

Caregiving near the end of life: Unmet needs and potential solutions

PATRICIA A. MANGAN, B.S.,^{1,2} KATHRYN L. TAYLOR, PH.D.,²
K. ROBIN YABROFF, PH.D., M.B.A.,² DAVID A. FLEMING, M.D.,³
AND JANE M. INGHAM, M.B.B.S.^{1,2}

¹Lombardi Cancer Center Palliative Care Program, Georgetown University, Washington, DC

²Cancer Control Program, Lombardi Cancer Center, Department of Oncology, Georgetown University, Washington, DC

³Center for Clinical Bioethics and Department of Internal Medicine, Georgetown University, Washington, DC

(RECEIVED April 9, 2003; ACCEPTED September 1, 2003)

ABSTRACT

Objective: A key aspect of the role of clinicians caring for patients in the setting of advanced illness focuses on attending to the needs of informal caregivers during the end-of-life period. The purpose of this study was twofold: (1) to complement and enrich existing quantitative findings regarding caregiver burden near the end of life, and (2) to identify potential solutions to caregivers' unmet needs in an effort to assist clinicians in the development of clinical interventions.

Methods: This qualitative study, using focus groups and content analysis of transcripts, was conducted in a comprehensive cancer center in Washington, DC. Seven focus groups were held: three with recently bereaved caregivers and four with active caregivers of patients with metastatic cancer and an expected survival of 6 to 12 months.

Results: Data were stratified into two broad categories: (1) general problems and (2) behaviors/activities that were helpful/would have been helpful in alleviating these problems. Within each of these two categories, five subcategories emerged: medical care (including provision of information, coordination of care, bedside manner, satisfaction with care), quality of life (including well-being, role adjustments), help from others (including practical assistance, social support), positives of caregiving, and unsolicited themes (including job flexibility, impact of the disease on the family, informational needs, relationship with patient).

Significance of results: Results suggest caregivers may benefit from more information about patient prognosis and hospice, attention to quality-of-life issues, and enhanced, direct communication with clinicians. Although information of this nature is likely to be known to palliative care clinicians, the specific details and verbal insights provided by caregivers give an important voice to existing quantitative data and may provide more detailed information to assist palliative care clinicians seeking to develop interventions to meet caregiver needs during the period near the end of life.

KEYWORDS: End-of-life, Caregiver, Palliative care, Qualitative analysis, Focus groups

INTRODUCTION

Current estimates reveal that approximately 52 million Americans serve as family caregivers for an ill or disabled adult (U.S. Department of Health and Human Services, 1998). Demographic trends such as the aging of the population (U.S. Bureau of the Census, 1999; National Institute on Aging, 2000) and the age-related incidence of illnesses such as cancer (Ries et al., 2000; Edwards et al., 2002) are likely to increase the proportion of the population in need of care. For example, within the next 50 years, the total number of cancer cases is expected to double (Edwards et al., 2002). Paralleling these demographic trends is an increased emphasis on control of health care costs, resulting in shorter hospitalizations and shifts in care to outpatient settings (Covinsky et al., 1994; Arno et al., 1999). These trends are likely to increase the prevalence of and need for informal caregiving.

The psychological, physical, and financial burdens associated with caregiving are well documented (Kiecolt-Glaser et al., 1987; Stone et al., 1987; Gallagher et al., 1989; Cohen et al., 1990; Pruchno et al., 1990; Schulz et al., 1990; Dean, 1995; U.S. Department of Health and Human Services, 1998; Arno et al., 1999; Metlife Mature Market Institute, 1999; Schulz & Beach, 1999), and these burdens are known to worsen as patients near the end of life (Emanuel et al., 2000; Sothill et al., 2001). Data from the SUPPORT study provided important epidemiologic information regarding the characteristics of caregivers (Covinsky et al., 1994), while other studies have documented the significant role strain and psychological burden of caregivers of patients with substantial care needs (Emanuel et al., 1999, 2000). Yet, in spite of this knowledge, studies continue to report that the needs of caregivers remain unmet (Hileman et al., 1992; Mor et al., 1992; Silveira & Winstead-Fry, 1997; Anderson et al., 2000). This finding has fueled the development of two recent reports from the Institute of Medicine calling for a removal of barriers to optimal palliative and end-of-life care and improvements in the training of palliative care clinicians to increase sensitivity to the needs of caregivers during this period (Field & Cassel, 1997; Kesselheim, 2001).

In an effort to further explore the nature of caregivers' unmet needs during the end-of-life period, a series of focus groups was held with informal caregivers of cancer patients. The purpose of this study was twofold: (1) to complement and enrich existing quantitative findings regarding caregiver burden near the end-of-life, and (2) to identify potential solutions to caregiver unmet needs in an

effort to assist clinicians in the development of clinical interventions.

METHODS

Participants

Participants were active ($n = 17$) and bereaved ($n = 15$) informal caregivers of patients with metastatic cancer. A caregiver was defined as the individual providing the majority of emotional and/or physical care to the patient throughout his/her illness. All enrolled caregivers were nonpaid, nonprofessional, and English-speaking. Bereaved caregivers were bereaved for a minimum of 3 months and a maximum of 36 months to be eligible for participation. Exclusionary criteria for both patients and caregivers included severe cognitive impairment and lack of access to a telephone.

For the active caregiving groups, a total of 41 patients were approached for consent. Of those, 17% ($n = 7$) refused to allow their caregiver to be approached regarding participation. Caregivers of the remaining 34 consenting patients were then approached, and 50% ($n = 17$) participated. For the bereaved caregiving groups, 26 caregivers were approached regarding participation, and 58% ($n = 15$) participated.

