

LEADERSHIP & PROFESSIONAL DEVELOPMENT

A Program of Research on Patient and Family Caregiver Outcomes: Three Phases of Evolution

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Since the 1990s, interest has increased in influencing patient outcomes by translating scientific findings into practice. The Committee on the Quality of Health Care in America, Institute of Medicine (2001), concluded that a large gap exists between research and practice in all of health care. To fill the gap, scientific evidence must meet established criteria used to judge whether research findings are ready for adoption (Titler et al., 2001). In addition, strategies must exist to facilitate the process of translating evidence, its adoption, and its sustainability. In this article, the evolution of the author's and her team's research program is described in three phases: phase 1, instrument development; phase 2, clinical trials testing of the role of the advanced practice nurse (APN); and phase 3, translation methods. The three phases summarize how one team of nurse researchers influenced changes in policy and clinical practice over time.

Phase 1: Instrument Development

More than 28 years ago, Jeanne Benoliel, DNS, FAAN, and I began a program of research related to patient and caregiver outcomes in cancer care. As a clinical nurse specialist and researcher, I worked to demonstrate the positive effects of interventions performed by APNs on relieving treatment-related symptoms and improving functional abilities. In 1976, we quickly learned that valid and reliable measurements were not available. As a result, the first phase of our research focused on developing scales to measure symptoms and functional status. Through a series of small pilot projects and a federally funded grant (McCorkle & Quint-Benoliel, 1983), the Symptom Distress Scale (McCorkle & Young, 1978) and the Enforced Social Dependency Scale (Benoliel, McCorkle, & Young, 1980) were developed. The impact of the worldwide use of the Symptom Distress Scale since 1986 has been significant. The scale has been used as an outcome measurement by investigators in more than 10 countries, and the original article about the scale in *Cancer Nursing* has

been cited in more than 330 scientific studies. It has been used in investigator-initiated research, in clinical trials through cooperative groups in the United States and Europe, in clinical trials through pharmaceutical companies, and in documenting support for the release of new drugs by the U.S. Food and Drug Administration. The scale also has been an important standard for the development of subsequent scales, including the Rhodes Adapted Symptom Distress Scale (Rhodes, Watson, Johnson, Madsen, & Beck, 1987), the Memorial Symptom Assessment Scale (Chang, Hwang, Feuerman, Kasimis, & Thaler, 2000; Portenoy et al., 1994), and the Given Symptom Severity Index (Given et al., 1993). Our work also paved the way for the documentation of fatigue and subsequent Fatigue Initiatives through Research and Education (FIRE®) (Mock et al., 1998), the pain initiatives (Ferrell, Grant, Chan, Ahn, & Ferrell, 1995), and, most recently, Sarna et al.'s (2004) documentation of symptom clusters.

Phase 2: Clinical Trials Testing

Once we had psychometrically valid and reliable scales to measure our outcomes, we were ready to move to the second phase of our research, that of testing the impact of the role of the APN. Through a series of clinical trials, we have been able to demonstrate consistent findings across several studies. What follows is a summary of the results from each study. (A list of the individually funded grants and related publications are listed in Figure 1.)

We designed several clinical trials that tested the effects of homecare interventions provided by APNs on patient and caregiver outcomes, funded by the Division of Nursing Public Health Service, National Center for Nursing Research, National Cancer Institute, National Institute of Nursing Research, and American Cancer Society.

The first study, a clinical trial titled "Evaluation of Cancer Management," was conducted to test the efficacy of a homecare intervention provided by APNs in Seattle, WA (McCorkle

et al., 1989). One hundred sixty-six patients diagnosed with lung cancer were assigned to one of three groups: an oncology homecare group that received care from oncology APNs, a standard homecare group that received care from traditionally prepared homecare nurses, or an officecare group that received whatever care patients required except home care. Patients who received care from the homecare nurses remained physically and socially independent longer than those who did not receive such services. The APNs assisted patients in minimizing symptom distress and maintaining independence longer in comparison to patients who received no nursing care in their homes. In addition, patients who received oncology home care had fewer rehospitalizations for symptoms and complications of their cancer therapies compared to patients in the other two groups.

