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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