Procedure

Over a 6-month period, seven focus groups were held, four with active and three with recently bereaved caregivers. All participants were recruited through an NCI-designated comprehensive cancer center in Washington, DC. We employed a maximum variation sample (Elder & Miller, 1995), seeking to increase diversity at each group by considering factors such as caregiver race and gender, relationship to patient, and patient tumor site. This study was approved by the Georgetown University Institutional Review Board.

All caregivers were identified through the lung, breast, gastrointestinal, and palliative care programs. *Active caregivers* of patients with metastatic disease and the potential for having a prognosis of 6–12 months were referred by attending physicians or the specialist oncology nurses. Eligible patients provided consent for the research assistant to approach their caregivers regarding participation. *Bereaved caregivers* were identified as having served as a primary caregiver prior to their patient's death. All participants provided informed consent.

Focus Groups

Each focus group was approximately 2 h in length and was moderated by two research team members. The moderators had no previous personal or professional contact with the participants. Guided by a semistructured focus group guide, moderators first solicited general opinions regarding broad topics related to caregiving, and subsequently explored more targeted questions (Stewart & Shamdasani, 1990). The broad topics covered were: (1) caregiver satisfaction and trust associated with medical care/treatment decisions, (2) caregiver burden (defined as emotional, physical, professional, or financial activity restriction resulting from caregiving), (3) positive aspects of caregiving, (4) caregiver physical health, and (5) caregiver depression and anxiety. Within each category, moderators prompted participants to consider two questions: (1) What *general problems* were encountered? (2) What *helped or would have helped* in dealing with these problems? At the conclusion of each focus group, investigators modified the focus group guide to include any new topics relevant for exploration in subsequent groups. Focus groups were conducted until it became apparent that no new themes were emerging.

Coding and Analysis

All focus groups were audiotaped and transcribed verbatim. Transcripts distinguished the statements of different speakers, but did not identify individual speakers by name. Therefore, individual caregivers could not be used as the unit of analysis. Instead, a “turn” (Castonguay et al., 1996; Goldfried et al., 1998), or the sentence(s) comprising each participant’s alternating turn at speaking, was used as the recording unit of analysis (Krippendorf, 1980; Stewart & Shamdasani, 1990).

The constant-comparative method was used in the analysis of the seven focus group transcripts (Glaser & Strauss, 1967; Glaser, 1978; Strauss & Corbin, 1990). “Open coding” was used to break down, conceptualize, and categorize the data into common themes (Strauss & Corbin, 1990). Three coders reviewed one transcript to establish a set of coding rules and preliminary themes. Two of the three coders then proceeded to independently code and come to consensus on all seven transcripts, with one coder reviewing all transcripts to maintain consistency. Throughout the process, preliminary category names were modified and category exemplars were shifted as new concepts emerged, until a final, comprehensive list of themes had been identified.

Measures

After each focus group, participants were sent home with a questionnaire packet to complete and return via mail. Included were the SF-12 (Ware et al., 1996), a generic measure of general health-related quality of life, and the CES-D (Radloff, 1977), designed to measure depressive symptomatology. The SF-12 contains Physical and Mental Component Summary Scores and has excellent test–retest reliability (Ware et al., 1996). The CES-D is a widely used 20-item scale with high internal consistency and good test–retest reliability. It is useful for epidemiological evaluations of depressive symptoms in high-risk groups in the general population (Radloff, 1977).

There are no potential conflicts of interest in this article. The study sponsor did not have a role in the study design, data collection and analyses, or manuscript preparation. The authors had full access to all of the data, and accept full responsibility for the integrity and accuracy of the data.

RESULTS

Table 1 presents descriptive characteristics of the sample. On average, caregivers were spouses in their mid to late 50s with middle- to upper-range income and educational levels. Table 2 provides the normative scores based on age for the SF-12 physical and mental component summary scores (Ware et al., 1996, 1998), along with the standard cutoff score indicating possible depression for the CES-D (Radloff, 1977). Of note, although both active and bereaved caregivers reported levels of physical functioning within the normal range of the general population on the SF-12, active caregivers reported more depressive symptoms and poorer levels of mental health than the general population on these standard measures.

Data were stratified into one of two broad categories based on the focus group guide: (1) general problems, and (2) behaviors/activities that were helpful or would have been helpful (i.e., potential solutions) in alleviating these and other problems. In an attempt to enhance the generalizability of the findings in our small sample, we asked caregivers to consider their experiences in all health care settings encountered throughout the course of their patient’s illness, both in the comprehensive cancer setting in which the study took place and in other institutions (e.g., primary care settings, specialty care settings, and other comprehensive cancer care institutions). Resembling the broad categories defined in the focus group guide, themes fell under five headings: medical care, quality of life, help

Table 1. Characteristics of Study Participants

	Active (<i>n</i> = 17) % (<i>n</i>)	Bereaved (<i>n</i> = 15) % (<i>n</i>)
Age		
Caregivers	30–79 years, <i>M</i> = 52.2, <i>SD</i> = 12.3	38–86 years, <i>M</i> = 57.4, <i>SD</i> = 13.3
Patients	49–78 years, <i>M</i> = 59.9, <i>SD</i> = 10.8	N/A
Gender		
Male	58.8 (10)	40.0 (6)
Female	41.2 (7)	60.0 (9)
Race		
Caucasian	76.5 (13)	86.7 (13)
African American	11.8 (2)	13.3 (2)
Asian	5.9 (1)	—
Indian	—	6.7 (1)
Refused	5.9 (1)	—
Relationship to patient		
Spouse	64.7 (11)	86.7 (13)
Daughter	29.4 (5)	6.7 (1)
Niece	5.9 (1)	—
Friend	—	6.7 (1)
Education ^a		
Graduate degree	41.2 (5)	53.8 (7)
Undergraduate degree	25.0 (3)	23.1 (3)
Some college	33.3 (4)	23.1 (3)
Employment ^a		
Full-time	75.0 (9)	46.2 (6)
Part-time	—	7.7 (1)
Retired	25.0 (3)	38.5 (5)
Full-time homemaker	—	7.7 (1)
Income ^a		
\$70,000+	66.7 (8)	61.5 (8)
\$50–69,000	16.7 (2)	7.7 (1)
\$30–49,000	8.3 (1)	15.4 (2)
\$10–29,000	8.3 (1)	7.7 (1)
<\$10,000	—	7.7 (1)
Patient disease		
Breast	35.3 (6)	20.0 (3)
Lung	29.4 (5)	26.7 (4)
Gastrointestinal	23.5 (4)	26.7 (4)
Ovarian	11.8 (2)	6.7 (1)
Other	—	20.0 (3)

