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*Further research is needed to develop effective interventions to lighten the emotional burdens borne by family caregivers of relatives with cancer.*

# Enhancing Caregiver Outcomes in Palliative Care

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**Background:** Families are increasingly replacing skilled health care workers in the delivery of unfamiliar complex care to their relatives with cancer, despite other obligations and responsibilities that characterize their lives.

**Methods:** The authors review the needs of cancer caregivers and describe intervention strategies not only presented in the literature, but also implemented in their own program of research to address those needs during the palliative phase of cancer.

**Results:** Research suggests that developing interventions that teach caregivers to become proficient in the physical and psychological aspects of patient care will benefit both patients and caregivers.

**Conclusions:** Despite the fact that a cancer diagnosis can cause major changes in family roles and functioning, as well as increased responsibility for complex care being absorbed by family caregivers, data supporting the effectiveness of caregiver interventions have been limited.

## Introduction

There is a growing body of literature supporting the fact that cancer is a disease affecting not only the person diagnosed but also the family.<sup>1,3</sup> The location of care for the seriously ill has quickly changed from the hospital, once the primary setting for care, to the home. Families are increasingly replacing skilled health care workers in the delivery of unfamiliar complex care to their ill family members despite the other obligations and responsibilities that characterize their lives. The economic impact of family involvement in

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the day-to-day experiences of living with cancer can be profound, especially due to the unavailability of support services in many geographic areas.

This demand on families is not new, although the caregiver role has changed dramatically from promoting convalescence to providing high technology care and psychological support in the home. Members of the patient's family are of vital importance in meeting the patient's physical and psychosocial needs and in accomplishing treatment goals.<sup>4,5</sup> The burden of caring for patients with a diagnosis of cancer, however, may adversely affect family caregivers who lack adequate resources or who are insufficiently prepared for this new, complex role. There is mounting evidence that changes in family roles and the burden placed on family caregivers may have negative effects on the quality of life of both cancer patients and their caregivers,<sup>6</sup> particularly during advanced stages of cancer. Despite growing evidence that significant others are assuming increasing responsibility for cancer care and that this responsibility has detrimental effects, there are little data that document the efficacy of standardized intervention strategies targeted at cancer caregivers, especially during specific time periods along the illness course.

Originally, palliative care was linked to situations in which patients were clearly near the end of life. However, the use of new, aggressive cancer treatments has forced us to reconceptualize palliative care as services integrated throughout the patient's and family's illness experience.<sup>7</sup> Palliative care by definition focuses on the multidimensional aspects of patients and families, including physical, psychological, social, spiritual, and interpersonal components of care. These components of care need to be instituted throughout all phases of the illness trajectory, not only at the point when patients qualify for hospice services. Palliative care also needs to be available and delivered across a variety of settings and not limited to inpatient units. The primary purpose of palliative care is to enhance the quality and meaning of living and dying for both patients and family caregivers. To date, health professionals have not utilized the potential of palliative care to maximize clinical outcomes for patients and family caregivers.<sup>8</sup>

Scientific advances have allowed us to extend the life span of cancer patients despite their complex and chronic health problems. The burden of their care usually falls on families who are often not adequately prepared to handle the physically and emotionally demanding needs that are inherent in cancer management. In addition, family members have increasingly become primary care providers within the context of other demands such as employment outside the home and competing family roles. The necessity among most of

our nation's family members to assume employment outside the home and to alter those arrangements when faced with a sick relative has created an as yet immeasurable strain on physical, emotional, and financial resources. The increasing responsibilities of the family to provide care in the face of limited external support and the consequences of that caregiving for patient and family present challenges for clinicians and provide unique opportunities for researchers.<sup>9</sup> This article presents an overview of the needs of cancer caregivers. We also describe intervention strategies reported in the literature as well as strategies implemented in our program of research that have been used to address those needs during the palliative phase of cancer.

This paper evolved from our comprehensive review of the impact of interventions on cancer caregivers for the *Annual Review of Nursing Research*<sup>10</sup> and is limited only to those studies that were judged applicable to palliative care. Our original intent was to limit the review to studies that defined specific outcomes; however, a lack of well-delineated outcome variables was revealed as a major gap in the literature. Thus, some studies that did not include outcome variables were included in the review because of their potential use in future studies.

