

SURVIVORSHIP ISSUES

THE NURSES' SHIFT

*Due at the hospital at early morn
Earlier than when new day is born
Patients await the important care
Provided by professionals who are aware
Of the great value of their skills.*

*Doctors provide directions from detailed study
To clarify diseases that may seem muddy
The nurse needs to provide a keen mind
That follow the instructions in kind
That reflect the strengths of the nurses' skills.*

*Patients in hospitals throughout the land
Must value the nurses whose skills do hand
A possible recovery to a grateful patient.*

*John B. Eberly
August 16, 1989*

(Used with special permission of John B. Eberly, a bone marrow transplant recipient [Summer, 1989] currently undergoing follow-up at Virginia Mason Medical Center.)

From the Editor

Survivorship: The Clinical Issues of Relevance

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Cancer survivorship is a major topic of interest at both the local and national levels. The American Cancer Society, among other foundations and interest groups, has established survivorship and quality of life as one of its major interest areas. The recent emergence of the National Coalition for Cancer Survivorship, an interest group of lay and professionals who advocate the positive aspects of living with the illness and "getting on" with one's life, shows the value survivorship has within the general public as well as with professionals. Its primary goal is to generate a nation-wide awareness of cancer survivorship. It endorses that there can be a vibrant life, even after a cancer diagnosis. In its mission statement, it promotes peer support, serves as an information clearinghouse, advocates interests of cancer survivors and encourages the study of cancer survivorship.

The papers in this current edition of PSONS contribute to our understanding of a wide variety of issues relevant to cancer survivorship. The paper by Klaich and Loveys summarizes the illness demands women with recently diagnosed breast cancer experience as they work through the meaning of the diagnosis, the ramifications of the disease and the impact of the illness on their lives. Unlike previously published material, this paper is grounded in the woman's experience from the woman's own points of view. [Prior reports have instead emphasized the woman's responses on standardized questionnaires with pre-determined categories, not the woman's own words.] The paper by Zahlis and Shands is exceptional in two regards: it summarizes the male partner's experience with recently diagnosed breast cancer in his wife/partner and, like the Klaich and Loveys paper, describes the male partner's experience from his own perspective and in his own language. To date, there is little known research or reports that offer us an understanding of the male partner's experience with potentially life threatening cancer. Both the

Klaich and Loveys and Zahlis and Shands papers offer a window into the illness and experience not previously afforded us.

The paper by Stetz and Hanson gives us important information on the reported well-being of elderly caregivers of persons recently deceased from cancer. Their analysis reveals that these elderly caregivers had regrets about aspects of the caregiving experience as they looked back on it and wished they would have sought assistance during the dying trajectory. These results, among many others they report, have major implications for clinicians working with the caregivers of persons with late-stage cancer.

The report by Haberman reminds us that advanced technological treatment for cancer, for example bone marrow transplantation, results in a host of issues with which we as nurses must be concerned. Often treatments proceed and technology advances at rates faster than our knowledge of the issues that patients and their families must face as recipients of the treatment technology. Haberman raises our consciousness about such concerns.

President's Message

Endings and Beginnings

A decade is coming to an end and the new will begin. This has been an incredible decade for PSONS. When it began, we called ourselves RONS and received considerable financial and other support from the Fred Hutchinson Cancer Research Center and the American Cancer Society. Through the years, we became a chapter of ONS, established greater self-sufficiency while maintaining collaborative relationships with other agencies, developed an outstanding newsletter, offered excellent annual symposia, held quarterly educational meetings, developed a logo and standardized our "look," introduced awards and educational grants, received awards and prizes from national, and supported a thriving group of committees.

What I see as most important this last decade and what will be the most important for the decade to come is the respect and

affection we have for each other. We have cared about each other and nurtured each other through professional and personal ups and downs. For some members, interaction may only occur at the annual symposium because distance prevents attendance at other meetings. But, there is a common interest and a bond we share and we can find a colleague's name in the directory and call with a question. The newsletter has provided opportunities for members to share their ideas and experiences and for the chapter to acknowledge the contributions of individuals to the oncology nursing profession. PSONS has thrived because of all of us and our commitment to oncology nursing and to each other.

As this year ends and the new begins, Joy, Pam, Barb and I wish you and your family a happy holiday season. We look forward to sharing the next decade with you.

ANNUAL PSONS SYMPOSIUM

"Horizons in Northwest
Oncology Nursing"
February 23-24, 1990
Bellevue Commons;
Bellevue, WA
(with a reception to be held
Friday, Feb. 23
at the
Bellevue Hyatt Hotel)

Keynote Speaker:
Margarita Suarez,
ARNP, PNP, MA
McCorkle Lecturer: Anne
Hughes, RN, MN

Breast Cancer: The Demands of the Illness

By Katherine Klaich, RN, MN
Barbara J. Loveys, RN, MN
University of Washington

What is the impact of breast cancer on the daily lives of women of child-rearing age? A study at the University of Washington School of Nursing, guided by Dr. Frances Lewis, RN is seeking the answer to this question. This paper is a preliminary report from that study.

Theoretical Framework

The impact of breast cancer and its subsequent treatment is thought to be a major turning point in a woman's life, one which precipitates a reevaluation and revision of her personal identity and her relationship with others (Psychological Aspects of Breast Cancer Study Group, 1987; Quint, 1963). While the nursing literature is replete with studies of the effects of breast cancer, much of that research has been guided by a clinical or medical "model of reality" (Rosser, 1981). These studies legitimate the concerns presumed to be relevant by the researchers, but fail to appreciate the complexity of a woman's day to day experience with breast cancer or the meanings she ascribes to those experiences.

The construct, demands of illness, has been described by Packard, Haberman, Woods and Yates (Submitted) as a framework for evaluating the illness experiences of persons with cancer. Demands of illness represent illness-related stressors, strains, or problems and are grounded in the theoretical literature on stress and coping (Lazarus & Folkman, 1984).