^aBased on responses to a self-administered questionnaire sent home with participants: Active *n* = 12, bereaved *n* = 13.

from others, positives of caregiving, and unsolicited themes. Unsolicited themes is comprised of four themes that arose from unprompted, spontaneous discussion within each focus group. Table 3 provides a detailed description of the themes and exemplars comprising each category. We present the results in the format in which they were elicited in the focus groups, first with a description of the difficult experiences and problems encountered, followed by a discussion of the potential solutions and positives of caregiving. Data are stratified by the two broad categories, and examples of each of the five headings within each category are provided.

GENERAL PROBLEMS

Caregivers were asked to describe the general difficulties associated with caregiving.

Medical Care

Noticeable cutbacks in the nursing staff in many health care settings, delayed diagnoses due to poor communication among health care professionals, lack of organization of patient charts, and misplaced scans and test results were several of the

Table 2. Characteristics of Study Participants—Mental Health

	Active ^a Mean (SD)	Bereaved ^a Mean (SD)
SF-12 Scores		
Mental health scale	33.9 (9.8) [50.45] ^b	47.7 (11.5) [50.57] ^c
Physical health scale	57.0 (9.1) [49.71] ^b	49.6 (8.5) [46.55] ^c
CES-D scores	22.1 (12.0) [16] ^d	14.0 (10.4) [16] ^d

^aBased on responses to a self-administered questionnaire sent home with participants: Active $n = 12$, bereaved $n = 13$.

^bNormative scores for the general population aged 45–54 on the SF-12 (higher scores indicate better health-related quality of life, with an average score of 50 and $SD = 10$).

^cNormative scores for the general population aged 55–64 on the SF-12.

^dCutoff score indicative of possible depression for the CES-D: higher scores indicate more depressive symptoms.

problems that were emphasized during the focus groups. One active caregiver reported:

It's very unsettling to understand that the doctor is looking at the report for the first time five minutes before you see him. I know that's how a clinic operates, but that doesn't give me a lot of confidence or trust in it.

Suboptimal performance by one clinician may lead to extended dissatisfaction and mistrust of other medical professionals. This active caregiver described her husband's missed diagnosis and her resulting distrust of subsequent physicians and "the system":

We came in with full trust until we found out that the physician last year forgot to tell him that he had a spot on his lung. Then we changed . . . we are really in a negative mode. I mean we don't trust the doctor. We don't trust anything.

Lengthy stays in hospital waiting rooms prior to appointments and administrative frustrations (e.g., repetitive paperwork) have escalated beyond a mere annoyance to this active caregiver:

The patient's time, it means nothing, and the caregiver's time means nothing. . . . Nine hours for a CAT scan? What are you complaining about, we got it done by one o'clock in the morning? . . . And the message behind that is that your time isn't valuable. And the message behind that is that you're dying and they don't care. Now, they don't feel that way, but that's the message behind it. Your time doesn't matter.

Quality of Life

Many examples arose concerning the physical, emotional, and practical impact of caregiving. These bereaved caregivers stated:

There were points in time where I was so tired I didn't know what I was doing.

I was angry, frustrated, it was a lot going on and I am not sure it was all appropriate, and I'm not sure if I was angry at her or angry at cancer or angry at other people.

I sort of stopped planning at all for the future. . . . Just very difficult to think of the future and anything but the most immediate and vital terms. Everything's a crisis.

Similarly, one active caregiver reported:

I didn't want to eat, I lost weight. But since then, I don't want to do anything, I don't want to exercise. I don't want to—I don't really care about the things I cared about in the past with my own health.

Additional difficulties in balancing home, work, and personal life in addition to caregiving responsibilities were described. This bereaved caregiver reflected on the adjustments she had to make when her husband became too ill to perform his usual duties:

One of the things I experienced was role reversal in a lot of the things he always did . . . particularly drive. When we would come into the city, he always drove. . . . But me driving into the city the

