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Individual Telephone Support For Family Caregivers of Seriously Ill Cancer Patients

Medical-surgical nurses are an important source of information and guidance for family caregivers during health care crises. The concerns expressed by family caregivers to nurse interventionists during a supportive and informational telephone intervention are described in this study. An analysis of telephone call content using constant comparison methods identified major stressors of the family caregiver during the illness trajectory.

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Cancer continues as the second leading cause of death in the United States with over 500,000 deaths per year (Minino & Smith, 2001). Seventy-five percent of families in the United States have at least one family member diagnosed with cancer (American Cancer Society, 2001). As the delivery of cancer care has shifted from inpatient to outpatient treatment, the 24-hour care of patients with cancer has become the responsibility of family members (Carter, Nezay, Wenzel, & Foret, 1998; Miaskowski, Kragness, Dibble, & Wallhagen, 1997; Rose, 1999). When a patient's condition deteriorates, family caregivers become a vital source of support (Schott-Baer, Fisher, & Gregory, 1995; Weitzner, McMillan, & Jacobsen, 1999). As a result, 20% to 30% of family caregivers suffer from psychological and mood disturbances (Blanchard, Albrecht, & Ruckdeschel, 1997). Usual roles and responsibilities are often shifted, adding further distress and decreasing caregiver quality of life (Steeves, 1996; Weitzner et al., 1999).

Because of the importance of the caregiver role, family caregiver health has become a major concern (Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). Caregivers neglect their own health to mobilize resources for the patient and may experience as much distress as the patient (Ferrell, 1998; Higginson & Priest, 1996; Rubert, Walsh, & Estrada, 2001, 2004). As the patient's condition deteriorates, caregiver stress heightens, anxiety increases, depression is prevalent, and quality of life is impaired (King et al., 1997).

During the past decade, investigators placed more emphasis in research on family caregivers (Blanchard et al., 1997; Given, Given, Stommel, & Azzouz, 1999; McGrath, 2001; McMillan & Mahon, 1994). Concern for family welfare was heightened when the 8-year multi-site hallmark investigation, "Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment" (SUPPORT), revealed deficits in communication among members of the health care team, lack of knowledge about family needs, and lack of successful interventions with family care-

Note: This investigation was one arm of a larger study that was funded by the National Institute of Nursing Research, M. Rubert, Principal Investigator (NR 050162-01, 1999-2002).

givers (Charlton & Ford, 1995; Hardwig, 1995; SUPPORT, 1998). SUPPORT researchers concluded that additional interventions for family caregivers in particular were needed (Given et al., 1999; Koazchik et al., 2001; McMillan, 1996; Weitzner et al., 1999).

The use of the telephone for health interventions has gained acceptance as a method to reach a number of vulnerable groups. These groups include cocaine-using pregnant women (Alemi, Stephens, Javalghi et al., 1996), community health patients (Alemi, Stephens, Muise et al., 1996), underserved cancer patients (Colon, 1996), caregivers of patients with Alzheimer's (Goodman & Pynoos, 1988), patients receiving radiation therapy (Hagopian & Rubenstein, 1990), depressed patients (Hunkeler et al., 2000), bereaved family members (Kaunone, Aaloto, Tarkka, & Paunonen, 2000), and hemophilia and HIV/AIDS patients and their family caregivers (Stewart et al., 2001). However, the use of the telephone to assist caregivers of seriously ill cancer patients was not found in a search of nursing literature.

The present qualitative study was completed by nurse interventionists who conducted individual telephone calls to family caregivers of seriously ill cancer patients. The telephone intervention, called the Individual Support Condition (ISC), was one arm of a larger "Tele-Care" quantitative study (Rubert et al., 2001; Rubert, 1999). The purpose of the current qualitative study was to describe and explore major sources of concern for family caregivers as they care for seriously ill family members.

Theoretical Framework

The theoretical framework for the study was Hogan's "Grief to Personal Growth" Experiential Theory of Bereavement (Hogan, Morse, & Tasón, 1996). Knowledge of this theory was used to assist interventionists as they interacted and processed interactions with family caregivers. The End-of-Life Phase describes the processes experienced by the family during the course of a patient's illness and up until the time of death

Table 1.
End-of-Life Phase of the Experiential Theory

1.	Getting the News – Getting the Diagnosis
	a. Shock
	b. Calculating the odds
2.	Dedicating Resources
	a. Family being there for the patient
	b. Accommodating care
3.	Negotiating Treatment
	a. Fighting for life
	b. Enduring stress
	c. Shutting it out
	d. Maintaining hope
4.	Losing the Battle
	a. Seeing the obvious
	b. Ending the suffering
5.	Death Occurs

From Hogan, Morse, & Tasón (1996).

(Hogan et al., 1996) (see Table 1). This phase of the theory was particularly helpful to interventionists when family caregivers reported that the patient's illness had become more serious.

