

# Informal Caregiver Training on Home Care and Cancer Symptom Management Prior to Hospital Discharge: A Feasibility Study

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**Purpose/Objectives:** To determine the feasibility of individualized caregiver training for home care and symptom management conducted at the bedside of older patients with cancer prior to hospital discharge.

**Design:** Pilot study.

**Setting:** The Extended Care Rehabilitation Center at the Durham Veterans Affairs Medical Center in North Carolina.

**Sample:** 7 female informal caregivers with a mean age of 56 (range = 26–76). More than half were African American. Most commonly, caregivers were spouses of the patients with cancer.

**Methods:** Individualized and experiential training on home care and cancer symptom management was conducted at the bedside of patients before hospital discharge. Caregiver demographic data were collected. An informal interview at the end of the training asked about the usefulness of the training in preparing for home caregiving.

**Main Research Variables:** Feasibility of the training.

**Findings:** Individualized bedside training to caregivers prior to hospital discharge is feasible. All caregivers noted the relevance of the content as well as the approach to the training.

**Conclusions:** When given an opportunity for training on symptom management and home care, informal caregivers were very interested in participating. The individualized approach gave caregivers an opportunity to have their particular needs met. The flexibility of when to conduct the training proved to be crucial when soliciting attendance. The biggest challenge was in recruiting caregiver subjects through patients with cancer.

**Implications for Nursing:** The impetus now is to look at the effects of the training on caregiver-patient variables as well as the cost-effectiveness and sustainability of such an approach to caregiver training.

By 2030, the number of older people with cancer in the United States is expected to double (Edwards et al., 2002). With shorter hospital stays and cancer treatments in ambulatory settings, a concomitant increase will occur in the number of community-dwelling, informal caregivers for patients (Andrews, 2001; Aranda & Hayman-White, 2001; Pasacreta & McCorkle, 2000). Symptom management has been identified as an essential component of effective home caregiving for older adults with cancer (Steinhauser et al., 2000). However, most informal caregivers do not feel confident that they possess the knowledge and skills to care for their loved ones while managing their symptoms at home (Aranda & Hayman-White; Schumacher et al., 2002; Steele & Fitch, 1996; Sutton, Clipp, & Winer, 2000). Low levels of confidence may negatively affect people's psychological well-

## Key Points . . .

- ▶ When given an opportunity for training on cancer symptom management prior to hospital discharge, informal caregivers were very interested in participating.
- ▶ Individualized bedside training with an opportunity to practice skills increased confidence among informal caregivers that they would be able to help their loved ones manage their symptoms at home.
- ▶ The flexibility of when to conduct the training proved to be crucial when soliciting participation from informal caregivers.

being (Bandura, 1997), and, in general, informal caregivers' psychological states already are vulnerable as a consequence of caregiving (Schulz & Beach, 1999; Schulz, Visintainer, & Williamson, 1990). Because of the reciprocal and intricate relationship in caregiver and patient dyads, when caregivers' psychological health deteriorates, it may have a negative impact on their ability to provide care, thus adversely affecting patients' conditions as well (Hodges, Humphris, & Macfarlane, 2005).

The period immediately after hospitalization has been found to be one of the most trying times in cancer symptom management (Giarelli, McCorkle, & Monturo, 2003; Laizner, Yost, Barg, & McCorkle, 1993; Weitzner, Jacobsen, Wagner, Friedland, & Cox, 1999). In addition, the use of emergency services is common among patients with cancer during the first two weeks after hospital discharge (Kurtin et al., 1990). One possible reason is that, in the current healthcare system, many patients with cancer still are acutely ill at the point of discharge

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(Laizner et al.); thus, many symptoms still may be unabated. Caregiving for older patients with cancer is particularly challenging because comorbidities complicate the illness process and the number of cancer-related symptoms increases with age (Sutton, Demark-Wahnefried, & Clipp, 2003). Therefore, formalized training should be offered to family caregivers prior to hospital discharge to prepare them for home caregiving, especially concerning symptom management.