## Family Caregiver Needs and the Impact of Caregiving

A number of studies have identified the needs of family members providing care to patients with cancer. Recognition of the burden that the diagnosis and treatment of cancer places on family members has appeared in the cancer literature since the early 1980s. A study by Grobe and colleagues<sup>11</sup> identified methods of education that were provided for 87 patients in the advanced stages of cancer and their homebound caregivers. This study reported that families perceived that little, if any, education was provided to them. Hinds<sup>12</sup> conducted a study examining the perceived needs of 83 family caregivers. Findings indicated that family members felt inadequately prepared to provide care for their sick relatives in the home and identified numerous informational and skill deficits.

Oberst and colleagues<sup>13</sup> conducted a study to assess family caregiving demands and to examine the caregivers' perceptions of providing care in the home environment. Caregivers reported that the majority of their time was spent providing transportation, offering emotional support, and maintaining the household. More than one third of caregivers reported a lack of assistance from health professionals in providing care. In addition, caregiver demands escalated as the treat-

ment regimen progressed. Another study<sup>14</sup> lends support to the isolative and stressful nature of caregiving in that 85% of a sample of cancer caregivers failed to utilize available resources to assist them in caregiving activities. In addition, 77% of the sample reported increased stress, and 28% required medication to help them cope with the burden associated with caregiving.

A number of review articles describe the impact of cancer on the family and family caregivers.<sup>1,2,15-18</sup> These accounts present persuasive documentation that caring for a person with cancer is a stressful experience and can have major emotional and physical consequences for caregivers. In their review, Sales and colleagues<sup>19</sup> concluded that a significant number of cancer caregivers exhibited psychological distress and physical symptoms. Predictors of caregiver distress included a number of illness-related patient variables including more advanced stages of cancer, disability, and complex care needs.

Weitzner and colleagues<sup>20</sup> noted the presence of increased depressive symptoms, anxiety, psychosomatic symptoms, restrictions of roles and activities, strain in marital relationships, and poorer physical health among family caregivers. Various dimensions of caregiver reactions have been identified by previous researchers.<sup>21-23</sup> Mor and colleagues<sup>24</sup> divided caregiving tasks into categories of personal care, instrumental tasks, and transportation. Each category was associated with greater demands as physiological factors of patients worsened or if their caregivers associated care with a high level of burden.<sup>25,26</sup> Foxall and Gaston-Johansson<sup>27</sup> described objective vs subjective burden in family caregivers of hospitalized bone marrow transplant patients. In their study, objective burden was linked to all health outcomes and occurred during critical time periods following bone marrow transplantation. Wallhagen<sup>28</sup> studied caregiver perception of caregiving demands and concluded that caregivers viewed personal demands (such as being with the patient as he or she declined) as more difficult than task demands. Given and colleagues<sup>21,29</sup> reported that patients' symptoms and symptom distress, declining mobility, and dependency with instrumental activities were linked to significant burden in family caregivers.

In general, the literature on caregivers of cancer patients highlights (1) the increasing number of patients who are being treated in ambulatory clinics with ongoing complex care needs, (2) the increasing number of complex tasks assumed by family caregivers, (3) the high proportion of unmet caregiver needs, (4) the subjective nature of the caregiving experience that encompasses both positive and negative elements, and (5) the conceptualization of caregiver burden as positively linked to negative reactions to caregiving.

## Framework

The trajectory framework developed by Corbin and Strauss<sup>30</sup> places living with cancer within the context of an illness with characteristics particular to chronicity. The trajectory framework provides a conceptual basis for understanding and shaping the experience of individuals living with cancer, especially as the disease shifts from controlled to progressive. The illness trajectory denotes the fluctuating, variable course of the illness over time. The trajectory is shaped by the vision held by each individual (patient, caregiver, nurse, physician) involved with the illness and its management. Trajectory management denotes the processes by which the illness course is shaped and includes medical and nursing interventions as well as complementary therapies and self-care strategies. Eight phases of the chronic illness trajectory (Table) have been proposed and defined.<sup>31</sup> The initial or pretrajectory phase occurs before any signs and symptoms are present. The trajectory onset phase occurs with the first onset of signs and symptoms and includes the diagnostic period. The crisis phase is when a potentially life-threatening situation arises (eg, a situation necessitating some form of emergency care such as an acute hospitalization). The acute phase follows the crisis phase and refers to the period when the patient's symptoms can be controlled by a prescribed regimen. Once symptoms are controlled, the stable phase evolves. The unstable phase is when the patient's symptoms are uncontrolled by the previously adopted regimen. The downward phase is characterized by progressive deterioration in mental and physical status, and the dying phase refers to a period of weeks, days, or