The study revealed the extreme burden that caregivers were experiencing and the increased responsibility that the caregivers were assuming for their loved ones. As a result, we secured a second grant, titled "Spouse Bereavement Study," to examine the psychological distress of family caregivers before and after the death of the enrolled patients with lung cancer (McCorkle, Robinson, Nuamah, Lev, & Benoliel, 1998). The purpose of the bereavement study was to test how the oncology homecare intervention for terminally ill patients with lung cancer affected spousal distress during the bereavement period. Forty-six dyads of patients with lung cancer and their spouses (from the 100 patients with spousal caregivers of the original 166-patient sample) were followed from entry into the study, at two months after diagnosis, and at six-week intervals

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- Title:** "Cancer Patient Responses to Psychosocial Variables"
Source: National Department of Health, Education, and Welfare; National Cancer Institute Grant Proposal. Funded by the Division of Nursing, Public Health Services
Grant number: NU 00730
Amount: \$97,512 (direct costs)
Dates: 1979–1981
Related publications:
 Benoliel, J.Q., McCorkle, R., & Young, K. (1980). Development of a social dependency scale. *Research in Nursing and Health*, 3, 3–10.
 Donaldson, G., McCorkle, R., Georgiadou, F., & Benoliel, J.Q. (1986). Distress, dependency, and threat in newly-diagnosed cancer and heart patients. *Multivariate Behavioral Research*, 21, 267–298.
 Drier, M., & McCorkle, R. (1984). Patient concerns at 3 and 6 months postdiagnosis. *Cancer Nursing*, 7, 235–241.
 Germino, B., & McCorkle, R. (1985). Acknowledged awareness of life-threatening illness. *International Journal of Nursing Studies*, 22(1), 33–44.
 McCorkle, R., & Benoliel, J.Q. (1983). Symptom distress, current concerns and mood disturbance after diagnosis of life-threatening disease. *Social Science and Medicine*, 17, 431–438. (major research paper describing study)
 McCorkle, R., & Saunders, J. (1985). Problems, coping strategies and coping effectiveness after diagnosis. Proceedings of the American Cancer Society Fourth Cancer Nursing Research Conference, June 18–20, Honolulu, Hawaii.
 McCorkle, R., & Young, K. (1978). Development of a symptom distress scale. *Cancer Nursing*, 1, 373–378.
 Mumma, C., & McCorkle, R. (1982–1983). Causal attribution and life-threatening disease. *International Journal of Psychiatry in Medicine*, 12, 311–319.
- Title:** "Evaluation of Cancer Management"
Source: Department of Health and Human Services, Health Resources and Services Administration, Division of Nursing
Grant number: NU 01001
Amount: \$593,707 (direct costs)
Dates: 1983–1986
Related publications:
 Kukull, W., McCorkle, R., & Drier, M. (1986). Symptom distress, psychosocial variables and lung cancer survival. *Journal of Psychosocial Oncology*, 4, 91–104.
 McCorkle, R., Benoliel, J.Q., Donaldson, G., Georgiadou, F., Moynour, C., & Goodell, B. (1989). A randomized clinical trial of home nursing care for lung cancer patients. *Cancer*, 64, 1375–1382. (major research paper describing study)
 Sarna, L., Lindsey, A.M., Dean, H., Brecht, M.L., & McCorkle, R. (1993). Nutritional intake, weight change, symptom distress, and functional status over time in adults with lung cancer. *Oncology Nursing Forum*, 20, 481–489.
 Sarna, L., Lindsey, A.M., Dean, H., Brecht, M.L., & McCorkle, R. (1994). Weight change and lung cancer: Relationships with symptom distress, functional status, and smoking. *Research in Nursing and Health*, 17, 371–379.
- Title:** "A Prospective and Concurrent Study of Spouse Bereavement"
Source: Department of Health and Human Services, Health Resources and Services Administration, Division of Nursing
Grant number: NR-01626-01
Amount: \$214,510 (direct costs)
Dates: 1986–1988
Related publications:
 Lev, E.L., Nuamah, I.F., Robinson, L., & McCorkle, R. (1995). Smoking behaviors, grief and bereaved family members' health status and psychological distress. *Journal of Smoking-Related Disorders*, 6, 99–108.
 McCorkle, R., Hughes, L., Robinson, L., Levine, B., & Nuamah, I. (1998). Nursing interventions for newly diagnosed older cancer patients facing terminal illness. *Journal of Palliative Care*, 14(3), 39–45.