Methods

The *caregiver* was defined as someone who had close ties to the patient and was expected to provide care to the patient in some way. Caregivers were recruited from local hospitals and a large regional cancer center when they accompanied the patient to outpatient treatment or were present during inpatient hospitalization. Inclusion and exclusion criteria were designed to recruit a broad range of English-speaking and Spanish-speaking caregivers age 45 and over. Age range was limited because of the nature of the group intervention and issues that were anticipated as a result of previous investigations with caregiver groups (Loewenstein, Rubert, Arguelles, & Duara, 1995).

The ISC protocol was approved by the University of Miami Institutional Review Board. Written informed consent was obtained from caregivers who met the following inclusion criteria: the participant identified self as the primary

caregiver for the patient, could speak and read English or Spanish, had a telephone, had no major hearing deficits, was not involved in another caregiver study, was age 45 and over, and agreed to participate in the project. Caregivers in this report were those that were randomized into the ISC arm of the study. These caregivers had previously agreed to the randomization procedure at the time of consent. After randomization, ISC participants were contacted by interventionists who reviewed the purpose of the study and answered questions (for example, implications of random assignment, roles of interventionists, duration and nature of intervention, study benefits, and risks) to reduce attrition (Phillips et al., 1995).

The Individual Support Condition Intervention

The goal of the ISC was to enhance the caregiver's ability to cope with the stressors resulting from the patient's illness. It was anticipated that caregivers would be receptive to the ISC because of (a) previous reports in the literature of the success of telephone interventions with other vulnerable populations, (b) caregiver vulnerability during stressful times, (c) caregiver lack of knowledge about how to address concerns with both the patient and health care professionals, and (d) caregiver motivation and availability as the best advocate for the patient.

The ISC consisted of one 20-minute telephone call to a family caregiver every other week for 10 weeks, for a total of five calls. The protocol allowed the supportive phone call to last up to 20 minutes. A typical call in this study lasted from 15 to 18 minutes. The ISC call was made by a nurse interventionist (one of two authors) who was able to provide the caregiver with emotional support, information, and assistance with problem solving. The process that evolved over time consisted of the following steps during each telephone call.

1. Introduction and inquiry about caregiver's well-being. "How are you?"

2. Asking about the status of the care recipient and inquiring if the caregiver had any specific concerns or problems.

If the caregiver responded "yes" to these queries, he or she was referred to various resources and/or community agencies based on the nature of the concern. During this conversation, the research team checked the status of the patient and continually reminded the caregiver to notify the researchers regarding any change in the status of the patient (such as hospitalization, death).

3. The interventionist followed with broad questions to seek information about what was going on in the family and to offer and identify other possible sources of support for the caregiver.
4. After 15 minutes, if the caregiver had not closed the conversation, the interventionist reminded the caregiver of the time remaining and asked if there were other concerns to speak about in the last 5 minutes.
5. The date and time of the next call were confirmed.

Throughout the phone call, the interventionist focused on the family caregivers and offered information and support. These conversations between the family caregivers and interventionist provided a specific time for caregivers to address how they were coping with their particular situation. Field notes by the interventionists documented both the content and process of each call.

Data Analysis

Data obtained during the individual calls were analyzed to identify specific categories present throughout conversations with all caregivers. To identify categories initially, the interventionists separately read and compared field notes from each interview. Key phrases were coded and codes were sorted. Throughout this process of data collection and analysis, memos were written as the analysts became sensitized to the emerging findings. Data were collected approximately every 2 weeks (5 calls over a period of 10

weeks), and categories that appeared repeatedly during each phone call were noted. Data recorded from each phone call were constantly compared to data from other phone calls (for example, notes from a second phone call to a participant were compared to the second phone call to other participants). To verify the frequency of initial codes and the categories that were developed from the codes, frequency tables were constructed to reflect each time a category was mentioned and were used to verify the degree of saturation of the major categories.

Analysts used first-level coding to define properties of each category. Categories were explicated by comments from participants. Memos recorded in interventionists' field notes were further validated by the frequencies of similar comments or concerns. Examples of caregiver responses were used to substantiate each category further. As data were studied, each category became more descriptive. Definitions of each category contained exact words from the caregivers. Following individual and group analysis of calls, categories were collapsed to the most parsimonious findings. Analysts compared individual codings. Consensus between the two interventionists was reached on the final set of categories. The final inter-rater check of the analysis was completed by the third author, who reviewed raw data and the analysis, and confirmed the findings.

Results

Forty-two out of 50 caregiver participants (84%) in the ISC completed five phone calls over a period of 10 weeks. Of the 42 caregivers who completed the intervention, 31 were English-speaking and 11 were Spanish-speaking. Of the eight caregivers who did not complete the intervention, five dropped the study for personal reasons. Three dropped or could not be reached when the patient died unexpectedly. Field notes from 210 phone conversations (42 caregivers at 5 calls each) were analyzed. Caregivers who com-

pleted the study were Caucasian-English speaking (67%), African-American-English speaking (7%), or Hispanic-Spanish speaking (26%). All caregivers were 45 years or older and were predominantly spouses of the patient (85%). Three caregivers (7%) identified themselves as significant others of the patient (were not married but had lived with the patient for several years). Two caregivers (4%) were daughters caring for a parent, and one caregiver was caring for her sister-in-law (2%). Of the caregivers, 29 were women (69%) and 13 were men (31%).