Eight Phases of the Chronic Illness Trajectory

Phase	Definition
1. Initial (or pretrajectory)	No signs or symptoms are present
2. Trajectory onset	The first signs and symptoms appear (including the diagnostic period)
3. Crisis	A potentially life-threatening situation occurs (eg, a condition requiring emergency care)
4. Acute	Symptoms require control with a prescribed regimen
5. Stable	Symptoms are managed and controlled
6. Unstable	Symptoms become uncontrollable by the previously adopted regimen
7. Downward	Mental and physical status deteriorates
8. Dying	Death is preceded by a period of days, weeks, or hours

hours preceding death. Theoretically, for the most effective management of the illness course, patients and caregivers require different types of interventions at various chronic illness phases. The first step in planning interventions using this framework involves determining where the patient falls on the trajectory. Once that determination is made, a plan of care with specific interventions for patients and caregivers can be implemented. Palliative care needs to begin with the acute phase and continue through the dying phase.

Northouse and Peters-Golden<sup>32</sup> identified two categories of intervention strategies — providing information and offering support — in which they examined the caregiver literature. However, there was a paucity of research to review, given the low number of intervention studies available. Selected studies that represent some of their critical findings are summarized.

## Informational Interventions

The value of providing information to cancer caregivers has been reported consistently in the research literature.<sup>33,34</sup> Reported in the literature with equally consistent frequency, however, is the difficulty that caregivers have in obtaining information from healthcare professionals, particularly physicians and nurses.<sup>33,35</sup> Despite the fact that it is often difficult to obtain, caregivers report that information is a critical element in helping them cope with the patient's illness.<sup>36,37</sup> Caregivers appear to be in the greatest need of information at the time of diagnosis,<sup>37</sup> during the hospital period (especially at the time of surgery),<sup>37,38</sup> at the start of new treatments,<sup>34</sup> at the time of recurrence,<sup>39</sup> and during the dying phase.<sup>40</sup>

In addition to providing information about the physical aspects of the illness, caregivers need to learn more about the emotional aspects of illness and recovery.<sup>32</sup> According to Oberst and Scott,<sup>41</sup> caregivers need to be informed about what to expect regarding the emotional aspects of the illness for both themselves and the patient. With this information, caregivers can be reassured proactively that their own psychological distress, as well as that of the patient, is to be expected and is not a sign of poor coping.

A number of studies illustrate educational interventions. One of the most successful palliative care interventions was developed by Ferrell and colleagues.<sup>42</sup> They examined the impact of a cancer pain education program on family caregivers of elderly cancer patients. Fifty family caregivers of elderly cancer patients who were at home and experiencing cancer-related pain were recruited for participation in this

quasi-experimental study. The patients were receiving active treatment (54%) or supportive care (35%), were newly diagnosed (67%), or were in remission (5%). Caregiver outcomes examined as a result of the intervention included quality of life, knowledge about pain, and caregiver burden. Caregivers reported significant burden associated with pain management, particularly in the psychological realm. The pain education program proved efficacious in terms of improving caregiver knowledge and quality of life. This study highlights the nature of many nursing studies in terms of describing interventions that teach caregivers to become proficient in the physical aspects of patient care. Also, this type of intervention has the added effect of indirectly improving the well-being of the caregiver.

## Support Interventions

Support interventions have been developed to provide direct psychological services to family caregivers, often from different disciplines, eg, social workers, psychologists, chaplains, and nurses. The sources of support available to cancer patients are many and varied, ranging from one-on-one interactions to a myriad of formal support groups and networks. Sources of support for family caregivers have lagged far behind those provided for patients.<sup>32</sup> Spouses in particular report little support from health professionals, which is often due to limited contact with physicians and nurses in hospital and outpatient settings.<sup>43,44</sup> This process would be improved if the referrals of family caregivers to mental health professionals increased during the critical phases of the patient's illness.

There is a dearth of information regarding the effectiveness of supportive interventions with cancer caregivers despite the implications from studies of informational interventions that many are inadequate. Sabo et al<sup>45</sup> developed a support program for husbands of women with breast cancer after surgery. Although only 6 of 24 husbands participated, attendees reported significantly more communication with their wives about the mastectomy than did husbands in the control group. It was also determined that the support group promoted increased communication between husbands and wives regarding intimacy, recurrence, and premature death.