 McCorkle, R., Robinson, L., Nuamah, I., Lev, E., & Benoliel, J.Q. (1998). The effects of home nursing care for patients during terminal illness on the bereaved's psychological distress. *Nursing Research*, 47, 2–10. (major research paper describing study)
 Robinson, L.A., Nuamah, I.F., Lev, E., & McCorkle, R. (1995). A prospective longitudinal investigation of spousal bereavement examining Parkes and Weiss' Bereavement Risk Index. *Journal of Palliative Care*, 11(4), 5–13.
- Title:** "Evaluation of Home Care for Cancer Patients"
Source: National Center for Nursing Research
Grant number: 1 R01 NR01914
Amount: \$321,161 (direct costs)
Dates: 1987–1990
Related publications:
 Jepson, C., Schultz, D., Lusk, E., & McCorkle, R. (1997). Enforced social dependency and its relationship to cancer survival. *Cancer Practice*, 5(3), 155–161.
 McCorkle, R., Jepson, C., Malone, D., Lusk, E., Braitman, L., Buhler-Wilkerson, K., et al. (1994). The impact of posthospital home care on patients with cancer. *Research in Nursing and Health*, 17, 243–251. (major research paper describing study)
 McCorkle, R., Yost, L., Jepson, C., Malone, D., Baird, S., & Lusk, E. (1993). A cancer experience: Relationship of patient psychosocial responses to caregiver burden over time. *Psycho-Oncology*, 2(1), 21–32.
 Taylor, E.J., Baird, S.B., Malone, D., & McCorkle, R. (1993). Factors associated with anger in cancer patients and their caregivers. *Cancer Practice*, 1(2), 101–109.
 Yost, L., McCorkle, R., Buhler-Wilkerson, K., Schultz, D., & Lusk, E. (1993). Determinants of subsequent home health care nursing service use by hospitalized patients with cancer. *Cancer*, 72, 3304–3312.
- Title:** "Nursing's Impact on Quality of Life Outcomes in Elders"
Source: National Center for Nursing Research
Grant number: R01 NR03229
Amount: \$740,428 (direct costs)
Dates: August 31, 1996–September 30, 2002
Related publications:
 Hughes, L.C., Hodgson, N.A., Muller, P., Robinson, L.A., & McCorkle, R. (2000). Information needs of elderly postsurgical cancer patients during the transition from hospital to home. *Image: The Journal of Nursing Scholarship*, 32, 25–30.
 Hughes, L.C., Robinson, L.A., Cooley, M.E., Nuamah, I., Grobe, S.J., & McCorkle, R. (2002). Describing an episode of home nursing care for elderly postsurgical cancer patients. *Nursing Research*, 51(2), 110–118.
 Jepson, C., McCorkle, R., Adler, D., Nuamah, I., & Lusk, E. (1999). Effects of home care on caregivers' psychosocial status. *Image: The Journal of Nursing Scholarship*, 31, 115–120.
 McCorkle, R., Strumpf, N., Nuamah, I., Adler, D., Cooley, M., Jepson, C., et al. (2000). A randomized clinical trial of a specialized home care intervention on survival among elderly post-surgical cancer patients. *Journal of the American Geriatrics Society*, 48, 1707–1713. (major research paper describing study)
 Nuamah, I.F., Cooley, M.E., Fawcett, J., & McCorkle, R. (1999). Testing a theory for health-related quality of life in cancer patients: A structural equation approach. *Research in Nursing and Health*, 22, 231–242.
 Robinson, L., Nuamah, I.F., Cooley, M.E., & McCorkle, R. (1997). A test of the fit between the Corbin and Strauss Trajectory Model and care provided to older patients after cancer surgery. *Holistic Nursing Practice*, 12(1), 36–47.
- Title:** "Impact of Home Care on Quality of Life Post Prostatectomy"
Source: American Cancer Society
Grant number: TPRB-98-010PBB
Amount: \$750,000 (direct costs)
Dates: January 1, 1998–December 31, 2000
Related publications:
 Giarelli, E., Monturo, C., & McCorkle, R. (2003). Caring for a spouse after prostate surgery: The preparedness needs of wives. *Journal of Family Nursing*, 9, 453–485.
 Knaf, G.J., Knaf, K.A., & McCorkle, R. (2005). Mixed models incorporating intra-familial correlation through spatial autoregression. *Research in Nursing and Health*, 28, 348–356.
 Maliski, S., Heilemann, M., & McCorkle, R. (2001). Mastery of postprostatectomy incontinence and impotence: His work, her work, our work. *Oncology Nursing Forum*, 28, 985–992.
 Maliski, S.L., Heilemann, M.V., & McCorkle, R. (2002). From "death sentence" to "good cancer": Couples' transformation of a prostate cancer diagnosis. *Nursing Research*, 51, 391–397.
 Robinson, L., Hughes, L.C., Adler, D.C., Strumpf, N.,