The Study and the Sample

For 2-1/2 years, nurse researchers followed 79 women, newly diagnosed with breast cancer, who were either partnered or single, all of whom had at least one school-aged child. Data for this paper was obtained from semi-structured interviews during the initial visits with these families. The women were asked about changes in their daily lives, things that were difficult or that they were

unprepared for, and anything else they felt was relevant about the experience of living with breast cancer.

The average age of the women in this sample was 41 years. The majority of the women were white, had a family income of greater than \$35,000 a year and had been married for an average of 15 years. The average number of children in the family was 2 and their mean age was 11.5 years. Eighty-two percent of the women had at least some college education, and 64% were working at least part-time. Fifty-four percent of the women had a modified radical mastectomy and only 21% had reconstructive surgery. At the time of the interview, the average length since diagnosis was 12.7 months, the range being 35 days to 2-1/2 years. Treatment following diagnosis varied among the women. All interviews were transcribed verbatim and then analyzed utilizing a qualitative methodology. The unit of analysis, a demand of the illness, was defined as a hardship or challenge that taxed the women's usual resources.

Demands of Living with Breast Cancer

Fourteen major categories were identified in the data. Excerpts from the interviews provide a rich account of the women's experience.

Treatment Issues. Demands of illness related to treatment issues were described by the women more frequently than any other demand. Included in this demand were interactions with the health care community for ongoing treatment and check-ups.

"Chemotherapy is not fun, because I don't like getting shots. I was asleep for the operation, but you're awake for the chemotherapy. I hate needles and you have to go really often."

Changes in Life Context/Perspective. The women reported changing their daily routines, schedules, activities and diets. Many gained a new outlook on life and re-evaluated life priorities. Some women, when asked

what had changed for them as a result of their illness, simply answered, "Everything!"

"My entire life just kind of disintegrated right there on the spot like a big bomb going off. It's not business as usual."

Acceptance of the Illness. The initial diagnosis was a trying period for many women and they described the shock and trauma of finding out they had breast cancer. Statements of "why me?" and "Why now?" were common, as were expressions like "I'm too young," or "It all happened too fast." The women also spoke of dealing with the chronicity of the illness in terms such as "It never goes away."

"I've always been so healthy, sometimes I just wonder why? Why did I get cancer? I think the most difficult thing is to hear that you've got it."

Social Interaction/Support. Changes in interpersonal relationships and social support were described. Real or anticipated reactions of others often constituted a demand, as did the need to talk about the disease or to ask for help.

"I mentioned it to one friend in the neighborhood who sees me all the time, and it hasn't made a difference. I mentioned it to another friend, and I haven't seen her since."

Physical Changes. The women described having to adjust to a variety of changes in their bodies such as weight gain, difficulty sleeping, fatigue and pain. Some said they were hypervigilant to "every little ache and pain" they now experienced.

"I notice that everyday it's an issue of sleep and rest. I get up and I say 'That was the fifth night of good sleep after six weeks of insomnia.' That fatigue affects your activity level."

Reconstructing the Self. The women described a process of viewing themselves in the context of their illness. They saw themselves as different from who they were before the diagnosis. They discussed a variety

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Demands of Breast Cancer

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of emotional reactions from "emotional ups and downs" to a feeling of "losing their marbles" or being "extraordinarily bananas."

"I feel like I'm looking at myself outside of myself. People might say I'll get back to my old self, but I don't think I'll be totally that way again."

Uncertainty. The women frequently dealt with uncertainty about their future. They talked about the possibility of recurrence in terms of always wondering and waiting.

"I think one of the most difficult things is just obsessing about the whole subject. If I could just forget about it for one day, it would be a blessing. I think about it constantly and I'm sick of it!"

Making Comparisons. Knowing about other women with the same illness was not always comforting. Some women had mothers and fathers who died from cancer. They found themselves comparing their parent's experience with their own.

"It's hard to be optimistic when you know other people with the same illness that aren't doing so well."

Acquiring New Knowledge. The women

reported having to absorb a great deal of information, but not always finding the answers they wanted.

"I'm very inquisitive. I want to know anything and everything."

Mortality Issues. The women spoke of the association of cancer with death. They reported being more aware of their own mortality.

"When someone gives you the word cancer, you have yourself buried and gone, because almost everyone I know of is... gone."

Financial/Occupational Concerns. Changes in jobs, real or anticipated, financial concerns and schedule conflicts were more problematic for single parents than for partnered women.

"I had a fear of not being able to make a living. I've always thought I could make it on my own, then, all of a sudden, I was afraid that I had lost that ability."

Making a Contribution. Some women felt a responsibility to help others as a result of their own illness experience.

"I think before this, I would have been concerned, but never quite found the time to be involved. Now, I make time. That's part of my own healing, too, I have no doubt. That's okay. We'll share the healing."

Clinical Implications

The human response to health is of concern to nurse clinicians and scientists alike. This study validated the complexity of this response. For instance, women reported being worried about matters of living and matters of dying simultaneously. Women worried about concrete issues, such as cleaning the house, as well as more abstract questions like, "Am I losing my spirit?" Clinicians are cautioned by this study to listen to their clients and deal with the problems as perceived by the women living with their illness.

Emotional responses, such as anxiety and depression, have been evaluated in many studies (Jamison, Wellisch, & Pasnau, 1978; Maguire et al., 1978; Taylor et al., 1985) almost to the exclusion of other facets of the illness. Such emphasis seems to legitimate psychiatric morbidity as a clinical priority (Rosser, 1981), whereas women in this current study described their emotional responses as only one facet of their effort to adapt to the illness.

Sexuality and feminine self image have also been described extensively in the literature (Penman et al., 1986; Polivy, 1977). The women in this study, however, did not focus on their sexuality as much as they described changes related to an inner knowledge of self

and concerns about others' reaction to them.

Along with a description of the demands of their illness, most women also described ways of dealing with those demands. Women reported a variety of coping strategies and seemed to possess answers as well as questions about their illness experience. What is notable for clinical consideration is that women are able to go beyond describing their concerns and include creative management methods as well.