Participants who completed the intervention verbalized common concerns, feelings, and situations in their experience as caregivers of a loved one with cancer. Five categories were derived from these data. These categories (*in italics*) are described below with verbatim examples following each category. Brief descriptions of each category with subcategories are displayed in Table 2. The five categories were: (a) *Bearing the Burden*, (b) *Distressing Feelings*, (c) *Learning to Cope*, (d) *Conditional Well-Being*, and (e) *Feeling Abandoned by Others*.

Bearing the Burden

Throughout the ISC intervention, many participants expressed feeling frustrated, trapped, and exhausted, and wanting to escape from their situation. This overwhelming sense of burden emerged within all categories. Caregivers felt they had no choice but to bear the burden of this situation. In spite of the desire to help the patient, some caregivers seemed to struggle with resentment that came from feeling that they had no time to dedicate to themselves and their needs. These caregivers described what they had sacrificed or given up in order to provide the care and attention they believed their loved ones needed.

- I gave up my job to take care of my spouse.
- You have to be by the side of the person constantly.
- He likes to manipulate me and wants me to be at his side at all times, but I have to live also.

Table 2.
Summary of Caregiver Burdens During the ISC Telephone Intervention

Categories	Description
Bearing the Burden	Caregivers described what they had sacrificed or given up in order to provide the care and attention they believed their loved ones needed.
Distressing Feelings Depression Resentment Helplessness Worry	These feelings revealed a prevailing sense of sadness, suffering, and uncertainty regarding the future. The expressions describing these thoughts and feelings fell into four subcategories.
Coping with Uncertainty Seeking support Making cognitive decisions Engaging in activities that would help them feel better Deception	Although many felt overwhelmed, these caregivers related a need to keep on going, to maintain hope, and plan for the future. They are making the best of it by using a variety of coping strategies (subcategories).
Conditional Well-Being	Caregivers described being at ease when their loved ones were well but at the same time, there was a fragile quality to the state of their well-being based on the ever-changing condition of the loved ones' health.
Feeling Abandoned by Others	Caregivers reported a sense of isolation that was associated with thoughts and feelings of being abandoned by those they expected would be providing support, help, and information at this critical time in their lives.

- I am so sick of it all. I finally left and took a walk. He was mad at me for talking to you (the researcher).
- I have no time for myself. I have a problem on my skin and I've had skin cancer in the past, but I just don't know when I can get to the doctor.
- I am so run down. I'm too old for this. My wife [the patient] was supposed to be caring for me [the husband].

Distressing Feelings

During the telephone conversations, the caregivers reported numerous distressing feelings that revealed a prevailing sense of sadness, suffering, and uncertainty regarding the future. These feelings fell into four subcategories: (a) depression, (b) resentment, (c) helplessness, and (d) worry.

Depression. Several participants expressed varying degrees of sadness and hopelessness that permeated their experience as caregivers. They described an attempt to gain some control over the feelings of depression, which in some cases led to difficulty in doing essential tasks.

- You keep things in your mind...they explode and you get depressed.
- I'm so depressed that I can't even drive.
- I stay busy but on some days the black mood catches up with me.
- I am worried, sad, and depressed.
- We both are pretty sad and depressed, but we don't talk about it.

Resentment. Feelings of resentment were manifested as anger and bitterness toward the role the caregivers had been forced to adopt. They never planned or expected to be in the role of caregiver. Suddenly, they were faced with new responsibilities and did not feel prepared.

- I have no time for me.
- Why is this happening to me? I thought she would be taking care of me now (this caregiver was 20 years older than his wife).
- He (the patient) has never been able to take charge; that's my role, and now it's worse.
- I have so much anger.

Helplessness. Participants expressed feeling helpless in a situation in which they had no control. They spoke about not having the strength to go on, and how nothing or no one was able to help and improve their situation. Particularly common were feelings of helplessness when a loved one was experiencing pain that could not be controlled by medication and when he/she had to wait for test results that could indicate progression of the disease.

- I feel helpless when he's in pain.
- Nothing seems to help.
- We swing like monkeys. No one keeps track and we do not know where we are going.
- We wait and wait and the results of the CT scan are still not available.
- All of this is too much for me to handle. Everything is going wrong and nothing is helping.
- Everything has a solution except death.

Worry. Caregivers revealed they were constantly worrying, experiencing a sense of uncertainty and fear about the present and the future. Whether it was related

to the symptoms produced by cancer, the effectiveness of treatment, the medications and their side effects, diagnostic tests, or a search for alternative approaches to treatment, there seemed to be a constant element of unpredictability about the loved one's condition. In addition, caring for a loved one with cancer had emotional and financial repercussions for caregivers. Worry was expressed in conversations as a feeling that is always there, an anticipation of the threat of what will happen next.