Nurses always have taken the lead in assisting and educating informal and family caregivers prior to the hospital discharge of their loved ones. Most hospitals embody the principle that discharge planning should commence at the time of admission. However, in reality, nursing practice for home discharge consists of teaching caregivers in spurts as dictated by nurses' time and workloads as well as caregivers' availability. What frequently occurs in many inpatient settings is that most discharge instructions are given to patients and caregivers on the day of discharge. A review of recent research literature revealed that studies on discharge planning have been focused mainly on patients in emergency rooms (Chorley, 2005; Ferrari et al., 2005) and surgical patients (Lee & Bokovoy, 2005; Reynolds, 2002). None was found involving older patients with cancer and their family caregivers. Current discharge practices for older patients with cancer may be inadequate because many informal caregivers perceive a lack of confidence and preparedness in assuming their role in home settings, particularly with cancer symptom management (Hudson, Aranda, & McMurray, 2002; Rose, 1999).

The purpose of this article, therefore, is to report the findings of a feasibility study about formalized caregiver training for home care and symptom management prior to patient discharge from an inpatient setting. Specifically, the study explored whether informal caregivers were willing to participate in one-on-one training at their loved ones' bedsides before hospital discharge and whether the caregivers found the training useful in increasing their confidence and preparing them for home caregiving. The study also provided the researchers an opportunity to pilot test an individualized and experiential approach to caregiver training. In the study, the researchers laid the groundwork for ongoing studies about the effects of individualized bedside training on caregiver and patient variables such as caregivers' psychological well-being and self-efficacy and patients' symptom intensity and distress, as well as their use of emergency services for cancer symptoms. Ultimately, the authors plan to investigate the cost-effectiveness and sustainability of such an approach to caregiver training.

## Conceptual Framework

The conceptual foundation of the study is Bandura's Self-Efficacy Theory. According to Bandura (1997), self-efficacy is the confidence or belief in your capabilities to organize and execute the courses of action required to produce given outcomes. In the context of cancer caregiving, it is a caregiver's confidence that he or she can provide care. Sources of self-efficacy include live modeling, performance exposure, positive appraisal, and performance mastery (Bandura, 1986, 1997). In individualized experiential training for caregivers, live modeling allows caregivers to observe people who have mastered skills perform interventions. Because caregivers have difficulty visualizing how tasks are achieved, observing

how tasks are performed is useful. Performance exposure allows caregivers to execute interventions under the guidance of healthcare professionals in an atmosphere that is supportive, with constructive feedback (positive appraisal). The goal is to enable caregivers to experience successful task performance, because performance accomplishment is the most influential source of efficacy (Bandura, Adams, & Beyer, 1977). In the proposed study, interventions for cancer symptom management requiring skills were demonstrated by an expert while caregivers observed (live modeling), and the caregivers then performed the interventions while the expert observed (performance exposure and positive appraisal) until the caregivers were able to complete the tasks successfully (performance mastery). When caregivers' involvement in cancer care was recognized and legitimized through participation in the training, they gained a possible increase in self-efficacy. In addition, caregivers could then attend to their own needs along with those of their patients (Morris & Thomas, 2001).

## Methods

### Setting and Sample

The pilot study was conducted in the Extended Care Rehabilitation Center (ECRC) at the Durham Veterans Affairs Medical Center (VAMC) in North Carolina. The ECRC was targeted because many older patients with cancer stay there while undergoing induction chemotherapy or radiation therapy. The ECRC has two wards, with more than 30 semiprivate rooms in each ward. Each semiprivate room has two beds and a curtain, which serves as a partition. Each room is equipped with a sink and a bathroom. The researchers designed the study to recruit informal caregivers of patients newly diagnosed with cancer because they anticipated that these caregivers were the ones who knew the least about cancer and its symptoms.