Nurses will benefit by assisting the woman to process both her concerns and her methods of dealing with them. In the process, the woman is empowered in the exchange.

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Breast Cancer: The Partner's Experience

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Breast cancer continues to be a major cause of death among women in the U.S. Today, 1 out of every 10 women is diagnosed with breast cancer (American Cancer Society, 1988). Many studies have documented the devastating effects the illness has on women, yet few studies have explored its effect on their male partners. For the man living with a woman with breast cancer, life can be greatly impacted as well.

The purpose of this study was to describe the demands experienced by the partner of a woman with newly diagnosed breast cancer (i.e., diagnosed within the last 2-5 years). Demands, for the purpose of the study, are defined as any use of the partner's time, intrapersonal resources, and energy as he manages the illness experience.

Partners were interviewed using the Demands of Illness Interview created for use in the study. The interview consists of 5 open-ended questions concerning what parts of their lives had changed, what things were difficult and what things did they feel unprepared for as a result of the breast cancer. The data were content analyzed using formal, specific methods.

Participants were recruited from the Seattle metropolitan area through nurse-intermediaries working in clinics and doctor's offices. A total of 67 partners of women with newly diagnosed breast cancer comprised the sample.

Discussion of Results

The most frequently talked about demand was that of finding out and accepting the illness; 65.7% of the men talked about this aspect of the illness experience. Their answer, when asked what did they feel unprepared for, typically gave rise to the response: "the whole thing." They talked repeatedly about their feelings of shock and disbelief as they grappled with accepting the diagnosis. Men used words such as "surprised," "surrealistic," and "traumatic" when describing their feelings about finding out about the breast cancer.

Over half of the men interviewed (52.2%) talked about their physical and emotional responses to the cancer. They described feelings of fear, remorse, loss and sadness, as well as physical symptoms of feeling sick and "throwing up." They often shared with the interviewer that they had been depressed, anxious and worried. Spouses' emotional and physical reactions have been reported in past research as well. These have included: increased incidence of

illness and somatic complaints (Oberst & James, 1985); sleep disorders and changes in appetite (Wellisch, Jamison & Pasnau, 1986); and loss of energy, increased moodiness and growing fears related to their own health and death (Sabo, Brown & Smith, 1986).

A significant proportion of the men (33%) talked about the challenge of dealing with the women's emotions in response to the breast cancer. Often they remarked that this was the most difficult part of the experience. They found the women to be depressed, fearful and easily upset. They described themselves as "dealing" with them by becoming a sounding board or a punching bag, and by "consoling" them and "trying hard to understand" what they were going through. Gotay (1984) also cited general emotional disturbances of the patient to be the second most commonly cited problem by spouses.

For many men (30%) being supportive was an important part of the experience. This often translated itself into a variety of behaviors. They described being more attentive, going to treatment sessions with her, and being more available. Emotionally, they supported her by being "patient," "tolerant," "lenient," and "more understanding." In a more abstract way the partners supported the women by letting them know they had "someone in their corner" and just by being "real supportive." Gotay (1984) documented that mates reported the fact that providing support was a key strategy for coping with the illness.

A few men talked about preparing themselves to be supportive. "Not letting it get to you. . . not pulling inside yourself; but be open and loving and supportive." In addition to talking about being supportive, 11% of the men talked of their own inadequacies in trying to do so. "It's just an enormous drain on her, and you can't really understand what she's going through. . . probably because of that you can't help very much." Sabo et al. (1986) noted, that for men participating in their study, anxiety arose out of their inability to give their wives enough emotional support through the crisis.

Nearly a third of the men (28%) talked about the uncertainty that the illness created in their lives. For many, uncertainty was not limited to concerns about the distant future but included issues

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The Partner's Experience

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related to the course and outcome of treatment, and even, on a day to day basis, what to expect. Men described themselves as being afraid of the unknown and frustrated by their inability to predict what would happen. This left them feeling they could not make plans, either long term or short term. Oberst et al. (1985) identified uncertainty as the fourth highest area of concern reported by spouses during the patients' hospitalization. These feelings of uncertainty increased over time and were related to the spouses' doubts about the efficacy of treatment.

Some men (28%) talked about the added responsibilities they had in managing the household duties as well as the day to day running of the household. They talked about cooking, shopping, doing the laundry, and scrubbing floors. Balancing additional home responsibilities with work responsibilities has also been documented as problematic for partners in studies by other investigators (Northouse & Swain,

1987).

When describing how they handled the illness, 27% of the men described a variety of behaviors and attitudes. Some men devised strategies; for example, one man called home before leaving work to ascertain his wife's mood. For many men, having a positive outlook, getting perspective, and not dwelling on "it" were commonly reported management strategies. A lower proportion of the sample claimed they turned the situation over to God.

Watching her was described by a certain number of men (21%) as a difficult part of the experience. They spoke of watching the emotional upheaval that the illness created in the women and seeing them cry. The physical effects of treatment were also uncomfortable to witness: seeing her wounds, her hair falling out, and seeing her in pain.

Often the men (22%) talked about the fear of losing their wives to the illness. Many men were overwhelmed by the thought of being alone and were actively trying to absorb this as a possibility.

"Anxiety that she might die even if it were ten years from now; it's still an awful thought."

Not all of the women in the study had undergone mastectomy as a treatment for their breast cancer and the men were never asked specifically about their responses to the loss of the breast. Nevertheless, 16% of the men spoke of it. Some men were surprisingly frank about their feelings. For some, the "physical disfigurement was shocking." But others talked about their fear, at the time of the mastectomy, that they would not be able to share this part of the experience, that they would not be "allowed to see the scar." Men talked about dealing with the loss of a part of her body and the grief that accompanied the loss, as well as the adjustment that both partner and wife had to make to it.

Clinical Implications

It is apparent from these results that men have many concerns, feelings, and insecurities related to the women's breast

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Coping with Breast Cancer: The School Age Child's Perspective

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A mother's breast cancer becomes part of their children's experience. School age children are in daily interaction with the mother, must live daily with the mother's illness and the mother's illness may potentially disrupt the family system in negative ways. Therefore, family adjustments made to help the child reestablish an equilibrium become an important aspect of the child's adjustment.