Table 3. *Definitions and Examples of Themes*

Theme	Definition	Exemplar
Medical care		
Provision of information by medical professionals	Statements pertaining to the <i>content</i> of the information provided/not provided by any health care professional	“My private physician told me there are counseling sessions and support groups I can go to.” “And my husband will say to me, ‘Well I know I’m not dying because nobody’s told me I’m terminally ill.’”
Satisfaction with care	General comments relating to the quality of care and technical skill of the HCT	“The care has been real good.” “I trust the doctor’s professional judgment.”
Coordination of care	Statements regarding the administrative and organizational functioning of the health care system, or issues of access, convenience, and proximity to care	“The surgery team was just not communicating at all with the oncologist and the other people involved with the care.” “No one had all of the paperwork in one spot.”
Bedside manner/interpersonal skills	Statements relating to the manner in which medical professionals communicate with both patient and caregiver	“I would’ve liked to have some time or a phone call [from the physician] to myself, just to tell me exactly what was going on.” “People would come into the room, unannounced, and they wouldn’t introduce themselves, we wouldn’t know why they were there.”
Quality of life/burden		
Caregiver well-being	Statements regarding the physical or emotional state of the caregiver	“I can’t sleep . . . I can never sleep.” “Maybe that was anger, washing the floor at 3 am. . . . It might have been putting it into an energy of some sort.”
Caregiver roles	Statements relating to the variety of responsibilities caregivers must take on and balance as part of the caregiving role	“Writing down all the medicine, keeping track of when he’s supposed to take this and that. It can be very confusing.” “When there were multiple teams taking care of different aspects of my wife’s health, I felt like I couldn’t figure out which ones were important, who was in charge, and what I needed to get from home”
Help from others		
Practical assistance	Includes all support—whether by professionals or lay persons—that assist caregivers in the <i>practical, hands-on</i> aspects of caring	“My daughter, she has actually taken over giving the shots.” “It would have been nice to have meals prepared. . . . Have the house cleaned or walk the dog or whatever it is.”
Social support	Statements relating to support received by caregivers from other nonprofessionals to provide emotional relief	“I have four children who are very supportive and a family that’s very supportive” “We have our church. We have other organizations that provide support.”
Positives of caregiving		
Positives of caregiving	These statements reflect what caregivers view as positive aspects that have come out of their caregiving experience	“I wanted to be a positive example for the kids . . . that’s a positive thing that came out of it.” “We’ve definitely grown closer because of the time we’ve spent together.”
Unsolicited themes		
Relationship of the caregiver with the patient	These statements are emotionally focused and relate to interpersonal issues between caregiver and patient	“The sicker they are, the more and more it is that you are together because you can’t stand not to be.” “It impacts her as she sees me getting run down and that upsets her.”
Informational needs (nonprofessional)	Information seeking by caregivers from sources other than the HCT.	“The internet was a very big help.” “Things are really sugarcoated when you read the books.”
Job flexibility	Characteristics of caregivers’ workplace that helps/hinders their ability to care for their patient	“This was before the Family Leave Act. You’re also using up all your vacation time.” “My office and everyone in it was lovely.”
Impact of disease on the family	These statements relate to the ways in which the caregiver perceives the patient’s illness has affected his/her family	“But for my daughters, twenty-two and twenty, both kind of in the busiest part of their lives in college . . . it restricts them.” “He never talks about his mom, so I have to wonder whether there’s a lot more going on in there.”

first few times. . . . I was a wreck. . . . That was a big role reversal to tell him, "Sit back and try to relax because now I am going to drive." I remember that was a big step for us.

Active and bereaved caregivers both reported having little time to themselves and difficulty coordinating their work schedules to ensure proper care for their patients. In addition, the role of protecting their patient's autonomy while at the same time ensuring patient health and safety as health declined proved to be difficult for some. Caregivers also reported having to take on the responsibility of shielding children and other family members from the impact of the patient's illness. One bereaved caregiver with school-aged children stated:

That was a burden for me, making sure that they were emotionally tuned into where they should be, whether they saw their mother enough, when they saw her, were they behaving correctly, that it wasn't a stressful visit. How often do I bring them? How often does she want to see them? What's it like when they're there? . . . The crisis of getting her out of the house in an ambulance a couple of times, when the ambulance is at the front door when the kids come home from school, it's pretty bad.

Help from Others

The notion of negative social support arose as participants described a fine line between well-intentioned interest from friends and family and burdensome attention:

It's a real dilemma. People who care, call. We'll come back from the chemo and there will be calls from friends and family. Well, that's the third time you tell the story. You don't want to do that. . . . They're very well-meaning, but just rehashing it just to rehash it, especially if it isn't great news . . . it really does wear on you.

Unsolicited Themes

Caregivers reported concerns about the impact of their patients' disease on their families, particularly their children:

There was really nothing at all in place at [the hospital] or any place else that we went . . . it wasn't like I was going to take him to chemotherapy . . . it's sort of not a good place for a nine, ten year old child.

Many caregivers also worried about the consequences of revealing their true emotions to their patients:

Sometimes I wonder is this contributing to making her want to give up so that it's easier for me. And I never want her to feel that way. I do think I go out of my way to make her not think that way.

POTENTIAL SOLUTIONS

Caregivers were next asked to describe behaviors that ameliorated problems related to caregiving. Additionally, they reported behaviors or services that they believe would have been helpful had they been available.

Medical Care

Active and bereaved caregivers agreed that better communication between all members of their patient's health care team (HCT), more reliable scheduling and handling of test results, and easier access to specialists and test facilities would have made the caregiving process easier. This active caregiver suggested:

I think time, longer hours, or even Saturdays occasionally would be helpful. And being able to actually get in for these tests before four or five days or before a weekend passes.

Caregivers also suggested several services that they felt would have been useful to them had they been made a part of the standard of care. These active caregivers recommended:

I think an initial appointment with a mental health provider when she was diagnosed. . . . I think they should have turned to me or turned to her and said, "Who is your primary caretaker? Let's get her in here . . . and let's just talk to that person and just assess that person's needs at that time."

You might have available organization skills type of thing, so you help people with the type of thing you need to keep on top of, the schedules and appointments and stuff . . . the insurance forms, the receipts. . . .

The significance of physician competence and technical skill was emphasized as a major component of overall satisfaction, particularly by those still in the active caregiving phase. Knowledge of cutting-edge treatments, awareness of clinical trials and

other treatment protocols in hospitals around the country, and successful pain management were all cited as preferred skills. One active caregiver believed that perceptions of physician competency might impact a patient's outcome:

If you think you've got somebody that's really competent, then you're much more prone to—I think the patient is more prone to respond.

