in preparing for their death on practical levels and offered moral support. Our results support the work by Stajduhar et al.²³ who recognized that caregivers with a positive approach to life were better able to cope with the demands of caregiving. As with our participants, other ways of coping were effective problem solving, making meaning, comparing the situation to others, and acting as advocates. Downe-Wamboldt et al.¹³ found that caregivers may view the disease as a challenge rather than a threat. This mind set was initially expressed by our participants but changed radically as disease progression became evident and death was imminent. As also reported by Given et al.,⁴⁰ our participants attempted to accept a "new normal;" however, a few were not coping well as evidenced by unhealthy behaviors, for example, poor nutrition and increased alcohol and cigarette consumption.

Remarkably, the qualitative data collected at only one data collection point early in the treatment phase reinforces the unique issues of this caregiver population, which are different from those of other cancer caregivers. For patients with advanced pancreatic cancer and their caregivers, the onset of physical

symptoms heralds an advancing illness and a change from a state of relative health. Although DuBenske et al.,¹⁴ James et al.,⁴³ and van der Molen⁴⁴ also found that caregivers seek information about disease, treatment options, and prognosis, in the case of advanced pancreatic cancer, a definitive diagnosis is often elusive and delayed. Caregivers express a lack of clear information from health professionals. As recognized in Michel's Theory of Uncertainty, a state of uncertainty exists in which both patients and family caregivers are vulnerable and express significant distress.⁴⁵ With a definitive diagnosis, the caregiver may further grapple with revealing or concealing the diagnosis from the patient. Caregivers and patients feel that everything happens too fast and they are overwhelmed.

With the condensed time frame-associated advanced pancreatic cancer, emotional preparation for patients or their family caregivers is also limited. It was astounding how, within weeks of the diagnosis of advanced pancreatic cancer, this sample of family caregivers could provide such rich descriptions of the burdens and benefits of the caregiving experience. Caregivers described the need to become "laser focused" on their relationship with the patient, with no time to waste to sustain the relationship and express love and care. As reported in other studies,¹⁸ the caregivers in this pilot study attempted to maintain "hope" and "normalcy," despite the odds. Yet, the contradiction revealed in our study was that caregivers' psyches moved them into thinking about their identity after their loved one's death, and almost prematurely, they articulated the major changes and transitions associated with the illness experience and perhaps the associated discoveries or gains. This is contrary to the results of Strang and Koop,²⁵ which suggest that the gains of caregiving are difficult to understand while the caregivers are going through the experience, but may be more readily identified retrospectively, as family caregivers are given an opportunity to reflect on their caregiving experience.

As potentially different from other caregiver populations, caregivers in this pilot study also mentioned a number of issues that are not pervasive in the caregiving literature. First is the violation of assumptions, also reported by Petrin

et al.²⁷ based on relatives of patients with pancreatic cancer, that even health conscious individuals may rapidly succumb to a terminal cancer. Furthermore, the family, extended family, and community understand the seriousness of a diagnosis of pancreatic cancer and collectively become quickly responsive. What may be different is the urgency and intensity of the response by caregivers with concern about physical proximity to the patient, perceptions about the need to care, competition between caregivers, and the invasion of their space and privacy. Also not described in the literature are the expressions of guilt as caregivers describe the desire to "will the patient into wellness," their anger when the patient will not eat, distress when the patient has profound fatigue, and an inability to accept the rapid changes in the patient's health. For several, there was recognition of the struggle for patients to maintain independence, whereas some caregivers became so protective that they imposed dependency on the patient, creating conflict in the relationship. As described by Petrin et al.,²⁷ life was governed by the patient's needs as caregivers dismissed their own needs and neglected their work and other important relationships.

The results of this pilot study align with the key recommendations identified at the National Institute of Nursing Research Palliative and End of Life Care Summit related to family caregivers, including use of a conceptual framework and mixed methods approach to explore caregivers' experiences.⁴⁶ The qualitative data suggest that there are several urgent needs of family caregivers of patients with advanced pancreatic cancer that warrant further in-depth exploration in future studies and have potential clinical implications. First is the idea of a "warning shot" in which patients and caregivers are told that pancreatic cancer is a possibility, particularly when the constellation of symptoms is suggestive. Perhaps the patients and caregivers would prefer the unspoken truth. Second is honesty and openness of health professionals in meeting informational needs regarding the progression of symptoms and full disclosure of the benefits and risks of treatment. Third is the use of an institutional guide to help caregivers navigate rather than feeling lost in the health care

system; a person who recognizes and welcomes them, personalizes the experience, and provides information and guidance. Fourth is a health professional who teaches them about the possible physical changes and management of related symptoms. Fifth is providing a direct opportunity to address the emotional needs of family caregivers, with time separately scheduled to listen to their concerns and feelings. Sixth is assessing caregivers' resources and coping mechanisms, with a focus on not only negative emotions and anticipatory loss and grief but also the discoveries or gains related to the illness experience that may support their resilience. Seventh is assisting caregivers in developing a plan that provides practical relief from caregiving and gives permission to take time to care for themselves, while balancing work and sustaining important relationships. Eighth is helping caregivers shift from a hope for cure to a hope for a peaceful death for their loved ones.