(Continued on next page)

Figure 1. Patient and Caregiver Outcomes Research Publications

Grobe, S.J., & McCorkle, R. (1999). Describing the work of nursing: The case of postsurgical nursing interventions for men with prostate cancer. *Research in Nursing and Health*, 22, 321–328.

Robinson, J.P., Pickett, M., Giarelli, E., Shults, J., & McCorkle, R. (2000). Effect of biofeedback-assisted pelvic muscle exercise training on

urinary symptoms and quality of life post-prostatectomy: Results of a pilot study. *Urogram*, 28(6), 18–21.

Title: “Nursing’s Impact on [Quality-of-Life] Outcomes in Ovarian Cancer”

Source: National Institutes of Health, National Institute of Nursing Research

Grant number: 1R01 NR07778

Amount: \$785,829 (direct costs)

Dates: August 1, 2003–May 31, 2006

Related publication:

McCorkle, R., Pasacreta, J., & Tang, S.T. (2003). Psychological issues in ovarian cancer: An overview and successful nursing intervention. *Holistic Nursing*, 17(6), 1–8.

Figure 1. Patient and Caregiver Outcomes Research Publications (Continued)

until the patient’s death. APNs assisted dying patients and their families through the living-dying transition. The intervention consisted of teaching family caregivers how to give personalized care in the home that focused on comfort and advanced symptom management. The APNs served as the central coordinators for care, and 24-hour access was provided. The spousal caregiver groups compared in the study only received treatment while the patients remained alive. Yet the outcome variable (spousal psychological distress) was measured at four time periods (at six weeks and at 6, 13, and 25 months) after the patient’s death. In caring for patients dying from lung cancer, the oncology homecare nurses were able to reduce the overall level of psychological distress among patients’ bereaved spouses. We believe it 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 standard homecare and officecare groups, the intensity of psychological distress experienced by spouses in the oncology homecare group differed clinically as well as statistically. The longitudinal measurements allowed us not only to determine that spouses in the oncology homecare group were less distressed but also to assess the duration of effectiveness of the oncology homecare model toward preventing or reducing distress. Lower levels of psychological distress were sustained in the group for a period of 13 months after the homecare intervention. By the 25th month, levels of psychological distress among the three groups no longer differed significantly. Perhaps if nursing care or psychological support of the family had been extended beyond the patient’s death into the period of bereavement, the benefits of the oncology homecare group would have been sustained even longer. This deserves further study, particularly in light of the findings of Stetz and Hanson (1992) that perceived needs among family caregivers change between the period of active caregiving and the period of bereavement.

The third grant, titled “Impact of Home Care,” was a quasiexperimental study designed to evaluate the impact of homecare services on patients’ symptom distress, mental health, enforced social dependency, and their health perceptions; family caregiving responsibilities; and caregiver burden after an acute hospital stay (McCorkle et al., 1994). The study extended the earlier work by (a)

exploring the impact of home healthcare services on patients diagnosed with cancers of various sites; (b) including two critical points on the illness trajectory: the initial diagnostic phase and initiation and monitoring of aggressive cancer treatments; and (c) 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, half newly diagnosed ($n = 115$, 49%); the others were admitted for ongoing management of their cancers. Data were obtained at hospital discharge and at three and six months postdischarge. A subsample of 49 patients who received home care and 11 patients who did not receive home care were analyzed because complete data were available across three waves of data collection. Patients receiving home care demonstrated statistically significant improvements in mental health and social dependency; patients not receiving home care did not improve on any variables. The caregiver sample included 103 family members ($n = 77$, 74% were spouses; $n = 11$, 11% were parents; and $n = 15$, 12% were children or siblings). A subsample 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 that patients died. Findings indicated that patients were being discharged from the hospital with ongoing needs for acute care. By three and six months posthospitalization, patients’ conditions stabilized or improved, but their caregivers continued to report continuing levels of burden. Caregivers reported that the patients’ illnesses had a negative impact on their finances, schedules, health, and caregiving responsibilities over time, long after patients improved (McCorkle et al., 1993).