Both active and bereaved participants reported that the interpersonal and communication skills of the HCT were an extremely important component of the provision of care near the end of life. Inclusion of the caregiver by the physician in conversations regarding the patient's medical care was considered to be of special importance. One bereaved participant noted:

I found in my case that [the doctor] was very open and took my phone calls and would talk to me, treated me, even though I wasn't the patient, [like] I was part of the team.

The importance of open, honest, and direct communication from the day of the patient's diagnosis regarding the realities of the caregiving role was also stressed. These bereaved caregivers explain:

You have to be very clear with caregivers about their role and when it's going to happen. I think there's this whole thing about being soft and they can't cope and being gentle with caregivers. I actually, in my opinion, I would have done much better if people had been much more direct with me.

If somebody had just pulled me aside and said, ". . . Here's what's going to happen to you, here's what you're going to go through."

Special efforts made by the caregiver's physician to address the potential physical and emotional consequences that may arise from caregiving were also highly praised by participants. Another bereaved participant stated:

He would turn to me and say, "How are you doing?" . . . He would say, "You're the caregiver. There's a lot on you. You're doing an awful lot. You did a great job," pumping me up and patting me on the back.

The need for effective communication from the HCT was an important factor in sustaining trust and satisfaction with care. Consensus between physi-

cian expectations and treatment goals and patient's/caregiver's concerns was considered vital. As one active caregiver explained:

I think there was a period when I didn't fully understand. . . . That is the only time there was ever a question about trust. I thought they began to lose control over what they were doing. And once I began to understand and became a little more enlightened about what the battle was. . . . I have just nothing but praise for them.

Caregivers reported that the HCT served as their primary source of information, ranging from treatment and disease-related information to community resources and support groups. Many expressed a need to have received more information about the patient's disease course and prognosis:

I would have liked to have known more about the physical process of his disease.

If I knew he wouldn't live a month longer, I would have taken time off.

In addition, bereaved caregivers expressed some ambivalence about the subject of hospice being broached during treatment:

I know it's a double-edged sword, because when you tell somebody that they're going to die, they probably will, but I think that hospice should be brought in much earlier in the process than they are.

Quality of Life

Caregivers reported many behaviors in which they could engage themselves to enhance well-being. Regular exercise, health checkups, and religious activities were all described as helpful. Caregivers described the desire to have more time to themselves, to go for a walk, to rest, or just to grieve privately from their patient. Thinking back, this bereaved caregiver reflected on his emotional state:

I should have gotten that counseling . . . and antidepressants.

Another bereaved caregiver described a need to be reminded of her own needs during the most intense period of her caregiving:

I think if someone had made me talk during that period, made me actually say my own name. . . . I had a hard time starting sentence with "I."

I really felt like, "Don't you want to hear about my husband's cancer?"

The adoption of new roles and responsibilities was also common among caregivers. Participants reported several behaviors that are considered helpful in that they increased their ability to serve as effective caregivers. Patient advocacy was a skill highly touted by both active and bereaved caregivers. Two active participants stated:

I think that the caregiver who's with that person in the hospital is the one . . . to sort of be the one pushing, the person who will push or watch and oversee.

I'm still, every day, finding out more and more things about how to work the system better for my wife.

Record keeping was another skill considered vital by active and bereaved caregivers:

I made up my own phone list. . . . Every time we changed from one protocol to the next, I changed the people on there so we know how to get through to people when we need them.

Unconditional patient support was also reported to be a key component to quality caregiving:

The bottom line is that it's my wife who has the disease. And, as long as she feels good about what she's hearing from her physician and he is laboring and he responds to all the concerns that we have, I guess I can live with it.

Help from Others

Caregivers described the usefulness of family and community support in easing the emotional burden of caregiving. Examples of support included thoughtful letters and messages from friends or church members, and adult children, extended family, and medical staff responding compassionately and being available to listen and provide encouragement in times of need. This caregiver described his satisfaction with attending a support group for his patient, but hesitated at the notion of a group specific to his own needs:

We do go to the cancer support group and it's been wonderful for both my wife and me. I have not joined a caregiver support group. I know at some point I will. I just have other priorities and things that are scheduled. I have other things to do.

Similarly, caregivers detailed the importance of practical assistance with activities related both to caregiving and outside personal responsibilities of the caregiver. Active and bereaved caregivers agreed that assistance with hands-on tasks involved with caregiving (e.g., administration of medications, intravenous fluids, intravenous feeding) was helpful, as were offers of assistance with meals, transportation, and babysitting services for caregivers with young children. This bereaved caregiver described her need for help during the time when her patient's practical care needs were highest:

In retrospect . . . my sister should have been trained, or somebody, to actually watch me for two weeks . . . you need to watch that caregiver and make sure she's getting sleep and actually has her wits about her.

Similarly, this bereaved caregiver recognized that her perspective on her own caregiving needs has changed since her patient passed away:

I didn't think so at the time, but I think respite care and counseling would have helped me a lot.

Positives of Caregiving

This category was devoted strictly to helpful behaviors or emotions that arose as a result of caregiving. Participants described the respect they felt for their patients, showing appreciation for their vulnerability. This bereaved caregiver reflected on the level of closeness it created for her entire family:

It was also very positive for my adult children. They all came home and took care of their father in a way they never, ever thought they would. It was a very beautiful, wonderful experience for them and for me to see this happening.

Unsolicited Themes

In this category the interpersonal dynamics of the patient-caregiver relationship were often described, including the process of working through emotions as the patient neared the end of life:

I was telling my wife that the hospice people are here, but I have all this hope and I want to convey this hope to my wife [so I told her] that I told the hospice people that [she's] sicker than [she is]. I kind of exaggerated to my wife, thinking that she needed to have that hope, and she didn't. She let me know that she didn't need it. . . . She brought

me along in that way. That was just a prime example how she brought me along.