The purpose of this study was to describe the ways in which the school age children cope with the mother's breast cancer and the ways they perceive their families help them cope. Previous studies, such as those by Lewis, Woods and Ellison (1985) and Wellish and others (1983), indicate that the family as a system is important to the child's adjustment to a parental chronic illness. Developmental theory suggests that the child's ways of coping with the mother's illness varies with the developmental age of the child.

Children from 77 families living in the greater Puget Sound Area participated in the current study. The families were predominantly married (70%), upper-middle class families, with an average family income between \$35,000 and \$40,000. The mothers were between 29 and 54 years old, with an average age of 41. The fathers were slightly older, with an average age of 43. Fifty percent of the mothers had modified radical mastectomies and another 27 percent had lumpectomies with nodes removed. The remaining 23 percent had lumpectomies with no nodes removed, a radical mastectomy or some other treatment. The average length of time since the mother's initial diagnosis was 13 months, with a range of 1 month to 32 months. A total of 133 children between the ages of 6 and 19 were interviewed from 77 families. The average age of children interviewed was 12 years old. Slightly more boys than girls were interviewed.

Interviews occurred in the homes, in a private place. All children in the study were asked questions about what their family did to help them cope with their mother's illness, what they did themselves to deal with the mother's illness, and who helped them cope.

Interviews were tape recorded, tran-

scribed and content analyzed according to the procedure described by Lewis, Haberman and Wallhagen (1986) and Krippendorf (1980). The analysis began by identifying the units of analysis, noun-verb statements. The statements were organized into mutually exclusive and exhaustive categories. The categories were next grouped into a more encompassing set of domains. Each domain reflects conceptually related but distinct sets of categories of activities.

How Families Helped Children Cope

Seven domains describe the ways in which the children saw the family helping them cope with the mother's breast cancer.

SEVEN DOMAINS OF HOW FAMILIES HELPED CHILDREN

•••

ACTING NORMAL
SPENDING TIME TOGETHER
BEING CONSIDERATE OF MOTHER
BEING CONSIDERATE OF ME
BEING OPEN ABOUT IT
NOT DWELLING ON IT
NOTHING

Acting Normal. Acting Normal reflects the extent to which families carried on with their usual activities and acted normal, including doing housework. From a family perspective, this domain may reflect the families' attempts to maintain a family equilibrium.

Spending Time Together. This domain included being with and engaging in recreational or social activities with at least one other family member. It represents an opportunity for the family members to energize each other and may well be an important means of showing the children that the mother is not seriously ill. A 9 year old son's statement demonstrates this.

"Sometimes we go to a nice restaurant, a great Mexican restaurant. It sort of makes me think that she's okay and she's really wild and she can just get up there and dance with me, or something. It makes you feel like she's not sick anymore, but she still is."

Being Considerate of Mother. Family

members engaged in behaviors or modified interpersonal practices to help the mother with the emotional or physical demands of the illness. "Being Considerate of Mother" included categories such as helping, taking care of or comforting mother, trying to understand how she feels, and monitoring her self-care. Younger children seemed more concerned about being considerate or thoughtful of the mother and with doing chores than did the older children. The following statement by a 9 year old boy illustrates one way a child was considerate of his mother.

"I know she's sick and I have to do things without her. So, let's say my dad's not home and my mom's here. But she's in bed sleeping, resting. I try not to bug her. I just try to figure it out myself, or I skip it and wait until she's awake or someone gets home to help me."

Being Considerate of Me. A small proportion of children were more specific in describing the ways that the family helped. "Being Considerate of Me" includes specific ways that the family helped the child, such as going to counselors or conveying a positive attitude about the illness.

Being Open About It. Another domain contains statements about addressing the mother's breast cancer. The predominant strategy was talking about the illness often through family discussion. Also, a few children went with the mother to the treatment place. Older children were more likely than younger children to report talking and thinking about the breast cancer. The importance of the parent's talking about the illness is illustrated by this 15 year old daughter.

"It's been kinda scary. I thought she was going to die, you know, for a little bit there, when she found out about it. But then, you know, once she told me more about it, I became more safe with the idea."

Not Dwelling on It. As children mature and seek to establish an identity separate from the mother or father, some denial of the mother's breast cancer may occur, especially if the illness has been defined by the family as the mother's problem. Of the children inter-

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Coping with Breast Cancer

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viewed, older children were more likely to report ignoring it or not talking or thinking about her illness. A 15 year old son explained why it was important to put his mother's illness out of his mind.

"You have to not let it get to you. You gotta find something else to occupy your mind. Cause if you sit around all day and thinking your mom's sick, she's gonna die, then the whole family will fall apart."

Nothing. The Nothing domain encompasses several different types of "Nothings." To some children the family did nothing to help them cope because the illness was over or it posed no particular problems requiring the family to help. A few children reported that nothing the family did helped them to cope.

What Children Did By Themselves

Children engaged in five domains of activities on their own which they say as helping them cope with their mother's illness.

DOMAINS OF WHAT CHILDREN DID BY THEMSELVES TO COPE

...

DOING REGULAR THINGS REFLECTING ON HER ILLNESS BLOCKING IT OUT DOING FOR MOTHER NOTHING

Doing Regular Things. This domain includes usual childhood activities including sports, watching TV, listening to the radio, doing household chores, being with friends and going to church.

Reflecting On Her Illness. Most children reported thinking or talking about her illness. Some children tried to understand her illness. Others thought about getting breast cancer. Still other children focused on self-soothing thoughts, such as telling themselves not to feel bad or that she would be okay. Children's reflections on the mother's illness may not always be apparent. One 9 year old daughter explains:

"But instead of watching TV, I went on the couch in front of the TV so she'd think that I'd been watching it, but I closed my eyes and I was thinking about her illness."

Blocking It Out. Not all children wanted to focus on the mother's illness. Some children made efforts to evade the illness by redirecting thoughts or engaging in diver-

sionary activities. Of those reporting "Blocking It Out" activities, most were older teenage children.