- I'm here, always worrying.
- I worry when she is not OK.
- We are continuing our lives but we are worried.

Coping with Uncertainty

Even though the caregivers were experiencing different degrees of distressing feelings, they were coping or trying to cope with their particular situation. Although many felt overwhelmed, these caregivers related a need to keep on going, to maintain hope, and plan for the future. Four types of mechanisms to cope with uncertainty emerged from the data.

Seeking support from others.

Caregivers described how family, friends, and others were helpful in providing relief, support, and information. They indicated they did not know how they would manage without these people in their life.

- It helps me to be with others (talking about a church group she goes to).
- My daughters are the shoulders I cry on.
- My 5-year-old granddaughter brings me joy.

Making cognitive decisions. In identifying how they were able to cope, other caregivers described a type of cognitive decision that had been made to gain some control over their situation. They were not demonstrating helplessness, but instead had decided on a method that would help them deal with the circumstances at hand.

- I just move forward without looking back.
- I leave things in God's hands, so He does what He thinks is best.

- We don't talk about how sick he is but he knows he is not getting any better. I'm going to insist that the doctor refer us to hospice.

Engaging in activities that would help them feel better. Some participants explained how they were able to face the difficulties that resulted from caring for a loved one with cancer by acting upon the problem, engaging in something that helped them and, at times their loved ones, to feel better. They planned distractions that could help to keep them busy. Some were creative solutions and others were activities that the caregiver could do alone or together with the patient.

- I am working all the time and she understands; that's how I've always coped.
- I can't stand to be in the room with him and watch TV because of his labored breathing, his constant fidgeting, his restlessness; so we watch the same program in different rooms and talk about the program with walkie-talkies.
- We are going to start going to Weight Watchers, as we are both gaining weight.

Deception. Two caregivers were faced with situations that led them to use deception to solve a problem. For them, coping with the situation meant that the caregiver decided to deceive the care recipient when nothing else would apparently solve the situation. They did not express regret at using deception as a means of making things better for their loved ones.

- My mother wished to get married by a priest to my stepfather before she died. The Catholic Church has never recognized their marriage because he was divorced and Jewish. They have been married for 30 years. We arranged for a "defrocked" priest who is openly gay to perform the wedding and she looked so beautiful and happy. Of course, she's in heaven now and knows we tricked her.
- My counselor is mad with me because I'm giving him (the patient) his antidepressant via

his tube feeding and he (the patient) doesn't know it. He was refusing to take the antidepressant by mouth but he's not depressed anymore and I just decided not to tell him. I feel it is the right thing to do and he is not able to make decisions now anyway.

Conditional Well-Being

Caregivers expressed a fragile sense of hope and well-being that was conditional on the well-being of their loved ones. If the patient was doing well, the caregiver reported to be doing well. This conditional well-being could fluctuate at any time and any change in the condition of the loved one could tip the balance. Caregivers described being at ease when their loved ones were well, but at the same time, there was a fragile quality to the state of their well-being that led them to feel like yoyos.

- I feel better when he's (the patient) better.
- While he's alive (the patient) there is hope.
- I see him (the patient) happier, so I'm happier.
- I have my moments; this is very hard to deal with. I feel like a yo-yo, up and down all the time. I am very much dependent on how she (the patient) is doing.

Feeling Abandoned by Others

Some caregivers reported a sense of isolation due to thoughts and feelings of being abandoned by those whom they expected would be providing support, help, and information at this critical time in their life.

- I have to do everything, nobody else will do anything.
- The system has failed me; it is blatant abandonment.
- God has abandoned me.
- When he really got sick, no one would help. When nothing is working, the health system fails you.

Discussion

The high rate of completion (84%) was an indication that the caregivers may have found the ISC helpful. It also supported the

effectiveness of the manner in which the participants were prepared by the research staff to participate in the study. The low attrition rate (16%) also provided support for the recruitment and consent procedures. During these recruitment procedures, the role expectations as a participant were explained to provide very clear understanding of what the participants would experience during the course of the study. Many of the caregivers expressed relief that they had been randomized into the individual condition, saying they preferred to discuss their concerns in a one-to-one format with an interventionist rather than in a group. The ISC placement may have also been a factor in the high rate of completion in this arm of the study.