Houts and colleagues<sup>46</sup> described a prescriptive problem-solving model for how care should be managed at home and what kind of information and training family caregivers should receive. The Prepared Family Caregiver Model summarized in the acronym COPE (Creativity, Optimism Planning, and Expert information) teaches caregivers how to develop and imple-

ment plans that address both medical and psychosocial problems and coordinate with care plans of health professionals. The model is based on extensive research regarding unmet needs of caregivers and problem-solving training and therapy. It is designed to help patients and family caregivers throughout the illness trajectory. According to the authors, the program empowers family caregivers and patients to cope with illness and helps to moderate caregiver stress. Judging the merits of this program is limited by the lack of outcomes to document the program's effectiveness.

Blanchard and colleagues<sup>47</sup> reported on the effects of a six-session intervention with spouses of cancer patients who were diagnosed more than 3 months before the recruitment effort began and who were not eligible for a hospice. They used a problem-solving intervention to help spouses solve individually identified problems. Follow-up at 6 months showed no significant impact associated with the intervention, even among those spouses who were most distressed. Interestingly, the patients of spouses who received the intervention showed a significant decline in depression. It could not be determined whether this was related to altered communication between spouses and patients following the intervention or relief on the part of patients that spouses were receiving help. Findings suggested the importance of studying the spouse/patient dyad as opposed to each person individually.

Heinrich and Schag<sup>48</sup> developed the "Stress and Activity Management" (SAM) intervention for spouses and cancer patients who had been treated or were presently receiving treatment for their cancer and who had been diagnosed 2 years prior to the intervention. The intervention consisted of structured, small group meetings held weekly for 2 hours over a 6-week period. Groups were designed to (1) educate patients and spouses about cancer and its impact, (2) teach specific skills, such as relaxation techniques, physical and recreational activities, that could be used to manage stress and daily problems, and (3) promote problem solving. Of 92 patients who met eligibility criteria, 51 participated in the study along with 25 of their spouses. Twenty-six patients and 12 spouses were randomized to the treatment group and 25 patients and 13 spouses to the control group. The primary outcome variables included psychological adjustment, depression, and anxiety that improved for both treatment and control groups and supports the notion of natural improvement in psychological status that occurs over time. The SAM patients and spouses reported high satisfaction with the intervention, although due to the self-selected nature of the treatment and control groups, it is likely that the control subjects also would have been satisfied. Support for the unique and positive impact of the

SAM treatment intervention came from the improvement in scores on the Cancer Information Test indicating that the program increased participants' knowledge about cancer and coping. This finding is noteworthy because most patients and spouses had been living with cancer for approximately 2 years and demonstrated minimal knowledge about their illness. SAM spouses in particular were more satisfied with the education and support they received than the control spouses who received the usual care and were not routinely included in physician office visits. Despite the small number of subjects studied and the self-selected nature of the sample, this study is noteworthy in several respects: a well-described replicable intervention, randomization, and clear delineation of outcome variables.

Goldberg and Wool<sup>49</sup> provided a counseling support intervention to newly diagnosed lung cancer patients and their spouses. The intervention consisted of 12 sessions that were geared toward specific goals such as maintaining support systems, promoting emotional expression, and facilitating negotiation of the health care system. Following intervention, no difference was found in psychological functioning of the control compared with the intervention groups. The authors suggested that the lack of intervention effect may be due to the relatively positive adjustment of couples in both groups reported before the start of the program. This again highlights the possibility that caregiver studies may be recruiting subjects who are accessible and available and thus least in need of intervention. In addition, caregivers who completed these studies were often those who cared for patients with early-stage disease, whereas those caregivers of patients with late-stage disease declined to join or the patients died before the study ended.

Innovative recruitment strategies need to be developed to target various complexities among caregivers (eg, those with limited resources, those needing respite services, and those having poor coping abilities) to ascertain whether interventions would prove to be effective if directed toward those who needed them most. In this vein, Pfefferbaum and colleagues<sup>50</sup> described a comprehensive program for newly diagnosed breast cancer patients and their family members that followed families preoperatively and postoperatively and impacted positively on coping outcomes. A mental health professional worked with the surgical team to provide counseling to patients and family members who were identified in advance as being in need of assistance. This notion of identifying caregivers who are at high risk for problems in specific areas and tailoring interventions to their special needs seems to be an important direction for research as implicated by the lack of positive findings in some of the studies reviewed.