Doing For Mother. This domain reflects the behaviors or interpersonal practices in which the children engaged to help the mother with the physical or emotional demands. Mostly, children who reported "Doing For Mother" were younger. Included in his domain were helping out mother and cheering her up.

Nothing. Not all children reported doing something by themselves to help cope with the mother's illness. The children who said "Nothing" mostly either viewed the illness as over or as "not a big deal." A few children said they did not do anything by themselves.

Who Helped Children Cope

The children often named more than one person who helped them cope with their mother's illness. Younger children named parents more than did older children, whereas older children named friends more than did younger children. Children also named family members, non-family adults, God and themselves as helping them cope. It is interesting that approximately 15% of children said no one helped them. Also, approximately 15% reported that they were not going through anything.

Clinical Implications

Both clinicians and mother may be concerned about how the school age child is coping with the mother's illness. However, some mothers may not initiate the topic with the children. Clinicians may need to take the initiative in their assessments and inquire about family level activities and attention given to the children. The domains and the corresponding categories in the current paper reveal that families engage in diverse activities to help the children cope with the mother's illness. Similarly, children engage in a range of activities to help themselves cope. Not all families or all children engaged in all activities. The diversity of strategies suggests that assessing for child's coping with the mother's breast cancer requires individual assessment.

Some concerns about how the children are handling their mother's illness may best be addressed by talking with the children. Recall the example of the child who hid her emotions from her mother by pretending to

watch TV. During the child's visit, the clinician could evaluate both the child's view of the family's efforts to help them cope and the child's view of the illness. The child could then be helped. Although normal child development will influence both the child's ability to understand and major areas of concern, most children genuinely seemed concerned in some way about their mother.

Although in this study children were not asked when they learned about their mother's illness, children did talk about going to visit their mother after surgery. Children who talked about that experience expressed fears they felt at that time about her dying. This suggests that interventions with children may need to begin early in the mother's treatment, just as education of the mother also begins early in her treatment.

The results also suggest that some children did not see themselves as needing to engage in coping behaviors. Therefore, clinicians are cautioned not to assume that the illness is a major family or child problem. However, only through careful assessment with family members will the clinician be able to make the fine distinction between truly not needing to cope and the family's inattention with mother's breast cancer.

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- This study was supported by a grant from the Center for Nursing Research, National Institute of Health, RO1 NR 01000-06. Parts of this paper were presented at the 1989 ONS National Congress, San Francisco*

Alterations in Perceptions of Caregiving Demands: During and After the Experience

Kathleen M. Stetz
University of Washington
Wanda K. Hanson
Visiting Nurses, Hospice of San Francisco

The management of persons with advanced cancer is a primary focus of health care services.

Families are being encouraged (and in some situations mandated) to become the major provider of care outside the health care institution during the treatment as well as the advanced stages of the illness (Davidson, 1979; Flynn & Stewart, 1979). This paper reports some of the results of a follow-up study which compared the caregiving demands reported during the caregiving phase to those reported after the death of the spouse in order to determine the demands which were perceived as most salient over time.

We asked:

1. What do spouse caregivers retrospectively report as the most difficult aspects of caring for a spouse with terminal cancer in the home?; 2. In what ways do retrospectively reported caregiving demands differ from those reported at the time of actual caregiving?; and 3. What personal regrets about the caregiving experience do spouse caregivers report?

Methods

A descriptive, longitudinal design was used to collect data at two times for the total study. Interview data was collected by in-depth interviews (Time 1) and a mail survey (Time 2). Results in the current paper are limited to Time 2 results.

Sample

Sixty-five spouses of persons with advanced cancer who were currently engaged in caring for their ill spouse in the home comprised the study sample. Participants were hospice programs or specialized services for cancer patients. Subjects were included in the second phase of the study if: (a) they had participated in phase one of the study; (b) a minimum of 6 months of time had passed since the initial interview; and (c) the ill spouse had died at least 1 month prior

to the date the survey was mailed. The data on these 31 persons (48% of the original sample) who participated in phase 2 is reported here.

Data Collecting Instrument

Since this study was a follow-up of the original study, subjects were mailed a questionnaire regarding their perceptions of the challenges and benefits of caring for a spouse at home. The questions were similar to the questions asked during the home interview at Time 1.

Procedures for Content Analysis

Content categories were identified in the initial study (Stetz, 1987). The category schemes and coding rules were developed according to Krippendorff, 1985. The same rules for development of the category scheme and coding were used in this follow-up study and interrater agreement was 86% (Swan, 1973).

Findings

Characteristics of the Sample

Thirty-one (48%) of the original 65 spouse caregivers participated in this follow-up study. Of these, 23 caregivers (74%) were wives and 8 (26%) were husbands. Forty-five percent of the spouse caregivers had assisted their ill spouses for more than six months with activities of daily living prior to their spouse's death. The couples had been married for an average of 33.9 years. The mean age of the spouse caregivers was 65 years. During the time of caregiving, the spouse caregivers reported spending an average of 23.2 hours, seven days a week in the home with 80% spending the entire 24 hours in the home.

Demands Experienced After the Death of the Ill Spouse

Nine mutually exclusive caregiving demand categories were identified during

the caregiving experience, previously reported in Stetz (1987).

From the written responses of 31 subjects to the follow-up survey after their spouse's death, eight mutually exclusive categories were identified. The four most frequently reported demands were also reported during the caregiving experience. These similar demands categories included *Standing By; Managing the Physical Care, Treatment Regimen and Imposed Changes; Alterations in Spouse Caregiver's Health and Well-Being; Constant Vigilance;* and *Alterations in Relationship with Ill Spouse*. Three additional categories were identified from the content analysis of Time 2 data; however, they were each only reported by one or two caregivers. These three categories included *Challenged Judgments; Timing of the Ill Spouse's Death and Turning Over Control to the Health Care System. Challenged Judgments* was defined as the experience of evaluative comments regarding the caregiver's performance as caregiver. *Timing of the Ill Spouse's Death* was defined as the difficulty the spouse caregiver has associating the date of the ill spouse's death with a specific, important time period. *Turning Over Control* was defined as the caregiver's perceptions that he or she must allow the health care system to be in control of the ill spouse's health management.