Interventionists used the End-of-Life Phase of the Experiential Theory as an overriding framework to guide caregiver interactions. In conversations with caregivers during the 10-week period of the ISC phone calls, several unique subcategories emerged. A category from this study, "Bearing the Burden," consisted of participants indicating that they had sacrificed themselves to the care of the patient and felt resentful. Authors noted that a similar category, "Dedicated Resources" in the End-of-Life Model, indicated that caregivers did all in their power to dedicate themselves to the ill family member without mentioning sacrifice or resentment. Two other categories in the End-of-Life Model, "Negotiating Treatment" and "Losing the Battle" process, were congruent with data from the current study. Caregivers usually entered the study at a point when the patient was undergoing surgery, chemotherapy, or radiation. Prior to entering the study, caregivers and patients had already experienced the "Getting the News – Getting the Diagnosis" and "Dedicating Resources" processes found in the End-of-Life Phase. Therefore, it was not surprising that the categories during the ISC intervention reflect the times the patient and family caregiver were "Fighting for Life", "Enduring Stress," "Shutting

It Out," and "Maintaining Hope" (parts of the third "Negotiating Treatment" process) or were "Seeing the Obvious" and "Ending the Suffering" (parts of the fourth "Losing the Battle" process). As the phone calls progressed and as the patient became more seriously ill, caregiver comments continued to confirm the End-of-Life Phase of the Experiential Theory.

After the initial phone call, interventionists agreed that caregivers were enthusiastic and looked forward to receiving future phone calls. Caregivers often gave the interventionists phone numbers if they were going to be out of town so that the interventionists could reach them at the new location during the next scheduled call. It seemed that caregivers felt supported and reassured when they knew that there was at least one interested person (the interventionist) who would inquire frequently about their situation and could be reached for assistance. Occasionally caregivers called the interventionists if their situation changed (for example, the patient was hospitalized); however, caregivers usually waited for the interventionists to call first. This reliance on another person to take the initiative, to offer nonconditional support, to call at the scheduled time with no changes, and to keep the caregiver welfare as a primary focus appeared to be the major advantage felt by caregivers during a time when there was little stability in their lives. They were particularly grateful for having someone available to listen.

During the telephone calls, and particularly during the last call, caregivers repeatedly expressed appreciation for the interventionists' concern and support. They also expressed hope that their participation in the study would help future caregivers. Many caregivers said that they began to care for their own health as a result of the ISC. For those caregivers who felt the most supported and became more informed, perhaps the positive effects of the ISC had a secondary benefit to the patients.

Two situations emerged that provided evidence of the extreme

needs and anxiety that could exist between a caregiver and the patient. Two caregivers (one male, one female) discussed with the interventionist the patient's resentment of the time the caregiver spent on the telephone with the interventionist. In one instance, the caregiver and the patient argued about this issue yet the caregiver chose to continue the study. In the other, the caregiver dropped from the study to reduce the conflict about the calls. In a recently completed caregiver study, Walsh, Martin, and Schmidt (2004) also noted patients' resentment and their request that caregivers *not* participate in the study because it took time away from tasks and the focus on the patient. This focus on the patient and the patient's illness also substantiates the "Bearing the Burden" category of this study.

During the course of the ISC, the interventionists' initial question was directed at inquiring about the caregivers' well-being. However, interventionists noted that the caregivers usually responded with an update about the patient and the degree of difficulty in their home situations. Caregivers would not initiate discussions about their needs unless asked directly. The interventionists also became aware that if the patient or home situation was favorable, caregivers would spend less time on the phone than when the patient was in a more critical condition. The opportunities for education during the calls frequently involved encouraging caregivers to spend time with others, teaching them about communication with health care providers, giving suggestions to caregivers on how to take care of themselves, and helping them to identify people and/or agencies that could serve as sources of support.

Future Directions

In the United States and internationally, other studies have supported the efficacy of even one supportive phone call to family members (Bucher, Houts, Glajchen, & Blum, 1998; Kaunone et al., 2000). Authors suggest that

Table 3.
A Guide for Family Caregivers

Family caregivers make many sacrifices to provide the care needed by their loved ones. The following suggestions promote both physical and mental health and may provide them with momentary relief from caregiver burdens.

Seek Support

- Family and friends want to help but often have no idea what to do. Give people suggestions such as, "Yes, you can bring us a meal on Thursday," or "I need for you to feed the cats while we are at the hospital."
- You may incorrectly assume that health care providers know what you and the patient need. To clarify your needs, you may want to write down specific questions and reminders (dietary needs or a special request to have a pet visit the patient).
- It may be helpful to join a family caregiver support group. Often local hospitals have these groups.
- Encourage brief phone calls or prearranged visits from children/grandchildren. Ask children to bring a picture, poem, card, or personal object for the patient. For young children, provide puzzles and/or art activities during the visit.
- If you belong to a religious community, seek comfort from other members or a spiritual leader to help you find strength during difficult times.
- Look for respite care/volunteers to relieve you to do errands or have free time to decompress (sources listed below can suggest where to call)
- Local/national organizations provide family support with information, financial aid, counseling, advocacy, and home care services. The following offer hotlines: American Cancer Society (800-227-2345); Cancer Care (800-813-4673); Cancer Hope Network (877-467-3638); National Cancer Institute (800-422-6237); Patient Advocate Foundation (800-532-5274); Hospice Foundation of America (800-854- 3402).