Not only is the proposed larger, prospective, mixed methods study of the experience of family caregivers feasible, it is critical if health professionals are to truly provide care to the unit of care, the patient, and the family. By identifying and addressing the negative aspects, while simultaneously reinforcing the positive aspects of caregiving, health professional can reduce the chance of physical and mental illness of caregivers and can provide the support needed so that caregivers can contribute to the care of the patient in positive and rewarding ways. Plant et al.²² remind health professionals that delivering supportive interventions for family caregivers involves predicting the nature of caregiver's needs and identifying the necessary knowledge and skills to meet the demands of caregiving. The results of this descriptive research will assist health professionals in developing differing models of care and tailored interventions to support caregivers of patients with advanced pancreatic cancer across the illness trajectory.

Disclosures and Acknowledgments

Internal funding from the University of Maryland was received for the pilot study. These authors have no disclosures to make.

References

1. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2012. *CA Cancer J Clin* 2012;62:10–29.
2. National Cancer Institute. Pancreatic cancer: A summary of NCI's portfolio and highlights of recent research progress. Available from <http://www.cancer.gov/researchandfunding/reports/pancreatic-research-progress.pdf>. Accessed March 2, 2013.
3. Smith BD, Smith GL, Hurria A, Hortobagyi GN, Buchholz TA. Future of cancer incidence in the United States: burdens upon an aging, changing nation. *J Clin Oncol* 2009;27:2758–2765.
4. Zarit S. Assessment of family caregivers: a research perspective. In: Family Caregiver Alliance, ed. *Caregiver assessment: Voices and views from the field*, Report from a national consensus development conference, Vol. II. San Francisco, CA: Family Caregiver Alliance, 2006:12–37.
5. Schubart JR, Kinzie MB, Farace E. Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro Oncol* 2008;10:61–72.
6. Family Caregiver Alliance. *Caregiver assessment: Principles, guidelines and strategies for change*. In: Report from a national consensus development conference, Vol. I. San Francisco, CA: Family Caregiver Alliance, 2006.
7. Vanderwerker LC, Laff RE, Kadan-Lottick NS, McColl S, Prigerson HG. Psychiatric disorders and mental health service use among caregivers of advanced cancer patients. *J Clin Oncol* 2005;23:6899–6907.
8. Dumont I, Dumont S, Mongeau S. End-of-life care and the grieving process: family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qual Health Res* 2008;18:1049–1061.
9. Salmon JR, Kwak J, Acquaviva KD, Brandt K, Egan KA. Transformative aspects of caregiving at life's end. *J Pain Symptom Manage* 2005;29:121–129.
10. Gaugler JE, Hanna N, Linder J, et al. Cancer caregiving and subjective stress: a multi-site, multi-dimensional analysis. *Psychooncology* 2005;14:771–785.
11. Higginson IJ, Gao W. Caregiver assessment of patients with advanced cancer: concordance with patients, effect of burden and positivity. *Health Qual Life Outcomes* 2008;6:42.
12. Hudson P. Positive aspects and challenges associated with caring for a dying relative at home. *Int J Palliat Nurs* 2004;10:58–65; discussion 65.
13. Downe-Wamboldt B, Butler L, Coulter L. The relationship between meaning of illness, social support, coping strategies, and quality of life for lung cancer patients and their family members. *Cancer Nurs* 2006;29:111–119.