Comparison of Demands During and After the Caregiving Experience

Differences existed in the pattern of reported demands in comparing caregiving demands with demands reported after the spouse's death. At the time of caregiving, *Treatment Regimen and Imposed Changes* was the most salient demand. However, after the death of the spouse what was remembered as most difficult was *Standing By* and observing the slow deterioration of the ill

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Long-term Survival After Bone Marrow Transplantation

Mel Haberman, RN, PhD
Fred Hutchinson Cancer Research Center

One marrow transplantation (BMT) is now an established alternative to conventional therapy for a variety of hematologic malignancies and immune disorders. Despite improved chances for disease-free survival after BMT, little is known about the nature of quality of long-term survival. In fact, of all the stages associated with BMT, the least is known about the final stage—long-term adaptation and recovery (Brown & Kelly, 1976; Haberman, 1988). This article includes a brief review of the research that has examined the quality of life of long-term survivors of BMT. Work currently underway by our research team is next described that investigates the quality of life and recovery of marrow recipients who have survived from one to fifteen years after BMT.

The late medical complications of BMT are well documented in the literature (Buchsel, 1986; Nims & Strom, 1988) and will not be reviewed in the current article. Although many nurses have extensive anecdotal or case history information about the problems facing long-term survivors, only three data-based articles on the long-term psycho-

social recovery exist. Hengeveld and colleagues (1988) investigated levels of depression, psychoneurotic symptomatology, and physical functioning in 17 adult survivors who had a mean survival time of 36 months. Although the majority of survivors showed remarkable emotional flexibility and elasticity, efforts to resume a normal life were hampered by fears of relapse, changed work status, permanent disability, loss of hobbies, demands of adhering to an ongoing treatment regimen, and by the need to remain vigilant to detect symptom recurrence. Hengeveld and group concluded that psychological functioning is closely related to the extent of physical impairment, particularly the presence of graft-versus-host disease (GVHD).

Despite this conclusion, the exact influence of GVHD on psychosocial functioning remains unknown. In a recent study by Andrykowski and associates (1989), chronic GVHD was not significantly related to either physical or psychosocial functioning in 23

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Alterations in Perceptions

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spouse. *Difficulties in Managing the Household and Finances* was not even mentioned after the death of a spouse as being a difficult aspect of caregiving. *Alterations in Well-Being and Constant Vigilance* was reported with the same frequency both during and in retrospect of the caregiving experience.

Personal Regrets

Spouse caregivers were also asked if they would have done anything differently in caring for their spouse at home. One-third of the caregivers wrote that they had "no regrets" or that they "would not do anything differently." Other caregivers, however, felt that they would alter some things about the experience. Forty-eight percent (N=16) wrote that they would have sought out additional resources and accepted the assistance that was offered. Three caregivers said that they would have more openly expressed their feelings and emotions to their dying spouse. Three other caregivers said they wished they had spent more time just "being with" their ill mate. It is also important to note that two caregivers stated that they wished they had used preventive health behaviors such as stress reduction techniques.

Implications for Clinical Practice

The current study raises two important implications for nurses involved in hospice care. The first is that caregivers' perceptions of hardships or difficult aspects of caregiving change as length of time since the death of a spouse increases. Although it is intuitively apparent that these changes may occur, clinicians do not typically address the importance of the change in perception. Focusing too strongly on the primary demands identified during the caregiving, without directing interventions towards assisting the client to cope with other "less" important demands, may result in the caregiver not receiving the needed support.

The second implication from this study relates to the issue of personal regrets. Two-thirds of the study sample reported that they would alter some aspects of their experience. Almost half indicated that they should have sought and used resources to assist them with caring for their ill spouse in the home. Caregivers may be initially reluctant to accept services and feel they need to wait until "things really get tough" before they allow themselves to request and receive assistance. Clinicians may want to introduce the concept of respite care early in the relationship with

the caregiver. It may be that the caregiver needs "permission" to have assistance because receiving assistance may be perceived as a sign of weakness or failure. It is imperative that the clinician convey to the caregiver that this assistance is a positive step towards retaining them in their role.

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- The research was partly supported by: a National Research Service Award No. NUI 05695, The Division of Nursing; a National Cancer Institute Predoctoral Training Award No. CA 09472, National Cancer Institute; and the Robert Wood Johnson Foundation Clinical Nurse Scholars Program, Princeton, New Jersey.*

Long Term Survival

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adult survivors (mean survival of 26.2 months). Post BMT functioning was significantly related to only one variable, namely, age at the time of transplant. Survivors older than 30 years of age at the time of transplant had poorer psychological, emotional and social functioning scores; reported more pain and nausea, disruption of leisure activities, and social isolation than recipients less than 30 years of age. Time elapsed since BMT was not related to any physical or psychosocial functioning variable.

Andrykowski's finding that neither physical nor psychosocial functioning improves with the passage of time alone corroborated the findings of Wolcott and colleagues (1986). Wolcott studied 26 adult survivors (mean survival of 42 months) and found that the time elapsed since BMT did not correlate with any measure of psychosocial functioning. However, the survivor's global assessment of their physical health status did improve over time after BMT. Significant emotional distress, low self-esteem, and a less than optimal quality of life were noted in 15-25% of recipients. Twenty-five percent of the survivors reported ongoing physical problems (diarrhea, nausea, vomiting, swallowing difficulties, mouth soreness, skin problems), high rates of infections, and high medical care utilization. Wolcott and group concluded that poorer physical functioning

was clearly related to poorer psychosocial adaptation.