Conserve Energy

- Try to identify times when you will answer the phone. Tape record a phone message or e-mail a note with an update on the patient's condition.
- Attempt to set limits. Tell friends when and if you and the patient want visitors. For example, you may say, "Things have changed and we request that you visit only on Sunday evenings for no more than 10 minutes."
- Determine how best to nourish your body. Some caregivers overeat; others have difficulty sitting down to eat a balanced meal.
- Set aside short times for rest without feeling guilty. The better you feel, the better care you will be able to provide.

Deal with Emotions

- You may have common distressing feelings of sadness, anger, depression, helplessness, worry, resentment, and uncertainty about the future. If you are unable to perform usual tasks, discuss your situation with your health care provider. If you do not have a health care provider, ask the patient's physician for a referral. You may be more likely to get sick when caring for others.
- Consider daily exercise as a powerful way to improve your physical and mental health. If you are limited in what you can do, ask a nurse for suggestions. Even short periods of walking are helpful. Swimming is a good exercise for all ages.
- Creative arts activities give brief relief from stress. If you are interested in activities created for families that can be completed at the bedside, e-mail the first author Dr. Sandra Walsh (walshmoore@aol.com) for an activity booklet for all ages.
- Use music to lower stress. Relaxation CDs are available in music stores.
- Any type of indoor and outdoor gardening may help relax and fortify you but should be done in moderation.
- Meditation of all kinds can relieve stress. Books and tapes are available at local bookstores that contain information on yoga, visual imagery, and meditation exercises. Prayer offers some people a sense of comfort and hope. Finding a special place surrounded by nature can also help nourish the spirit.
- If you are able to concentrate on reading, ask friends for suggestions (books, novels, or magazines). Take reading materials or something to do (crossword puzzles, needlework) when you are waiting at physicians' offices.
- Many people find that writing about their experiences can ease tension. Keeping a journal helps get feelings out and can be done anywhere.

nurses who care for patients and have contact with family caregivers during hospitalization should take a leadership role in instituting supportive phone calls to family caregivers to promote and sustain caregiver health.

A *long-term goal* of this study was to improve the well-being of family caregivers of seriously ill cancer patients. In this investiga-

tion, caregivers indicated by their receptivity and completion of the ISC intervention that the telephone calls met a need and provided a mechanism for nurse interventionists to offer them help. The ISC would be an excellent way for students to come to know families in a different way following hospitalization and might be used as an adjunct to

home visits, particularly when the family lives a long distance from the hospital. Thus, the use of the telephone, particularly for followup care in the community, might be included in the nursing student's clinical education. Certainly the concerns expressed by caregivers in this study should be shared with student nurses to prepare them to include care-

givers in the care of the patient.

The issues discussed during the ISC increased knowledge about the critical needs of the family caregiver of the seriously ill patient. Findings should be integrated into theory and clinical medical-surgical courses in both undergraduate and graduate education to reinforce the importance of including the family in the care of the patient. Findings have been disseminated at health care research conferences (Rubert et al., 2001, 2004) and will continue. Findings have also been shared with staff from organizations (for example, hospice, home health agencies) that provide end-of-life care to advance quality of life in family caregivers of those patients served by these agencies. Authors continue to share results both locally and regionally with lay public and in nursing education and clinical settings.

Because of small numbers (n=11) of Hispanic participants in the ISC, cultural issues were not explored in this study. Therefore, cultural similarities and differences related to end of life should be explored further. Although field notes were extensive, additional information could have been obtained and perhaps additional categories uncovered if conversations had been taped and transcribed. In future studies research should address the issues of taping telephone conversations; that possibility, if desired, should be a part of the consent procedures.

Because additional approaches to care are needed for family caregivers particularly as they face serious illnesses of loved ones (Davies, 1997; Foley, 1999; Robak, 1999; Schumacher, Stewart, & Archbold, 1998), the ISC offered a strategy to partially address this need. While supportive interventions have been described for caregivers who are able and willing to leave home (Bedini & Phoenix, 1999; Carter et al., 1998), gaps in care continue (Emanuel, von Gunten, & Ferris, 2000; Jordan, 2000; Robak, 1999; Wilkes, 1997). Offering the ISC intervention in the caregivers' home via the telephone offered a different option by providing them the opportuni-

ty to receive help at home when it was difficult to leave the patient.

The experience had a profound effect on the interventionists, who grew to admire and respect the family caregivers. The ways that the caregivers coped, their ability to function and to carry on while bearing great burdens, and their courage during the weeks and days often just before a loved one's death were a constant source of inspiration for the interventionists. The research team became even more sensitive to the caregiver plight and will continue to share the findings of this investigation.

Implications for Nurses

As found in the SUPPORT study (Hardwig, 1995; SUPPORT, 1998), family members continue to focus on the patient's pain and suffering. Therefore, relief from the patient's pain and information regarding pain management should remain a high priority. Any support and information the medical-surgical nurse can provide will assist the family caregiver, especially as the patient's condition worsens. Family caregivers in this study confirmed that the best support may come from a nurse who takes a few minutes to listen. Family caregivers are comforted when nurses offer expressions of concern for the caregivers' welfare and when nurses acknowledge the difficulties caregivers are experiencing. For hospital nurses, one phone call after hospitalization to inquire about the patient and family may provide comfort. Nurses and nurse administrators may want to consider instituting such a telephone contact program. Additional study of interest could determine if there are differences in patient satisfaction results before and after followup calls are instituted.