14. DuBenske LL, Wen KY, Gustafson DH, et al. Caregivers' differing needs across key experiences of the advanced cancer disease trajectory. *Palliat Support Care* 2008;6:265–272.
15. Edwards SB, Olson K, Koop PM, Northcott HC. Patient and family caregiver decision making in the context of advanced cancer. *Cancer Nurs* 2012;35:178–186.
16. Furlong KE, Wuest J. Self-care behaviors of spouses caring for significant others with Alzheimer's disease: the emergence of self-care worthiness as a salient condition. *Qual Health Res* 2008;18:1662–1672.
17. Given B, Wyatt G, Given C, et al. Burden and depression among caregivers of patients with cancer at the end of life. *Oncol Nurs Forum* 2004;31:1105–1117.
18. Given BA, Given CW, Sherwood PR. Family and caregiver needs over the course of the cancer trajectory. *J Support Oncol* 2012;10:57–64.
19. Kurtz ME, Kurtz JC, Given CW, Given BA. Depression and physical health among family caregivers of geriatric patients with cancer—a longitudinal view. *Med Sci Monit* 2004;10:CR447–CR456.
20. McMillan SC, Small BJ, Weitzner M, et al. Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer* 2006;106:214–222.
21. Northfield S, Nebauer M. The caregiving journey for family members of relatives with cancer: how do they cope? *Clin J Oncol Nurs* 2010;14:567–577.
22. Plant H, Moore S, Richardson A, Cornwall A, Medina J, Ream E. Nurses' experience of delivering a supportive intervention for family members of patients with lung cancer. *Eur J Cancer Care (Engl)* 2011;20:436–444.
23. Stajduhar KI, Martin WL, Barwich D, Fyles G. Factors influencing family caregivers' ability to cope with providing end-of-life cancer care at home. *Cancer Nurs* 2008;31:77–85.
24. Stajduhar KI, Nickel DD, Martin WL, Funk L. Situated/being situated: client and co-worker roles of family caregivers in hospice palliative care. *Soc Sci Med* 2008;67:1789–1797.
25. Strang VR, Koop PM. Factors which influence coping: home-based family caregiving of persons with advanced cancer. *J Palliat Care* 2003;19:107–114.
26. Williams AL, McCorkle R. Cancer family caregivers during the palliative, hospice, and bereavement phases: a review of the descriptive psychosocial literature. *Palliat Support Care* 2011;9:315–325.
27. Petrin K, Bowen DJ, Alfano CM, Bennett R. Adjusting to pancreatic cancer: perspectives from first-degree relatives. *Palliat Support Care* 2009;7:281–288.
28. Sherman DW, Ye XY, Beyer McSherry C, et al. Symptom assessment of patients with advanced cancer and AIDS and their family caregivers: the results of a quality-of-life pilot study. *Am J Hosp Palliat Care* 2007;24:350–365.
29. Sherman DW, Ye XY, McSherry C, et al. Quality of life of patients with advanced cancer and acquired immune deficiency syndrome and their family caregivers. *J Palliat Med* 2006;9:948–963.
30. Steinhauer KE. Measuring end-of-life care outcomes prospectively. *J Palliat Med* 2005;8(Suppl 1):S30–S41.
31. Hebert RS, Arnold RM, Schulz R. Improving well-being in caregivers of terminally ill patients. Making the case for patient suffering as a focus for intervention research. *J Pain Symptom Manage* 2007;34:539–546.
32. Salpeter SR, Malter DS, Luo EJ, Lin AY, Stuart B. Systematic review of cancer presentations with a median survival of six months or less. *J Palliat Med* 2012;15:175–185.
33. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: an overview of concepts and their measures. *Gerontologist* 1990;30:583–594.
34. Pfeiffer E. A short portable mental status questionnaire for the assessment of organic brain deficit in elderly patients. *J Am Geriatr Soc* 1975;23:433–441.
35. Ely M, Anzul M, Friedman T, Garner D, Steinmetz AM. *Doing qualitative research: Circles within circles*. London: Falmer Press, 1991.
36. Pusa S, Persson C, Sundin K. Significant others' lived experiences following a lung cancer trajectory: from diagnosis through and after the death of a family member. *Eur J Oncol Nurs* 2012;16:34–41.
37. Sherman DW, Haber J, Hoskins CN, et al. Differences in physical, emotional, and social adjustment of intimate, family, and nonfamily patient-partner dyads based on a breast cancer intervention study. *Oncol Nurs Forum* 2009;36:E185–E197.
38. Sherman DW, McSherry CB, Parkas V, et al. Recruitment and retention in a longitudinal palliative care study. *Appl Nurs Res* 2005;18:167–177.
39. Sherman DW, Ye XY, McSherry C, et al. Spiritual well-being as a dimension of quality of life for patients with advanced cancer and AIDS and their family caregivers: results of a longitudinal study. *Am J Hosp Palliat Care* 2005;22:349–362.
40. Given BA, Sherwood P, Given CW. Support for caregivers of cancer patients: transition after active treatment. *Cancer Epidemiol Biomarkers Prev* 2011;20:2015–2021.
41. Blum K, Sherman DW. Understanding the experience of caregivers: a focus on transitions. *Semin Oncol Nurs* 2010;26:243–258.
42. Sherman DW. Reciprocal suffering: the need to improve family caregivers' quality of life through palliative care. *J Palliat Med* 1998;1:357–366.