The common themes that emerge from these three studies of long-term recovery after BMT include: (a) late medical complications consistently impede long-term psychological and social recovery. However, the exact relationship between these outcome variables remains unclear; and (b) neither physical nor psychosocial functioning improve with the passage of time alone. Rather, the effect of late medical complications on psychosocial functioning appears indirect, operating through an unknown set of mediating variables. Despite these suggestive trends, the findings of these studies remain inconclusive due to the availability of only small samples and the exclusive use of cross-sectional designs. Moreover, since the three studies used different instruments and outcome variables to measure late medical complications and psychosocial functioning, it is virtually impossible to make direct comparisons across the studies.

Our current understanding of long-term recovery after BMT is also limited by an absence of published research on the cognitive, neuropsychological, and vocational changes experienced by adult survivors. Considerable anecdotal evidence exists from Fred Hutchinson Cancer Center nurses, physicians, and social workers indicating that some survivors report memory, attention and concentration deficits. These cognitive impairments

hamper the survivor's ability to read, watch TV, carry on a normal conversation, or to return to work or school. No studies have been performed on BMT survivors to examine either the impact of chemoradiotherapy regimens on cognitive functioning or the affect of cognitive impairment on vocational/school functioning. Hengeveld and colleagues (1988) did report that only 29% of their sample were employed at a mean of 36 months after BMT while Wolcott and group (1986) found only 35% of their sample employed at a mean of 42 months post BMT. The relationship between chemoradiotherapy toxicities and cognitive or vocational functioning was not tested in these studies. What is clearly needed is a series of research studies designed to overcome the limitations of the existing research on long-term survival after BMT.

Current plans are underway at the Fred Hutchinson Cancer Research Center to identify aspects of long-term recovery that are problematic to marrow recipients as well as to document the beneficial outcomes of BMT. The knowledge gained from future planned studies will help us design future intervention trials aimed at improving the quality of life and survival after BMT.

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ATTENTION

All PSONS Members
(Especially Board members &
Committee Chairpersons)

The deadlines for items to be included in the 1990 Newsletter issues are as follows:

Winter, 1990 • November 29
Spring, 1990 • March 2
Summer, 1990 • June 1 (post-ONS congress issue)
Autumn, 1990 • August 3
1990 Special Year-End Issue • September 28

Please submit your calendar of meetings for 1990 as soon as possible and all committee reports throughout the year by the above dates.

Thanks!

Clinical Practice Review

Cancer Lifeline: Helping Families Manage the Challenge of Cancer

Ellen Zahlis R.N., M.N.
Family Consultant, Cancer Lifeline

Cancer Lifeline is a community-based non-profit organization offering 24-hour, 7-day a week phone referral and supportive counseling. Callers to the line include cancer patients, their friends and relatives. We receive about 3500 calls a year from people needing to talk, wanting help in problem solving around issues related to cancer, or desiring names of resources (ranging from names of support groups to sources of wigs).

Last year, in an effort to respond to the needs of callers, Cancer Lifeline began the Family Support Program. This program provides meetings in the families' homes to give family members an opportunity to talk about their concerns and to raise questions related to the diagnosis as well as questions about how best to care for a family member.

My position with Cancer Lifeline is to facilitate these home meetings.

A recent example of a family meeting might best illustrate how families use this time together. In this case, mom had been recently diagnosed with pancreatic cancer. Both mom and dad lived together in a small town in Oregon and were visiting daughters living in the Seattle area. The family members at the meeting included mom and dad, their four daughters and a son-in-law. Mom had read about pancreatic cancer and felt she did not want to undergo treatment that seemed to offer such little promise. She was very concerned about the quality of her life and did not want to drag out her illness and pose a burden for her family. Her husband was having difficulty accepting the diagnosis and his wife's decision not to have treatment. The daughters were frustrated that their mother was not more open to exploring treatment

options and angered that she had made the decision not to prolong her life and burden the family. Further discussion revealed that pain management, coping strategies and an understanding of the grieving process were also issues for family members. Family members used the time to express their concerns, talk about their feelings and give feedback to each other about the handling of the cancer. I helped the family to clarify issues, provided names of resources for further information, talked to them about the grief process and self-care measures.

These meetings provide families with an opportunity to explore concerns important to them and to become further informed about issues related to cancer diagnosis. Families can request a meeting by calling the Cancer Lifeline business office, 461-3866, or the Lifeline at 461-4542. These meetings are offered at no charge, but donations are encouraged.

Continuing Education

Cancer—Its Effect on Self-Image and Intimate Relationships (VIDEOCASSETTE)

Sponsored by: Lincoln Medical Education Foundation

Rental: \$25/3 days - VHS (\$40 Beta)

Purchase: \$250 - VHS (\$265 Beta)

Contact: 402-483-4581

Cancer Video

Lincoln Medical Education Foundation

4600 Valley Road

Lincoln, NE 68510

Oncology Nursing '89 — Pain Management in the Oncology Patient

Sponsored by: Greater Baltimore Chapter ONS and the Health and Education Council, Inc.

Nov. 30 - Dec. 1 (Pre-Conference Seminar Nov. 29)

Stouffer Harborplace Hotel, Baltimore, MD

\$160.00 (Pre-Conference Seminar \$92)

Contact Hours: 11.4 (7.5 for Pre-Conference Seminar)

Contact: (301)686-3610

The Health and Education Council, Inc.

7201 Rossville Blvd.

Baltimore, MD 21237

First National Conference on Cancer Nursing Research

Sponsored by: American Cancer Society

Nov. 30 - Dec. 2, 1989

Hyatt Regency, Atlanta, GA

Contact Hours: Pending

Contact: (404)577-1234

Trish Greene, R.N., M.S.N.

Vice President for Nursing

1599 Clifton Rd. N.E.

Atlanta, GA 30329

AIDS: A Conference for Health Care Professionals

Sponsored by: American Red Cross/

Seattle-King County Chapter

December 12 (#WPAC 4893)

Red Cross Headquarters; Seattle, WA

\$45.00

CEU: 8.2 contact hrs.

Contact: 206-323-2345

American Red Cross

1900 25th Ave. S.