For home health nurses, the use of the telephone for followup visits may provide enough guidance to shorten or even eliminate some visits. Conversely, telephone calls between scheduled home visits may uncover new information necessitating an additional visit but preventing more serious later complications. The "Guide for Family Caregivers" (see Table

3) provides useful tips for medical-surgical nurses to share with family caregivers in promoting excellence in family care. ■

References

- American Cancer Society. (2001). *Cancer facts and figures 2000*. Atlanta, GA: Author.
- Alemi, F., Stephens, R.C., Javalghi, R.G., Dycles, H., Butts J., & Ghardiri, A. (1996). A randomized trial of a telecommunications network for cocaine using pregnant women. *Medical Care Supplement*, 34(1), 510-520.
- Alemi, F., Stephens, R.C., Muise, K., Dyches, H., Mosavel, M., & Butts, J. (1996). Educating patients at home: Community health rap. *Medical Care*, 34(Suppl. 10), OS21-OS31.
- Bedini, L.A., & Phoenix, T.L. (1999). Recreation programs for caregivers of older adults: A review and analysis of literature from 1990 to 1998. *Activities, Adaptation and Aging*, 24(2), 17-34.
- Blanchard, C.G., Albrecht, T.L., & Ruckdeschel, J.C. (1997). The crisis of cancer: Psychological impact on family caregivers. *Oncology*, 11(2), 189-194.
- Bucher, J.A., Houts, P.S., Glajchen, M., & Blum, D. (1998). Telephone counseling. In J.C. Holland (Ed.), *Psycho-oncology* (pp. 758-766). New York: Oxford University Press.
- Carter, M.J., Nezay, I.O., Wenzel, I., & Foret, C.M. (1998). Leisure education with caregiver support groups. *Activities, Adaptation and Aging*, 24(2), 67-81.
- Charlton, R., & Ford, E. (1995). Medical education in palliative care. *Academic Medicine*, 70, 258-259.
- Colon, Y. (1996). Telephone support groups – A nontraditional approach to reaching underserved cancer patients. *Cancer Practice*, 4(3), 156-159.
- Davies, B. (1997). Fading away during terminal illness: Implications for bereavement in family members. In K.J. Doka (Ed.), *Living with grief: When illnesses is prolonged* (pp. 27-33). Washington, DC: Hospice Foundation of America.
- Emanuel, L.L., von Gunten, C.F., & Ferris, F.E. (2000). Gaps in end-of-life care. *Archives of Family Medicine*, 9, 1176-1180.
- Ferrell, B.R. (1998). Suffering. In R.M. Carroll-Johnson, & N.J. Bush (Eds.), *Psychosocial nursing care along the cancer continuum*. Pittsburgh, PA: Oncology Nursing Press, Inc.
- Foley, K. (1999). A 44-year-old woman with severe pain at the end of life. *JAMA*, 281(20), 1937-1945.
- Given, C.W., Given, B.A., Stommel, M., & Azzouz, F. (1999). The impact of new demands for assistance on caregiver depression: Tests using an inception cohort. *The Gerontologist*, 19(1), 76-85.
- Goodman, C.C., & Pynoos, J. (1988). Telephone networks connect caregiving families of Alzheimer's victims. *Gerontologist*, 28(5), 602-605.
- Hagopian, G.A., & Rubenstein, J.H. (1990). Effects of telephone call interventions on patients' well-being in a radiation therapy department. *Cancer Nursing*,

Walsh, S.M., Estrada, G.B., & Hogan, N. (2004). Individual telephone support for family caregivers of seriously ill cancer patients. *MEDSURG Nursing*, 13(3), 181-189.