## Overview of Our Program of Research: Patient and Caregiver Outcomes

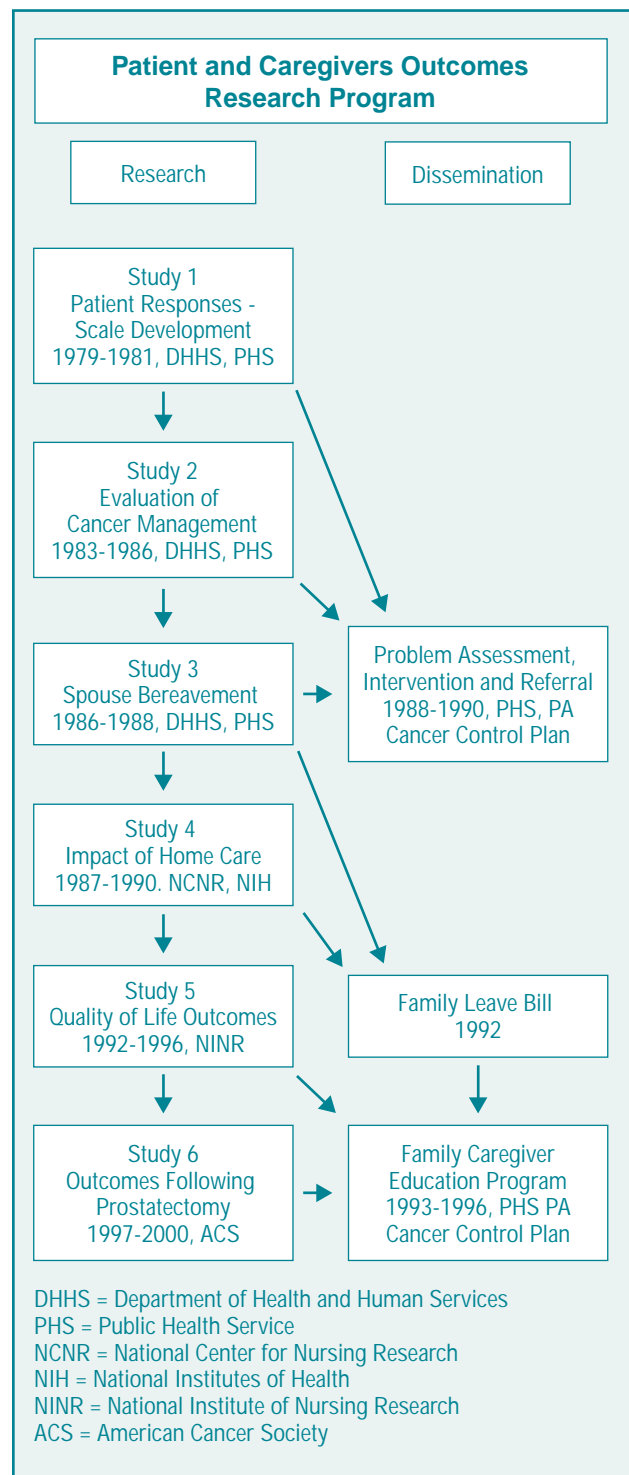
Approximately 25 years ago, the Patient and Caregiver Outcomes Research team began a program of research based on the assumption that cancer is a crisis for the person diagnosed with cancer and for the family. Initially, a series of studies were designed using the

crisis framework.<sup>51</sup> This framework was subsequently expanded to include the management of the illness trajectory as critical events occurred over the course of the illness.

Our research was designed to help patients and caregivers during the patients' illness, and the caregiver interventions were apart from the management of the patients' illness. The Figure presents a diagram of the interrelationship of the studies. Initially in the 1970s, our first federally funded study, "Patient Responses to Psychosocial Variables (#NU00730)," began with the development of two outcome measures: the Symptom Distress Scale (SDS) and the Enforced Social Dependency Scale (ESDS) in which we established psychometrically sound scales to evaluate patient outcomes.<sup>52,53</sup> Both scales have been widely used and have documented that patients experience a range of distressing symptoms and functional limitations associated with cancer therapies and the disease itself. To develop interventions that would prepare family caregivers to care for patients, it was essential to document the extent of the needs of the patients, and these scales facilitated that process.