Informal caregiver subjects were primary caregivers of older veterans, aged 50 and older, who were undergoing induction treatment for cancer in the ECRC and were expected to be discharged after treatment. A primary caregiver was defined as an individual who lived in the same household as the patient and provided the most "hands-on" care. Inclusion criteria for caregiver subjects were being age 18 years or older; able to speak, read, and write English; and able to spend time at the bedsides of their patients with cancer in the ECRC to participate in the training.

After the researchers obtained approval from the VAMC institutional review board, they recruited subjects one at a time over three months through referrals from the medical director of the ECRC. Because the intent of the pilot study was to look at the feasibility of providing training for home care and cancer symptom management, the medical director only referred caregivers of older patients with cancer with planned discharge dates and home care issues (e.g., limited mobility, feeding tubes, wound care) or cancer symptoms (e.g., pain, constipation, skin irritation). Thus, caregivers of older patients who were asymptomatic and independent in their activities of daily living were excluded from participation.

### Procedure

The ECRC medical director reviewed lists of new patients every Thursday for potential subjects. The principal investigator (PI) communicated with the medical director every Friday

for a list of potential recruits. The PI approached patients during the second half of their estimated stays in the ECRC. For example, if a patient was expected to be in the ECRC for three months, the PI approached the patient during the second half of his or her estimated length of stay. Therefore, the caregiver training was based on the patient's condition as close to the discharge date as possible.

The PI met with each referred patient to explain the study and to determine whether he or she had a primary caregiver. When a patient had a primary caregiver, the PI requested from the patient the caregiver's telephone number. The PI also left her contact number so that the caregiver or patient could contact the PI with any questions about the study.

The PI contacted primary informal caregivers by telephone to determine eligibility, explain the individualized training, and invite participation. Once a caregiver agreed to participate, he or she was asked for a convenient time to have the individualized training. Flexibility was observed in scheduling: nights and weekends, in addition to days and weekdays, were given as options. In addition, mileage reimbursement was provided to participating caregivers.

Each caregiver had a choice to receive the training in one or two sessions. If the caregiver chose one session, he or she was asked to allot at least an entire morning or afternoon. If the caregiver chose two sessions, he or she was asked to allot at least two hours for the first session. All caregivers were informed that the time allotment was a gross estimate of the length of the training. All were assured that they would not be kept longer than the time allotted for each session but that more than one session might be necessary. A day before scheduled training, the PI consulted with the ECRC medical director and staff nurses about the patient's condition so that areas covered in the training were specific and appropriate.

## Caregiver Training

Individualized training began after caregivers signed the consent form. The PI, an experienced advanced practice nurse, conducted the training. The caregivers' loved ones (i.e., patients with cancer) were encouraged to be part of the training.

Training started with brief discussion of patient care needs and cancer symptoms. The training consisted of basic areas of cancer symptom management as outlined in Table 1. Training in other symptom areas was conducted when applicable to a patient's condition, most commonly helping with dyspnea and fatigue. With each care need or symptom, the discussion focused on nonpharmacologic interventions that could be implemented in home settings to assist patients. When applicable to a particular homecare need or cancer symptom, teachings on home medications also were incorporated.

The PI ensured that the training was interactive, requiring the caregivers, and the patients when present, to interact as well as to participate in problem solving for specific symptoms or care needs. The PI focused the training on interventions as they applied to patients. For example, for decreased appetite, the PI asked the caregiver (or patient) about foods that the patient loved to eat, then explained how to make them more palatable to the patient. If a patient was a vegetarian, the discussion focused on maintaining or increasing caloric intake using calories from plants and plant products.