- 13(6), 339-344.
- Hardwig, J. (1995). SUPPORT and the invisible family. *Hastings Center Report*, Nov-Dec, S23-S25.
- Higginson, I., & Priest, P. (1996). Predictors of family anxiety in the weeks before bereavement. *Social Sciences Medicine*, 43(11), 1621-1625.
- Hogan, N.S., Morse, J., & Tason, M. (1996). Toward an experiential theory of bereavement. *Omega: Journal of Death and Dying*, 33, 43-65.
- Hunkeler, E.M., Meresman, J.F., Horgreaves, W.A., Fireman, B., Berman, W.H., Kirsch, A.J., et al. (2000). Efficacy of nurse telehealth care and peer support in augmenting treatment of depression in primary care. *Archives of Family Medicine*, 9, 700-708.
- Jordan, J. (2000). Introduction: Research that matters: Bridging the gap between research and practice in thanatology. *Death Studies*, 24, 457-467.
- Kaunone, M., Aaloto, P., Tarkka, M., & Paunonen, M. (2000). Oncology ward nurses' perspectives of family grief and a supportive telephone call after the death of a significant other. *Cancer Nursing*, 23(4), 314-324.
- King, C.R., Haberman, M., Berry, D.I., Bush, N., Butler, I., Dow, K.H., et al. (1997). Quality of life and the cancer experience: The state-of-the-knowledge. *Oncology Nursing Forum*, 24(1), 27-41.
- Koazchik, S.L., Given, C.W., Given, B.A., Pierce, S.J., Azzouz, F., Rawl, S., et al. (2001). Improving depressive symptoms among caregivers of patients with cancer: Results of a randomized clinical trial. *Oncology Nursing Forum*, 28(7), 1149-1157.
- Loewenstein, D.A., Rubert, M.P., Arguelles, T., & Duara, R. (1995). Neuropsychological test performance and prediction of functional capacities among Spanish-speaking and English speaking patients with dementia. *Archives of Clinical Neuropsychology*, 10, 75-88.
- McGrath, P. (2001). Caregivers' insights on the dying trajectory in hematology oncology. *Cancer Nursing*, 24(5), 413-421.
- McMillan, S.C. (1996). Quality of life of primary caregivers of hospice patients with cancer. *Cancer Practice*, 4, 191-198.
- McMillan, S.C., & Mahon, J. (1994). The impact of hospice services on the quality of life of primary caregivers. *Oncology Nursing Forum*, 21, 1189-1195.
- Miaskowski, C., Kragness, L., Dibble, S., & Wallhagen, M. (1997). Differences in mood states, health status, and caregiver strain between family caregivers of oncology outpatients with and without cancer related pain. *Journal of Pain and Symptom Management*, 13, 138-147.
- Minino, A.M., & Smith, B.L. (2001). Deaths: Preliminary data for 2000. *National Vital Statistics Reports, CDC*, 49(12), 1-39.
- Phillips, L.W., Morrison, E., Steffl, B., Chae, Y.M., Cromwell, S.L., & Russell, C.K. (1995). Effects of the situational context and interactional process on the quality of family caregiving. *Research in Nursing & Health*, 13(3), 205-216.
- Robak, R. (1999). Loss, death, bereavement: Where are the empirical studies? *Psychological Reports*, 84, 701-702.
- Rose, K.E. (1999). A qualitative analysis of the information needs of informal caregivers of terminally ill cancer patients. *Journal of Clinical Nursing*, 8(1), 81-88.
- Rubert, M.P. (1999). *Tele-care for caregivers of the terminally ill*. National Institute of Nursing Research (NR05162-01). Bethesda, MD: National Institutes of Health.
- Rubert, M.P., Walsh, S., & Estrada, G. (2001). Tele-care for caregivers of cancer patients. *New Horizons Research Conference*. University of Miami and Sigma Theta Tau: Miami, Florida.
- Rubert, M.P., Walsh, S., & Estrada, G. (2004). Tele-care for caregivers of cancer patients. *Journal of the Psychological, Social, and Behavioral Dimensions of Cancer*, 13(1 Suppl.), S6-S7.
- Schott-Baer, D., Fisher, L., & Gregory, C. (1995). Dependent care, caregiver burden, hardiness, and self-care agency of caregivers. *Cancer Nursing*, 18(4), 299-305.
- Schumacher, K.L., Stewart, B.J., & Archbold, P.G. (1998). Theory. Conceptualization and measurement of doing family caregiving well. *Image - The Journal of Nursing Scholarship*, 30(2), 63-69.
- Steeves, R.H. (1996). Loss, grief, and the search for meaning. *Oncology Nursing Forum*, 23(6), 897-903.
- Stewart, M.J., Hart, G., Mann, K., Jackson, S., Langille, L., & Reidy, M. (2001). Telephone support group intervention for persons with hemophilia and HIV/AIDS and family caregivers. *International Journal of Nursing Studies*, 38(2), 209-225.
- SUPPORT. (1998). Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. *Special Supplement: Hastings Center Report*, 25(6), S3-S6.
- Walsh, S., Martin, S., & Schmidt, L. (2004). Art at the bedside: The effects of an art infusion intervention with family caregivers of cancer patients. *Journal of the Psychological, Social, and Behavioral Dimensions of Cancer*, 13(1 Suppl.), S11-S12.
- Weitzner, M.A., Jacobsen, P.B., Wagner, H., Friedland, J., & Cox, C. (1999). The caregiver quality of life index-cancer (CQOLC) scale: Development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research*, 8, 55-63.
- Weitzner, M.A., McMillan, S.C., & Jacobsen, P.B. (1999). Family caregiver quality of life: Differences between curative and palliative cancer treatment settings. *Journal of Pain and Symptom Management*, 17(6), 418-428.
- Wilkes, P. (1997, July 6). Dying well is the best revenge. *The New York Times Magazine*, 32-38.