Seattle, WA 98144-4708

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Puget Sound Chapter of the Oncology Nursing Society

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PSONS NEWSLETTER

Published quarterly by the Puget Sound Chapter of the Oncology Nursing Society with the support of the American Cancer Society.
Editor: Kathleen Block

Letters, articles and announcements are requested from all PSONS members and other readers on topics of interest. Neither Puget Sound Chapter of the Oncology Nursing Society, the Oncology Nursing Society, the editorial board of the Quarterly, nor the American Cancer Society assume responsibility for the opinions expressed by authors. Acceptance of advertising does not indicate or imply endorsement by either of the above-stated parties.

Submit materials for publication to Kathleen Block, PSONS Editor, P.O. Box 85058, Seattle, Washington, 98145-1058. (206) 223-6819

PUGET SOUND CHAPTER HOTLINE!

PSONS has a telephone answering machine. For questions, concerns and comments regarding Chapter activities, please call:
(206) 462-5385
24 Hours

Leave your message, name, telephone number and best times to reach you, on the tape recording.

Calendar

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Dealing with Nicotine Addiction
Sponsored by: Visiting Nurse Service
December 13
8:30 a.m. - 10 a.m.
Free
Seminar Leader: Ken Manske
Visiting Nurse Service
400 N. 34th St.
Suite 109
Seattle, WA
For more information or to register, contact Anne Marie Maguire or Carol Taylor at 548-8100

Challenges & Opportunities in Cancer Nursing
Sponsored by Good Samaritan Cancer Center and Outreach Services,
Good Samaritan Medical Center
February 16-17, 1990
Sunburst Resort Hotel, Scottsdale, Arizona
Cost: \$80 (after January 25 - \$95); Students \$50
Contact Hours: Pending
Contact: 1-800-443-5972
Teri Quesnell or Deborah Todd
Good Samaritan Regional Medical Center
Outreach Services - 12A
1111 East McDowell Rd.
P.O. Box 2989
Phoenix, AZ 85060-2989

The Partner's Experience

Continued from Page 6

cancer. They are often unclear as to their expected role in the total experience, and as to how they can best support the women. They may be surprised by their own responses and often have no one with whom they can discuss their feelings. Many men appreciated the opportunity to talk about their experiences and many of them commented that this was the first time they had shared these thoughts and feelings.

Assisting the partner to meet his need for information and to aid in his understanding of treatment options can often help him to be more supportive of his mate. Many men need to feel included and want to be assured that they are doing all they can to be supportive. Nurses can help partners by including them in the care, answering questions, and by listening to their concerns.

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Research in this paper was supported by a research grant from the Center for Nursing Research, ROINR 0100, National Institute of Health.

CALL FOR EDUCATION EXHIBITS

The 1990 PSONS Symposium, February 23-24 will present a unique opportunity for interested persons to display educational materials for the benefit of all meeting participants. A small area has been reserved both days at the Bellevue Concourse for the display of posters, brochures, videos and any other educational materials that may have been used in the past.

If you are interested in displaying anything please note the following guidelines and return the bottom of this page to: Pamela Moore, PSONS, 2033 Sixth Avenue, #900, Seattle, WA 98121:

- all materials shall have been used prior to 1990, i.e. anything submitted to ONS this year is not eligible.
- all materials must have been developed and used by the person submitting
- materials do not necessarily need to have been accepted at a major meeting
- you do not have to attend the meeting in order to display your materials
- arrangements can be made to present videos if so requested

Further questions should be directed to Pam Moore at 441-9762

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NAME: _____

ADDRESS: _____

CITY/ STATE/ ZIP: _____

TELEPHONE: _____

I wish to display the following materials at the 1990 Annual Symposium on February 23 and 24 at the Bellevue Concourse:

(Specify items — brochures, posters, videos, etc.)

Place reserve the following space: (check where applicable)

_____ Table top (Specify how much)

_____ Floor space (Specify approximate dimensions)

_____ Wall space (Specify approximate dimensions)

_____ Video player

Please list any additional requirements/requests: _____

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Pamela Moore, PSONS, 2033 Sixth Avenue, #900, Seattle, WA 98121 as soon as possible.

Attention Committees!

Your meeting schedule can appear in every issue!! Please submit your calendar of events prior to each deadline (as listed elsewhere in this newsletter) so that we may keep our membership informed! Thanks!

NOVEMBER

S	M	T	W	T	F	S
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5	6	7	8	9	10	11
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26	27	28	29	30		

November

- 8 - PSONS Meeting
- 13 - Symposium Committee Meeting - 4:30 - 5:30 pm, Swedish Hospital B-Floor Conference Rm. #1. (Contact Judy Kornell at 467-5021 to confirm date/time)
- 16 - Government Affairs Committee - 7 pm, 8621 5th Ave. NE (Call 525-3727 for additional information.)
- 23 - *Happy Thanksgiving (USA)*
- 27 - Symposium Committee - 4:30 - 5:30 pm
- 29 - Winter 1990 Newsletter Deadline (NEWSLETTER WILL BE SENT TO MEMBERS IN JANUARY '90)

DECEMBER

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December

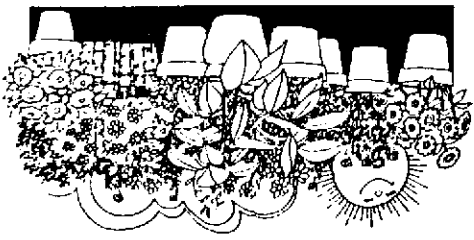
- 11 - Symposium Committee - 4:30 - 5:30 pm (see Nov. 13 for location information)
- 21 - Government Affairs Committee - 7pm (see Nov. 16 for location information)
- 23 - *Happy Chanukah*
- 25 - *Merry Christmas*

JANUARY

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January 1990

- 1 - *Happy New Year*
- 8 - Symposium Committee - 4:30 - 5:30 pm (see Nov. 13, 1989 for location information)
- 18 - Government Affairs Committee - 7 pm (see Nov. 16 for location information)
- 22 - Symposium Committee - 4:30 - 5:30 pm (see Nov. 13 for location information)



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