The fourth study, titled “Quality of Life Outcomes in Elders,” was designed as a randomized clinical trial to test the effects of the APN role on quality-of-life outcomes of newly diagnosed postsurgical older patients with cancer and the psychological status of the caregivers at discharge and three and six months later (McCorkle et al., 2000). More than 375 patients with eight different types of cancer and 217 caregivers were recruited and followed after hospitalization. Subjects were assigned randomly to an experimental

or control group. The experimental group received a one-month, standardized nursing protocol (SNIP). One hundred and ninety patients (51%) were assigned to the intervention group and 185 (49%) to the usual-care group. Both groups were equivalent on all variables except stage at diagnosis; the intervention group contained patients with more late-stage cancers. Patients in the control group received standard postoperative care in the hospital and routine follow-up in outpatient surgical clinics after discharge. The purpose of the SNIP was to enhance recovery from surgery, improve quality-of-life outcomes, and extend survival. The intervention was developed as a protocol that consisted of standard assessment and management guidelines, doses of content, and schedules of contacts. APNs followed specific guidelines to assess and monitor physical, emotional, and functional status of patients; provide direct care when needed; assist in obtaining services or other resources from the community; and provide teaching, counseling, and support during the period of surgical recovery. Nurses also functioned as liaisons to healthcare settings and providers, as well as to patients and families in the provision of technical and psychological support. By the end of November 1996, 93 (25%) patients had died. Of them, 41 (44%) were from the intervention group and 52 (56%) were from the usual-care group. For all patients who died, cause of death was documented. Cancer was listed either as the primary or secondary cause on all death certificates. Other causes listed were pulmonary embolus, heart failure, sepsis, and cardiac arrest. The mean follow-up period was 24 months (range = 1–44 months).

Patients receiving the homecare intervention survived longer than the usual-care group, after adjusting for stage of disease at diagnosis and total length of hospitalization during surgery. The risk of death increased 104% among usual-care patients (adjusted hazard ratio = 2.04, confidence interval = 1.33–3.12, $p = 0.001$) compared to those in the intervention group. Late-stage patients had a fourfold increase in their risk of dying compared with early-stage patients. At the end of the 44-month follow-up period, none of the cases had been lost to follow-up. The survival advantage of the group receiving home care by oncology APNs was especially significant among late-stage patients; the patients in the

intervention group had lived an average of seven months longer than those in the usual-care group. A higher proportion of late-stage disease existed in the intervention group after randomization (38% compared to 26% in the control group, $p = 0.01$), making the finding of greater survival even more compelling. For the caregivers, their psychological status improved from baseline to three months and stabilized thereafter; but for a subgroup of caregivers who had physical health problems, the psychological status of those in the treatment group declined over time compared to those in the control group. As a result, we concluded that caregivers of patients with cancer who had physical problems of their own were at risk for psychological morbidity as they assumed the caregiving role (Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999).

The fifth study, titled “[Quality-of-Life] Outcomes Following Prostatectomy,” was designed to test the effects of home nursing interventions provided by APNs on patient and caregiver outcomes after surgery for prostate cancer. Patients and their spousal caregivers were recruited prior to surgery, and outcome data were collected postsurgery and at one, three, and six months after hospitalization. One hundred and twenty-two dyads, men and their spouses, were recruited. The study built on the previous work in that the intervention provided by APNs was extended from four weeks to eight weeks. In the immediate postoperative period, interventions were targeted to focus on postoperative recovery and management of symptoms including pain, bladder spasms, constipation, fatigue, sleep disturbances, and edema (Pickett, Cooley, Patterson, & McCorkle, 1996). Patients and caregivers were informed about postoperative complications and were taught how to recognize warning signs to prevent emergencies. Considerable emphasis was placed on patient teaching, highlighting the challenge and foreign nature of managing chronic illness. Once a patient’s physical recovery was stable, the intervention was expanded to include bladder training and psychological support to increase intimacy and communication skills between the dyad (Maliski, Heilemann, & McCorkle, 2001; Robinson et al., 1999). One of the critical aspects of the intervention for caregivers was helping them to assume the role of caregiving. Because they were 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 did not readily realize or accept that a caregiving role existed (Giarelli, Monturo, & McCorkle, 2003).