DISCUSSION

Results from this study enrich existing quantitative data generated from large studies of caregiver needs (Hileman et al., 1992; Covinsky et al., 1994; Silveira & Winstead-Fry, 1997; Emanuel et al., 1999, 2000; Anderson et al., 2000). The language used by these caregivers gives a voice to existing data and can be used by clinicians involved in the delivery of palliative care to enhance their understanding of caregiver burden and illuminate possible solutions to these problems.

Caregivers in this study reported a need for more information about patient prognosis, hospice, and challenges accompanying the caregiving role. These data support the conclusion drawn in a recent report outlining a need for improvements in palliative care for cancer (Kesselheim, 2001), stating that patients and caregivers are often undereducated on the medical and psychosocial realities of the end-of-life period, and that even when they are educated, they may misunderstand the information (Smith & Swisher, 1998). Further evidence reveals that patients and families are unlikely to initiate discussions about death and dying themselves (Pfeifer et al., 1994); yet, until such discussions occur, patients and caregivers cannot prepare for the end-of-life period or gain any control over the patient's plans for dying (Abraham, 2003). Bereaved caregivers emphasized the importance of physician bedside manner, communication, and trust, echoing the results of a recent study of the preferences of bereaved family members for patients at the time of death (Steinhauser et al., 2000). Clearly, palliative care clinicians are in an important position to help educate caregivers and to assist them in facing the uncomfortable realities that occur near the end of life.

Our results also suggested that caregivers may benefit when physicians are attentive to quality-of-life issues such as depression and anxiety, physical health, and role strain. Caregiver scores on the SF-12 mental health subscale and the CES-D certainly suggest a population for whom trials of interventions would be important. Although the role of the palliative care team in the provision and coordination of services to alleviate burden has not been extensively studied in the United States, our data suggest that if clinicians can provide help in tangible ways by, for example, assisting caregivers in their advocacy role or by improving access to services and reducing barriers to treatment and disease education, they may reduce caregiver bur-

den by reducing the need for caregivers to "work the system." Similarly, opportunities exist for clinicians to offer practical advice regarding how to keep track of medications and results and assist in care coordination near the end of life. Finally, our data raise the question of the importance of regular monitoring of caregiver psychological health with the goal of attending to issues of depression and anxiety. A recent study reported that caregivers who report that physicians listened to their opinions about the patient's illness were significantly less likely to be depressed than those whose physicians did not listen (Emanuel et al., 2000). It will be important to investigate further the ways in which clinicians may assist caregivers in maintaining their well-being, perhaps through improved clinician-caregiver communication or through assisting with the establishment of approaches to the provision of medical, social, and practical support.

Our respondents suggested that trust in physicians may be damaged when there is a lack of effective communication and full disclosure regarding the patient's health. Despite the emphasis on the importance of physicians' technical skill as a component of trust, frustrations about communication and lack of attentiveness can have a negative impact on patients' and caregivers' sense of trust. Although some studies have evaluated the complexities of trust in physicians, satisfaction with medical care, and their relationship to patient and caregiver outcomes (Safran et al., 1998, 2001), this area remains an important one for future exploration, particularly during the time when a patient's physical health is declining.

The complexity and diversity of caregiver needs and preferences was demonstrated in this study. The caregivers in this study revealed many conflicting preferences. For example, while some commented that the availability of respite care would be useful, others reported that they were not comfortable allowing others to help care for their patient. Additionally, some caregivers believed that physicians should have addressed the issue of hospice earlier in the process, yet others were concerned that such discussions would have prompted patients to "give up too soon." Some caregivers believed that other caregivers could benefit from support groups or individual counseling, yet commented that such would not be useful for themselves. Still other caregivers reported not wanting such interventions at all. It was not uncommon for bereaved caregivers to reflect that, in hindsight, support and/or other interventions may have been helpful. Indeed some reported that they had refused support interventions offered by clinicians yet later reflected that they wished they had con-

sidered such recommendations. These contradictions illustrate the complexity of cultural, personal, and societal factors that must be considered when caring for caregivers, and may provide some insights into the mixed effectiveness of a limited number of interventions targeted toward caregivers to date (Pasacreta & McCorkle, 2000; Thompson & Briggs, 2000; Given et al., 2001; McCorkle & Pasacreta, 2001). The inconsistencies and variability in preferences for interventions also illustrate the significance of communication between clinicians and patients/caregivers, as well as the importance of communication between the primary oncology team and other specialists to ensure that caregivers and patients receive an individualized plan of care that is responsive to their needs over time.

The sample represented in this study is unique in several ways. First, they are younger on average than most samples found in other caregiving studies. Additionally, male and female caregivers were represented almost equally, whereas women are often overrepresented in other studies. Despite being a highly educated population with significant financial resources that may have served to increase access to care, this sample nevertheless encountered significant problems. Although the population of active caregivers scored in the normal range for physical health on the SF-12, their scores for mental health were somewhat lower compared to population norms. Similarly, scores were slightly elevated on the CES-D. These data serve both to describe this population and to provide data upon which outcomes could be established for the assessment of caregiver interventions. This study is also unique in its inclusion of both active and bereaved caregivers to evaluate potential differences in insights into the end-of-life period. While there was a trend for bereaved caregivers to be more apt to discuss *positives of caregiving* and affirmative comments in the category of *relationship of caregiver with patient*, overall, stated priorities for care were similar between active and bereaved groups.