43. James N, Daniels H, Rahman R, et al. A study of information seeking by cancer patients and their carers. *Clin Oncol (R Coll Radiol)* 2007;19:356–362.
44. van der Molen B. Providing patient information—Part 1: assessing information needs of patients. *Eur J Cancer Care (Engl)* 2007;16:312.
45. Mishel MH. Reconceptualization of the uncertainty in illness theory. *Image J Nurs Sch* 1990;22:256–262.
46. McGuire DB, Grant M, Park J. Palliative care and end of life: the caregiver. *Nurs Outlook* 2012;60:351–356.

Table 1
Components of the Stress Process Model

-
- Caregiving context that includes sociodemographic characteristics of the patient and caregiver, history of illness, history of caregiving, and factors associated with the caregiving experience.
 - Primary stressors that arise directly from the patient's illness and may include the patient's symptoms or impairment, ability to perform activities of daily living, cognitive deficits, and behavioral problems, and stressors such as caregiver burden, including the subjective assessment of the degree to which the caregiver perceives each event, including possible role overload (time and energy), role captivity (trapped in the caregiving role), and the loss of relationship (lost intimacy and social exchanges).
 - Secondary stressors that include tension and conflict in maintaining other roles in one's life such as employment and family relationships; interruptions in other areas of the caregivers' life; and intrapsychic strains, which erode a person's self-concept, particularly related to a sense of caregiver mastery.
 - Coping that includes the ways of handling caregiver stress. Resources that include social, financial, and the internal resources that increase the ability to manage and cope with stressful experiences. Resources also include social support which involves information, material or financial support, and instrumental or emotional support, as well as perceived discoveries or gains of the caregiving experience, such as personal growth or sense of mastery.
 - Changes/transitions, which are acute or gradual in nature, are experienced by the patient and caregiver during the illness trajectory.
 - Outcomes that include positive and negative health outcomes and identification of unmet needs.
-

Table 2
Interview Guide Based on the Stress Process Model

Stress Process Model (Pearlin et al., 1990)	Qualitative Data
Caregiving context	<ol style="list-style-type: none"> 1. Tell me about the history of your family member's illness. (enrollment only) 2. Tell me about your history as a family caregiver. (enrollment only) 3. Can you tell me about what is involved in caregiving? 4. Tell me what your role has been in caring for your family member.
Primary stressors	<ol style="list-style-type: none"> 1. What stressors have occurred due to the patient's illness? (i.e., patient's symptoms, patient's ability to perform activities of daily living, or thinking, memory, or behavioral changes) 2. In what ways are you experiencing burden or strain as a caregiver? 3. Tell me about any losses that you are experiencing given your family member's illness. 4. Describe any gaps in the provision of care by health professionals for you as the family caregiver.
Secondary Stressors	<ol style="list-style-type: none"> 1. Tell me about any tension or conflict you have in maintaining other roles in your life such as those related to work, family or social life. 2. What knowledge and/or skills do you need for caregiving? 3. What is difficult or what is easy with regard to your caregiving role?
Coping/resources/discoveries/gains	<ol style="list-style-type: none"> 1. How are you coping with this experience? 2. What, if any, concerns do you have about the way you are coping? 3. What resources are needed to help you cope with this experience? (i.e., information, practical help, financial help, emotional support) 4. What have you discovered or learned through this experience? 5. Tell me about any positive aspects or possible gains associated with caregiving. 6. In what, if any ways, have you experienced personal growth?
Changes/Transitions	<ol style="list-style-type: none"> 1. What changes are you experiencing? 2. Are there any turning points or transitions in relation to the illness? 3. What meanings or expectations are associated with these changes? 4. How are you responding to these changes? 5. How do you plan on moving forward?
Outcomes	<ol style="list-style-type: none"> 1. What are the negatives outcomes of caregiving? 2. What are the positive outcomes of caregiving? 3. What are your unmet needs?

Table 3

Steps of Qualitative Data Analysis

-
- 1) Developing detailed knowledge of the content of the interviews and logs by reading line by line with the highlighting of specific words or phrases
 - 2) Noting impressions of the participant's statements
 - 3) Listing tentative headings and reflecting on recurring ideas
 - 4) Analyzing verbatim statements and listing them under the identified headings with the grouping of similar concepts or ideas
 - 5) Summarizing new impressions
 - 6) Comparing the data so that the commonalities and differences in participants' statements can be examined
 - 7) Establishing themes based on analysis of the data
-