The current funded clinical trial is designed to test the APN’s role with women after surgery for ovarian cancer (McCorkle, Pasacreta, & Tang, 2003). In the study, we have added the consultative role of the psychiatric liaison nurse and have added cost outcomes, including the use of healthcare services. To date, we have enrolled 102 women

in the study. See Table 1 for a summary of the overview of the individual studies and key findings.

Phase 3: Translation Methods

Figure 2 is a diagram of the summary of the studies and their influence on changes in research, practice, and policy. The development and dissemination of the Symptom Distress Scale has influenced the advancement of science related to symptom assessment and symptom management in patients with cancer and other chronic diseases around the world. Our research and the work of others, including Barbara Given, PhD, RN, FAAN, and Kathy Stetz, RN, MN, PhD, have influenced policy at the federal level. In the mid-1980s, our team was involved in gathering legislative support for the Family Leave Bill. When President Clinton took office, the bill was signed and became law. The bill provides family caregivers with the right to take leave from work to care for ill family members with the promise that their jobs will be available when they are ready to return.

Our research has been used to establish programs to train healthcare professionals and prepare family caregivers. The timing of the research coincided with two studies commissioned by the Cancer Control Advisory Board of the Pennsylvania Department of Health. Houts, Yasko, Kahn, Schelzel, and Marconi (1986) and Houts et al. (1988) examined the unmet psychosocial needs of patients with cancer and their caregivers. The first study, a randomized survey of 629 patients with cancer and 397 caregivers, reported that 51% of the sample had at least one unmet need. The most commonly cited unmet need was for emotional support. In the second study, a stratified random sample of 433 family caregivers of patients who died, 72% of the patients had at least one unmet need during the 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 healthcare professionals to (a) identify patients’ and caregivers’ psychosocial needs, (b) intervene within the scope of their professional practice, and (c) refer patients and families to resources in healthcare institutions or communities at large. Programs in institutions had to be jointly directed by a nurse and social worker. The structured intervention in our program of research formed the content for the curriculum. The outcomes of the program are reported elsewhere (Barg et al., 1992, 1994).

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 workers in 19 community hospitals in eastern Pennsylvania to develop

programs in their institutions. Ortho Biotech Products, L.P., provided a grant to implement the program. The goal was to educate and support caregivers of patients with cancer at home. The program outcomes were achieved by preparing oncology nurses and social workers to offer a six-hour psychoeducational program for caregivers and to put caregivers in touch with local resources to meet their needs. Between April 1994 and April 1997, 504 caregivers participated in 79 family caregiver education programs. Some of the programs have been sustained in community hospitals, and content from the program was added to the University of Pennsylvania’s OncoLink Web site. A description of the program, its content, and an evaluation of outcomes are reported elsewhere (Barg et al., 1994).

Another area in which we have campaigned for change is related to the criteria used to make referrals for home care at the time that postsurgical patients are discharged from the hospital and the hiring of APNs in community homecare agencies to respond to the referrals. We have demonstrated that APNs can make significant differences in patient recovery after hospitalization for surgery. Patients who qualify for home care need to be evaluated by APNs, and APNs need to work as oncology experts with homecare staff over time. Patients who do not qualify for referral because they have no apparent need for skilled care but who are at high risk for developing complications need to be monitored by APNs for changes in status. If patients with complex physical problems are discharged to their homes to family caregivers whose physical health is compromised, then homecare referrals are essential, and other services must be provided. When formal home services are initiated for ill patients, the services should be expanded to include assessment and monitoring of ill caregivers. The family unit as a whole needs to receive care, not only the designated ill member for whom the referral was made, thereby ensuring the patient and caregiver the opportunity to become stabilized. One model for implementing our findings would be to test the role of APNs who are employed by home health agencies and who follow patients who have had surgery and are at high risk for developing postoperative complications with short-term follow-up. This includes patients who

- Are older than 70 years
- Are scheduled for additional cancer treatments, especially combination therapy
- Are hospitalized longer than seven days
- Have four or more comorbidities
- Have late-stage cancer
- Live with ill caregivers
- Are scheduled for aggressive chemotherapy prior to their incisions healing.