Building on that work, we designed several clinical trials that tested the effects of home care interventions on cancer patient outcomes and caregiver outcomes. These trials were funded by the National Cancer Institute (NCI), the National Institute of Nursing Research (NINR), and the American Cancer Society (ACS). Generally, results suggest that home-based interventions provided by advanced practice nurses assisted patients in minimizing symptom distress and maintaining independence longer compared with patients who received no nursing care in their homes. In addition, the interventions have been shown to assist patients with improving health outcomes, and they have enhanced caregiver outcomes. In the remainder of this paper, we present an overview of our program of research related to caregiver outcomes.

The second study, "Evaluation of Cancer Management (#NU01001)," was a clinical trial conducted to access the efficacy of a home care intervention provided by advanced practice nurses in the community in Seattle.<sup>54</sup> A total of 163 patients with a diagnosis of lung cancer were assigned to one of three groups: an oncology home care (OHC) group that received care from oncology advanced practice nurses, a standard home care (SHC) group that received care from the traditionally prepared home care nurses, or an office care (OC) group that received whatever care they required except home care. All patients recruited into this study were diagnosed with stage III lung cancer and had a limited life expectancy. Patients who received care from the OHC and SHC nurses remained physically and



Interrelationship of research studies to dissemination activities.

socially independent for a longer period of time than patients who did not receive such services. In addition, patients in the OHC group had fewer rehospitalizations for symptoms and complications of their cancer therapies compared with the other two groups. This second study revealed the extreme burden the caregivers were experiencing and the increased responsibility they were assuming as the patients' disease shifted from a chronic illness to a terminal illness.

We subsequently secured a third grant, "Spouse Bereavement Study (#NR-01626)," to examine the psychological distress of family caregivers before and after the death of the enrolled patients with lung cancer.<sup>55</sup> The purpose of this study was to test the effects of the OHC intervention for terminally ill lung cancer patients on spousal distress during the bereavement period. The sample was limited to patients who died and their surviving spouse. Forty-six lung cancer patient and spouse dyads of the 100 patients with spouse caregivers of the original 166 patient sample were followed from entry into the study at 2 months after diagnosis and at 6-week intervals until the death of the patients. Advanced practice nurses assisted dying patients and their families through the living-dying transition. The intervention consisted of teaching family caregivers how to provide personalized care in the home; this focused on comfort and advanced symptom management. The advanced practice nurse served as the central coordinator for care, and 24-hour access was provided. It must be emphasized that the spouse caregiver groups compared in this study (OHC, SHC, and OC) received treatment only while the patients remained alive. Yet the outcome variable (spousal psychological distress) was measured at four time periods — 6 weeks, 6, 13, and 25 months — after patients' deaths. In caring for patients dying of lung cancer, the OHC nurses were able to reduce the overall level of psychological distress among the patients' bereaved spouses. We believe this was the first empirical evidence to link specific nursing models of home care for the dying with bereavement outcomes among survivors. Compared with spouses in the SHC and OC groups, the intensity of psychological distress experienced by spouses in the OHC group differed clinically as well as statistically. These longitudinal measures made it possible not only to determine that spouses in the OHC group were less distressed but also to assess the duration of effectiveness of the OHC model toward preventing or reducing distress. It is striking that lower levels of psychological distress were sustained within this group for a period of 13 months after the home care intervention. By the 25th month, levels of psychological distress among the three groups no longer significantly differed. Perhaps if nursing care or psychological support of the family had been extended beyond the patient's death into the period of bereavement, the effects of the OHC group

may have been sustained even longer. This warrants further study, particularly in light of the findings of Stetz and Hanson,<sup>56</sup> which perceived that needs among family caregivers change between the period of active caregiving and the period of bereavement.