This study was limited by a small sample size and sample selection bias resulting from the possibility of a lower referral rate of caregivers of patients with more complicated cases. Further, the demographic homogeneity of the sample and the low response rate (approximately 50%) limit the generalizability of these findings. In spite of these limitations, the present study has added depth to the caregiving literature by identifying potential solutions to caregivers' unmet needs through qualitative analyses. Additionally, while the specific needs and recommendations of caregivers may depend upon the nature of the care recipient's illness or disability, the diverse responsibilities of cancer pa-

tient caregivers (Given et al., 2001) make them an excellent group from which to draw recommendations. Caregivers of patients with diseases other than cancer have reported similar needs for information and support (Ward & Cavanagh, 1997; Zwygart-Stauffacher et al., 2000; Cohen et al., 2001), along with a like set of goals addressing support and educational needs, coping strategies, and practical caregiving skills (Parks & Novielli, 2000; Siliman, 2000).

In pursuit of the goal to improve end-of-life care, it is important for clinicians to develop interventions that attend to both the personal needs of informal caregivers and to their needs in relation to their efforts to ensure that those they care for are well supported. Recently in the United States, the Council on Scientific Affairs of the American Medical Association recommended a model of care that urges physicians to validate the difficulty and significance of the caregiving role (Council on Scientific Affairs, 1993) and that considers the caregiver as a partner with the physician in the patient's care (Council on Scientific Affairs, 1993; McWhinney, 1997). Such validation may provide a buffer against stress and burden (Zarit et al., 1980; Council on Scientific Affairs, 1993), thereby increasing the caregiver's quality of life and potentially enabling them to better serve their patients. The detailed accounts provided by the caregivers in this study can serve to illuminate the development of interventions designed to meet caregiver needs and improve the overall quality of palliative and end-of-life care.

ACKNOWLEDGMENTS

This research was supported by the National Institute of Nursing Research, #1R21 NR05225.

An abstract of this paper was presented at the annual meeting of the Society of Behavioral Medicine, April 2002. This abstract was published in the *Annals of Behavioral Medicine* 2002; 24 (supplement): S169.

REFERENCES

- Abraham, J.L. (2003). Update in palliative medicine and end-of-life care. *Annual Review in Medicine*, 54, 53–72.
- Anderson, R.T., Bradham, D.D., Jackson, S., et al. (2000). Caregivers' unmet needs for support in caring for functionally impaired elderly persons: A community sample. *Journal of Health Care for the Poor and Underserved*, 11, 412–429.
- Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs*, 18(12), 182–188.
- Castonguay, L.G., Goldfried, M.R., Wiser, S., et al. (1996). Predicting the effect of cognitive therapy for depression: A study of unique and common factors. *Journal of Consulting and Clinical Psychology*, 64, 497–504.