As problems occur, patients can be referred for longer APN care through home care, reducing the chance that they will develop

Table 1. Summary of Studies and Key Findings

| Study (Author) | Design and Sample | Methods | Intervention | Key Findings |
|---|--|---|---|--|
| Patient responses (McCorkle & Quint-Benoliel, 1983) | Descriptive; two waves. N = 113; 61 patients with cancer and 52 with heart disease | SDS, ESDS, ICC, and POMS | None | Patients with cancer suffered more physical distress and mood disturbances than patients with heart disease at diagnosis. Symptom distress was the most consistently important exploratory variable, affecting social dependency, concerns, and mood disturbance over time. |
| Evaluation of cancer management (McCorkle et al., 1989) | Randomized, controlled trial; three groups; five waves. 166 patients with lung cancer and 100 spousal caregivers | For patients, SDS, ESDS, health perceptions, rehospitalizations, complications, and BSI; for caregivers, health perceptions and GEI | Office care only Standard home care plus office care; mean length of care = six weeks Care from an advanced practice nurse plus office care; mean length of care = 11 weeks | Advanced practice nurses assisted patients with minimizing symptoms and maintaining independence longer than patients who did not receive home care. The two homecare nursing groups reported worse health perceptions than the officecare-only group, indicating that nurses also can assist patients in acknowledging the reality of their situations. |
| Spouse bereavement (McCorkle et al., 1998) | Randomized, controlled trial; three groups; four waves after patient death. N = 91 of the 100 spouses in the prior study | BSI, health perceptions, and GEI | Interventions occurred only during patients' illness and dying. | Spouses' psychological distress after patients' deaths was significantly lower in the advanced practice nurse intervention group compared to two other groups until the 25-month time point, when scores were similar across groups. |
| Impact of home care (McCorkle et al., 1993, 1994) | Quasi-experiment; two groups; three waves. 233 patients with multiple solid cancers and 103 family caregivers | For patients, SDS, ESDS, health perceptions, CESD, MHI-5, and BSI; for caregivers, health perceptions, CRS, and PCR | Home care; mean length of care = 7.5 weeks; mean number of visits = 14.5 | Home care assisted patients in reducing symptom distress and improving mental health and functional status over time. Caregivers continued to report increased burden over time, even as patients stabilized and improved. Their finances, schedules, and health were impacted. |
| Quality of life in older people after surgery (Jepson et al. 1999; McCorkle et al., 2000) | Randomized, controlled trial; two groups. 374 patients with multiple solid cancers and 217 family caregivers | For patients, SDS, ESDS, CESD, and MHI-5; for caregivers, CDS, CRS, and CESD | Care from an advanced practice nurse; eight contacts; three home visits; five phone calls; one month | Patients in the intervention group lived an average of seven months longer than those in the control group. Quality of life in both groups was similar over time, even though more late-stage patients were in the intervention group. Significant differential effects were found among caregivers with physical problems. |
| Quality of life after prostatectomy (Giarelli et al., 2003; Maliski et al., 2001) | Randomized, controlled trial; two groups. 122 patients and 122 spousal caregivers | For patients, SDS, MOS-SF-36, and CESD; for caregivers, CARES sexual and marital subscales, PCR, CDS, and CESD | Care from an advanced practice nurse; 16 contacts; eight home visits; eight phone calls; eight weeks | Advanced practice nurses facilitated quality-of-life outcomes for men and their spouses over time after radical prostatectomy. Significant differences were found in physical functioning and marital relations. Spouses were significantly more depressed than patients over time. |
| Quality of life after ovarian surgery | Randomized, controlled trial; two groups. 102 patients | SDS, ESDS, CESD, MOS-SF-36, cost outcomes, and healthcare utilization (e.g., rehospitalization) | Care from an advanced practice nurse plus psychiatric liaison nurse; 18 contacts; five months | Women are being enrolled through May 2006. |

BSI—Brief Symptom Inventory; CARES—Cancer Rehabilitation Evaluation System; CDS—Caregiving Demands Scale; CESD—Center for Epidemiological Studies Depression Scale; CRS—Caregiving Reactions Scale; ESDS—Enforced Social Dependency Scale; GEI—Grief Experience Inventory; ICC—Inventory of Current Concerns; MHI-5—Mental Health Inventory of the Medical Outcomes Study Short-Form Health Survey-36; MOS-SF-36—Medical Outcomes Study Short-Form Health Survey-36; PCR—Physical Caregiving Responsibility; POMS—Profile of Mood States; SDS—Symptom Distress Scale

unstable critical complications. Another potential model to test would have APNs employed through ambulatory services. In this case, APNs' salaries may be higher in outpatient settings because of the opportu-

nity to bill directly, and the coordination of services might be enhanced by direct, on-site integration with members of the cancer team. The two models of care need to be developed in more detail and tested.