The fourth grant, "Impact of Home Care (#NR01914)," was a quasi-experimental study designed to evaluate the impact of home care services on patients' symptom distress, mental health, and enforced social dependency. It also analyzed the health perceptions of cancer patients and family caregiving responsibilities and caregiver burden following an acute hospital stay.<sup>57</sup> This study extended our earlier work by (1) exploring the impact of home health care services on patients diagnosed with cancers of various sites, (2) including two critical points on the illness trajectory — the initial diagnostic phase and the initiation and monitoring of aggressive cancer treatments, and (3) including patients who had at least one complex need at discharge and were at high risk for the development of further physical and psychosocial problems. A total of 233 patients with multiple solid tumor diagnoses were enrolled in the study, 115 of whom were newly diagnosed. The others were admitted for ongoing management of their cancers. The caregiver sample included 103 family members (77 were spouses, 11 were parents, and 15 were children or siblings). Data were obtained at hospital discharge and at 3 and 6 months following discharge. A sample of 34 subjects (17 patients and 17 caregivers) for whom both patient and caregiver outcomes were completed on all three occasions was analyzed. The main reason for the high rate of attrition was patient mortality. Findings indicated that patients were being discharged from the hospital with ongoing acute care needs. By 3 and 6 months post-hospitalization, patients' conditions stabilized or improved, but their caregivers continued to report ongoing levels of burden. Patient outcomes strongly correlated with caregivers' financial burden, impact on schedule, and physical caregiving responsibilities at 3 and 6 months.<sup>6</sup>

The fifth study, "Quality of Life Outcomes (#NR03229)," was designed as a randomized clinical trial to examine changes in the psychological status of caregivers of newly diagnosed postsurgical older cancer patients at discharge and at 3 and 6 months later. Within a week after discharge from the hospital, patients were randomly assigned to either the treatment or control group. Patients in the treatment group received a Standardized Nursing Intervention Protocol (SNIP) provided by advanced practice nurses. This consisted of weekly home visits and telephone calls 4 weeks after discharge. The nursing interventions included assessing and monitoring the patient's condition, managing symptoms, and teaching caregivers how

to problem solve, administer medications, and provide self-care behaviors. Caregiver outcomes were measured using standardized measures. Overall, caregivers' psychological status improved from baseline to 3 months and stabilized thereafter; but among caregivers with physical problems, the psychological status of those in the treatment group declined over time compared with those in the control group. We concluded that caregivers of cancer patients who had physical problems of their own were at risk for psychological morbidity as they assumed the caregiving role.<sup>58</sup>

The sixth study, "Outcomes Following Prostatectomy (#TPRB-98-010PBP)," is currently in its final year of a 3-year investigation. The purpose of this study is to test the effects of home nursing interventions provided by advanced practice nurses on patient and caregiver outcomes following curative surgery for prostate cancer. Patients and their spouse caregivers are recruited prior to surgery, and outcome data are collected postsurgery surgery and at 1, 3, and 6 months following hospitalization. A total of 138 men and their spouses have been recruited. This study builds on our previous work in that the intervention provided by advanced practice nurses is extended from 4 weeks to 8 weeks. In the immediate postoperative period, attention is focused on management of symptoms including pain, bladder spasms, constipation, fatigue, sleep disturbances, and edema.<sup>59</sup> Patients and caregivers are informed about postoperative complications and taught how to recognize warning signs to prevent emergencies. There is considerable emphasis on patient teaching, which highlights the challenge and foreign nature of managing a chronic illness. Prior life experiences and formal knowledge seem to be of little help immediately after surgery. Once the patient's physical recovery is stable, the intervention is expanded to include bladder training and psychological support to increase intimacy and communication skills between the dyad.<sup>60</sup> In this study, we are purposefully linking the nursing interventions directly to patient and caregiver outcomes to demonstrate the exact mechanism. One of the critical aspects of the intervention for caregivers is helping them assume the role of caregiving. Because they are in the midst of the same crisis of coming to terms with the existential concerns of a new cancer diagnosis or other critical event, they do not readily realize or accept that a caregiving role exists.

## Translation of Our Results to Policy and Practice

We have used our research outcomes to influence policy at the federal level, to establish guidelines for discharging patients from local hospitals, to establish

programs to train health professionals, and to implement programs to prepare family caregivers. In the mid 1980s, our team was involved with gathering legislative support for the Family Leave Bill, but it wasn't until 1993 that the bill was signed and made into law. This bill provides family caregivers with the right to take a leave to care for an ill family member with the assurance that a job will be available upon return.

Another area in which we have campaigned for change is related to the criteria used to make referrals for home care at the time seriously ill patients are discharged from the hospital. If patients with complex physical problems are discharged to their home to a family caregiver whose own physical health is compromised, then additional referrals and home services need to be provided. Also, if formal home services are requested and obtained for the ill patient, the services need to be expanded to include assessment and monitoring of the ill caregiver. Care needs to be provided to the family unit as a whole, not only to the designated ill member for whom the referral was made. This ensures both patient and caregiver the opportunity to become stabilized.