- Cohen, C.A., Pringle, D., & LeDuc, L. (2001). Dementia caregiving: The role of the primary care physician. *Canadian Journal of Neurological Science, 1*, S72–S76.
- Cohen, D., Luchins, D., Eisdorfer, C., et al. (1990). Caring for relatives with Alzheimer's disease: The mental health risks to spouses, adult children, and other family caregivers. *Behavior, Health and Aging, 1*, 171–182.
- Council on Scientific Affairs, American Medical Association (1993). Physicians and family caregivers. A model for partnership. *Journal of the American Medical Association, 269*, 1282–1284.
- Covinsky, K.E., Goldman, L., Cook, F., et al. for the SUPPORT investigators (1994). The impact of serious illness on patients' families. *Journal of the American Medical Association, 272*, 1839–1844.
- Dean, M. (1995). A law that would care for the carers. *Lancet, 345*, 1101.
- Edwards, B.K., Howe, H.L., Ries, L.A.G., et al. (2002). Annual report to the nation on the status of cancer, 1973–1999, featuring implications of age and aging on U.S. cancer burden. *Cancer, 94*, 2766–2792.
- Elder, N.C. & Miller, W.L. (1995). Reading and evaluating qualitative research studies. *Journal of Family Practice, 41*, 279–285.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., et al. (1999). Assistance from family members, friends, paid care givers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine, 23*, 341(13), 956–963.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., et al. (2000). Understanding economic and other burdens of terminal illness: The experience of patients and their caregivers. *Annals of Internal Medicine, 21*, 132(6), 451–459.
- Field, M.J., Cassel, C.K., & Institute of Medicine, Committee on Care at the End of Life. (1997). *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press.
- Gallagher, D.R., Rivera, P., Lovett, S., et al. (1989). Prevalence of depression in family caregivers. *Gerontologist, 29*, 449–456.
- Given, B.A., Given, C.Q., & Kozachik, S. (2001). Family support in advanced cancer. *CA: Cancer Journal for Clinicians, 51*, 213–231.
- Glaser, B., & Strauss, A.L. (1967). *The Discovery of Grounded Theory*. Hawthorne, NY: Aldine de Gruyter.
- Glaser, B.G. (1978). *Theoretical Sensitivity: Advances in the Methodology of Grounded Theory*. Mills Valley, CA: The Sociology Press.
- Goldfried, M.R., Raue, P.J., & Castonguay, L.G. (1998). The therapeutic focus in significant sessions of master therapists: A comparison of cognitive-behavioral and psychodynamic-interpersonal interventions. *Journal of Consulting and Clinical Psychology, 66*, 803–810.
- Hileman, J.W., Lackey, N.R., & Hassanein, R.S. (1992). Identifying the needs of home caregivers of patients with cancer. *Oncology Nursing Forum, 19*, 771–777.
- Kesselheim, A.S. (2001). The current state of patient and family information about end of life care. In *Improving Palliative Care for Cancer*, Foley, K.M. & Gelband, H. (eds.), pp. 132–152. Washington, DC: Institute of Medicine and National Research Council.
- Kiecolt-Glaser, J., Glaser, R., Shuttleworth, E., et al. (1987). Chronic stress and immunity in family caregivers of Alzheimer's disease victims. *Psychosomatic Medicine, 49*, 523–535.
- Krippendorff, K. (1980). *Content Analysis: An Introduction to Its Methodology*. Beverly Hills, CA: Sage Publications.
- McCorkle, R. & Pasacreata, J.V. (2001). Enhancing caregiver outcomes in palliative care. *Cancer Control, 8*, 36–45.
- McWhinney, I.R. (1997). *A Textbook of Family Medicine*. New York: Oxford University Press.
- Metlife Mature Market Institute. (1999). *The Metlife Juggling Act Study: Balancing Caregiving with Work and the Costs Involved*. New York: Metropolitan Life Insurance Company.
- Mor, V., Allen, S.M., Siegel, K., et al. (1992). Determinants of need and unmet need among cancer patients residing at home. *Health Services Research, 27*, 337–360.
- National Institute on Aging. (2000). Progress report on Alzheimer's disease: Taking the next steps. NIH Publication No. 00-4850. Washington, DC: NIA, NIH, U.S. Department of Health and Human Services.
- Parks, S.M. & Novielli, K.D. (2000). A practical guide to caring for caregivers. *American Family Physician, 62*, 2613–2622.
- Pasacreata, J.V. & McCorkle, R. (2000). Cancer care: Impact of interventions on caregiver outcomes. *Annual Review of Nursing Research, 18*, 127–148.
- Pfeifer, M.P., Sidorov, J.E., Smith, A.C., et al. (1994). The discussion of end of life medical care by primary care patients and physicians: A multicenter study using structured qualitative interviews. *Journal of General Internal Medicine, 9*, 82–88.
- Pruchno, R.A., Kleban, M.H., Michaels, J.E., et al. (1990). Mental and physical health of caregiving spouses: Development of a causal model. *Journal of Gerontological Psychological Sciences, 45*, 192–199.
- Radloff, S.F. (1977). The CES-D Scale: A self-report depression scale for research in the general population. *Applied Psychological Measurement, 1*, 385–401.
- Ries, L.A.G., Wingo, P.A., Miller, D.S., et al. (2000). The annual report to the nation on the status of cancer, 1973–1997, with a special section on colorectal cancer. *Cancer, 88*, 2398–2424.
- Safran, D.G., Montgomery, J.E., Chang, H., et al. (2001). Switching doctors: Predictors of voluntary disenrollment from a primary physician's practice. *Journal of Family Practice, 50*, 130–136.
- Safran, D.G., Taira, D.A., Rogers, W.H., et al. (1998). Linking primary care performance to outcomes of care. *Journal of Family Practice, 47*, 213–220.
- Schulz, R. & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *Journal of the American Medical Association, 282*, 2215–2219.
- Schulz, R., Visintainer, P., & Williamson, G.M. (1990). Psychiatric and physical morbidity effects of caregiving. *Journal of Gerontology, 45*, P181–P191.
- Silliman, R.A. (2000). Caregiving issues in the geriatric medical encounter. *Clinical Geriatric Medicine, 16*, 51–60.
- Silviera, J.M. & Winstead-Fry, P. (1997). The needs of patients with cancer and their caregivers in rural areas. *Oncology Nursing Forum, 24*, 71–76.
- Smith, T.J. & Swisher, K. (1998). Telling the truth about terminal cancer. *Journal of the American Medical Association, 279*, 1746–1748.
- Soothill, K., Morris, S.M., Harman, J.C., et al. (2001). Informal carers of cancer patients: What are their unmet social needs? *Health and Social Care in the Community, 9*, 464–475.

- Steinhauser, K.E., Clipp, E.C., McNeilly, M., et al. (2000). In search of a good death: Observations of patients, families, and providers. *Annals of Internal Medicine*, 132, 825–832.
- Stewart, D.W. & Shamdasani, P.N. (1990). *Focus Groups, Theory and Practice*. Newbury Park, CA: Sage Publications.
- Stone, R., Cafferata, G.L., & Sangl, J. (1987). Caregivers of the frail elderly: A national profile. *Gerontologist*, 27, 616–626.
- Strauss, A.L. & Corbin, J. (1990). *Basics of Qualitative Research: Grounded Theory Procedures and Techniques*. Newbury Park, CA: Sage Publications.
- Thompson, C. & Briggs, M. (2000). Support for carers of people with Alzheimer's type dementia. Cochrane Database of Systematic Reviews, CD000454. <http://www.Cochrane.org>
- U.S. Bureau of the Census (1999). *Statistical Abstract of the United States: 1999*. Washington, DC: U.S. Bureau of the Census.
- U.S. Department of Health and Human Services (1998). Informal caregiving: Compassion in action. Based on data from the National Survey of Families and Households (NSFH). Washington, DC: Department of Health and Human Services.
- Ward, H. & Cavanagh, J. (1997). A descriptive study of the self-perceived needs of carers for dependents with a range of long-term problems. *Journal of Public Health and Medicine*, 19, 281–287.
- Ware, J., Jr., Kosinski, M., & Keller, S.D. (1996). A 12-item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care*, 34, 220–233.
- Ware, J.E., Kosinski, M., & Keller, S.D. (1998). *SF-12: How to score the SF-12 Physical and Mental Health Summary Scales*, 3rd ed. Lincoln, RI: Quality Metric Inc.
- Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly: Correlates of feelings of burden. *Gerontologist*, 20, 649–655.
- Zwygart-Stauffacher, M., Lindquist, R., & Savik, K. (2000). Development of health care delivery systems that are sensitive to the needs of stroke survivors and their caregivers. *Nursing Administration Quarterly*, 24, 33–42.