Conclusions and Future Study

This article presents an overview of our patient and caregiver outcomes research through three phases of development. Our

Research (Funding)

Dissemination

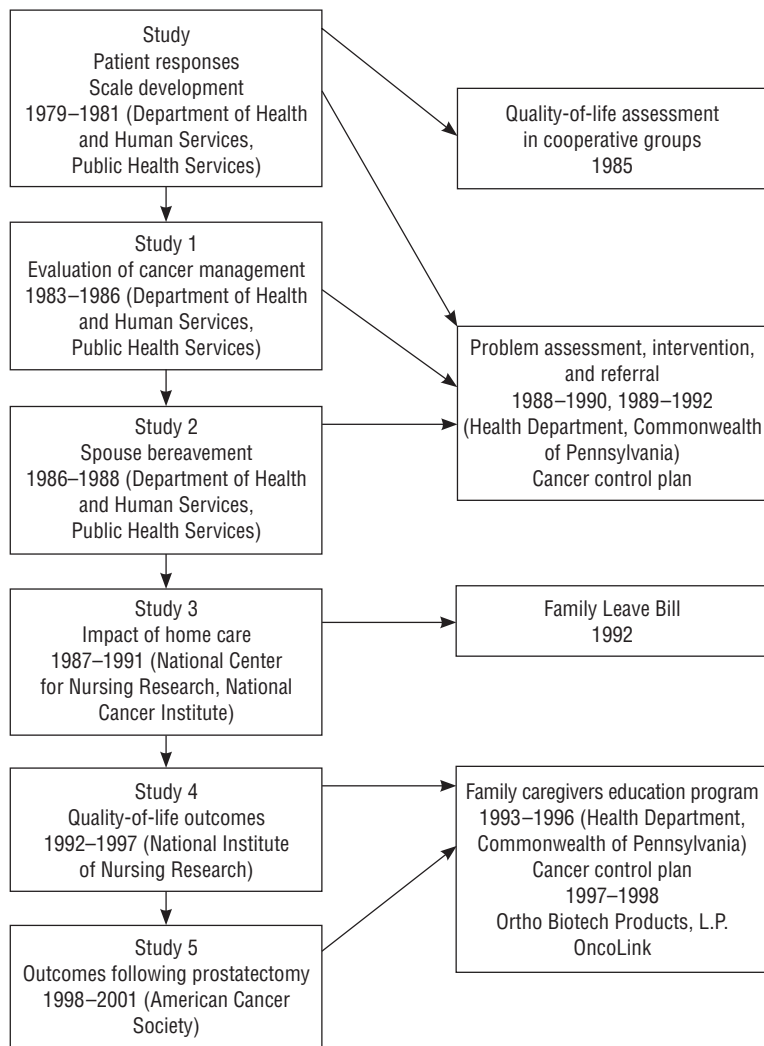


Figure 2. Patient and Caregiver Studies and Their Influence on Policy and Practice

successes have included the development of scales to measure outcomes in patients with cancer and the documentation of the impact of the role of the APN on patient and caregiver outcomes through a series of studies. Our efforts to introduce the role of the APN in homecare agencies throughout the country and to change the criteria for referring patients for follow-up care have not kept pace with our findings. Although the first two phases have had significant impact, work in the third phase is just beginning. Clearly, additional work is needed with regard to the identification of organizational factors that must be considered when testing changes in clinical practice (Bradley et al., 2004). Because research examining the methods for translating research related to the role of the APN into practice is in its infancy, the field would be enhanced greatly by emphasizing interdisciplinary efforts to facilitate coordination across departments and disciplines.

Current trends in health care focus on cutting costs in acute-care settings, which results in a shift of care from the hospital to the home. Despite what may seem to be societal cost savings and enhanced efficiency of the healthcare system, the locus of the financial, physical, and emotional burden of cancer care often is shifted to family caregivers, who may incur emotional, economic, and physical consequences. Interventions that enhance patients' recovery and maintain the health of caregivers must be a priority in our efforts to test methods for translating evidence into practice. Our research consistently has demonstrated that APNs can make a difference in the recovery of patients after cancer surgery. Now we must decide how to make it happen in clinical practice.

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