The timing of our research coincided with two separate research studies commissioned by the Cancer Control Advisory Board of Pennsylvania Department of Health. Houts and colleagues<sup>61,62</sup> examined the unmet psychosocial needs of cancer patients and their caregivers. In the first study, a randomized survey of 629 cancer patients and 397 caregivers, they reported that 51% of the sample had at least one unmet need. The most cited unmet need involved emotional support. In the second study, a stratified random sample of 433 family caregivers of patients who died, they reported that 72% of the patients had at least one unmet need during their final month of life. The needs cited most often included activities of daily living (42%), emotional support (21%), physical assistance (21%), communication problems with medical staff (20%), and medical insurance (19%). Subsequently, the Board funded a statewide continuing education program to teach health care professionals to (1) identify the psychosocial needs of patients and caregivers, (2) intervene within the scope of their professional practice, and (3) refer patients and families to resources within the health care institution or in the community at large. Our team was funded to implement this program jointly directed by a nurse and social worker. The structured intervention in our previous research formed the content for the curriculum used throughout all four geographic locations in the state of Pennsylvania. The outcomes of the program are reported elsewhere.<sup>63</sup>

The next logical step to bring about changes in patient and caregiver outcomes was to empower caregivers to be prepared to provide care. We used our

established network of nurses and social worker teams in 19 community hospitals in the greater Delaware valley area to develop programs in their own institutions. The goal of the program was to educate and support caregivers who would care for cancer patients at home. The program outcomes were achieved by preparing oncology nurses and social workers to offer a 6-hour psychoeducational program for caregivers and to put caregivers in touch with local resources to meet their needs in the community. Between April 1994 and April 1997, 504 caregivers participated in 79 family caregiver education programs. Some of these programs have been sustained in the community hospitals. Findings confirmed the chronic and consuming nature of cancer caregiving. Data indicated that the caregivers' perception of burden did not worsen even when caregiving tasks increased in intensity. Caregiver perceptions of their own health actually improved over time. In addition, the number of caregivers who said they were well informed and confident about caregiving after program attendance increased over time. A complete description of program and its content are reported elsewhere.<sup>64</sup>

## Conclusions and Directions for Future Study

Despite the fact that a cancer diagnosis can cause major changes in family roles and functioning in addition to increased responsibility for complex care being absorbed by family caregivers, data supporting the effectiveness of caregiver interventions have been limited at best. In this article, we presented an overview of the needs of family caregivers, discussed the types of interventions that can meet those needs, and summarized the development of our program of research and how we have implemented the findings to change policy and practice. Additional work is needed with regard to the identification of factors that predict those caregivers at highest risk for distress. Our work has consistently shown that caregivers who are ill themselves have difficulty caring for patients with complex care needs. Interventions for those experiencing high levels of distress also need to be tested at different points in the cancer trajectory to determine, for example, if interventions are most effective at certain points in the illness, whether interventions can be preventive across illness stages, or whether different types of caregiver interventions need to be implemented at different stages of the cancer. In many studies reviewed, the authors did not always identify the patients' stage of disease. Therefore, it was unclear where they were positioned on the illness trajectory.

Overall, interventions targeted at caregivers of cancer patients have been developed by nurse and non-

nurse researchers. In general, nurses tend to develop interventions that are geared toward increasing the proficiency of caregivers to address the physical and psychosocial needs of patients. Nonnurse researchers tend to develop a greater abundance of individual and group psychological interventions directed specifically at caregivers. Since research examining the efficacy of caregiver interventions is clearly in its infancy, the field would be greatly enhanced with an emphasis on interdisciplinary efforts that capitalize on each discipline's theoretical orientation and clinical strengths. There is also a need to test caregiver interventions over time with homogeneous groups of patients at specific points on the illness trajectory. Researchers need to develop and use a common set of outcome measures that are sensitive to change. Positive results will come from studying only those populations of caregivers who are at high risk for developing their own psychological and physical problems.

Current trends in health care focus on cutting costs in acute care settings that result in a shift of care from the hospital to the home. Despite what may seem to some to be societal cost savings and enhanced efficiency of the health care system, the locus of the financial, physical, and emotional burden of cancer care is often shifted to family caregivers who may incur emotional, economic, and physical consequences. Intervention initiatives underscore the need for caregiver advocacy in these changing times.

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