**Table 1. Cancer Symptom Areas in Each Caregiver Training**

Topic	Discussion
Prevention of infection	Assessment of caregiver's knowledge Prevention of infection Discussion of signs and symptoms of infection Central line care and dressing change, Foley catheter care, and wound care, as applicable
Pain control	Pain assessment Guidelines for pain medication Nonpharmacologic interventions
Maintenance of adequate nutrition	Assessment of the patient's problem with nutrition Guidelines for maintaining or increasing caloric intake Oral care Tube feeding, if applicable
Prevention and management of constipation or diarrhea	Assessment of patient's problem with bowel elimination Discussion of strategies that alleviate or prevent constipation or diarrhea
Medication regimen related to cancer symptoms	Assessment of medications Discussion of each medication: purpose and side effects

The training combined didactic teaching and actual performance of the skills necessary to carry out homecare procedures, if any were required. For interventions that required skills, the PI modeled performance of the interventions. Afterward, the caregivers were asked to demonstrate the interventions while the PI observed and offered guidance and positive feedback as necessary. For example, in the case of a patient requiring feeding through a gastrostomy tube, the PI initially showed the proper way to inspect and handle the tube, aspirate the feeding solution using a syringe, and flush the tube with water after feeding. The PI initially fed the patient while the caregiver observed. Midway through the feeding, the caregiver was asked to give the feeding herself while the PI observed and gave positive feedback as appropriate. If the patient did not participate in the training, the PI brought in the contraptions associated with a gastrostomy tube feeding (e.g., gastrostomy tube and a 60-cc syringe) and still allowed the caregiver to go through the steps of how to give a tube feeding.

Adequate time was provided for questions and repeated caregiver demonstrations of learned materials if requested. Because each caregiver had different learning needs and skills, the caregivers guided the duration of training. Training only concluded when caregivers expressed satisfaction with the adequacy of learned materials and confidence in assisting patients at home. At the end of training, caregivers received a copy of *A Manual for Informal Caregivers on Cancer Symptom Management* (Hendrix, 2004), a book developed by the PI that contains a list of nonpharmacologic and supportive interventions for cancer symptom management. Using the Flesch-Kincaid criteria (Flesch, 1974), the readability of the manual was at the seventh-grade level.

## Data Collection Procedure

Data were collected regarding personal characteristics of caregivers, including gender, age, race and ethnicity, marital status, relationship to patient, and occupation. An informal interview was conducted with each caregiver at the end of training for input regarding the usefulness of the training in preparing him or her for home caregiving. Three main questions were asked: “Do you think that this training has been helpful to you?” “How can we improve the training?” and “Would you recommend this training to all family caregivers of older patients with cancer?” The amount of time for training also was documented.

## Results

### Sample

Through convenience sampling, the researchers were able to recruit seven caregivers. All seven were female, with a mean age of 56 (range = 26–76), and more than half were African American. Most commonly, caregivers were the patients’ spouses. Other demographic characteristics of the caregivers are shown in Table 2. All subjects resided quite a distance from the Durham, NC, area, driving 119–282 miles roundtrip to participate in the training.

During the three-month enrollment period, the medical director of the ECRC referred 22 patients to the study. Of those, 15 (68%) had primary caregivers at home; however, almost half of those patients (n = 7) refused to allow their caregivers to be contacted for the training. A common reason for refusal was to avoid placing additional burden on their caregivers. Most said that their caregivers were busy working and would not have time to perform the training. The remaining eight patients provided contact information for their caregivers or agreed to have their caregivers contact the PI when they visited.

Seven of the eight caregivers agreed to participate. Three of them contacted the PI first to inquire about the study and eventually agreed to participate. The PI contacted the remaining five by telephone. One caregiver declined to participate because of a scheduling conflict (specifically, her work schedule varied from day to day, so she was unable to commit to a

specific time for the training). All seven participating caregivers agreed to have the training in one continuous session, with four requesting a Saturday.

The duration of the training ranged from three to six hours; five of the seven subjects had the training for four hours. One caregiver decided to have a second day of training: Four hours were conducted on day 1 and two hours on day 2. Although the patients were not formally invited to participate in the training, four of seven joined their caregivers during the entire training session.

After training was completed, all subjects noted the relevance of the content as well as the approach to the training. All believed that the bedside training with an opportunity to practice skills was effective in increasing their confidence that they would be able to help their loved ones manage their symptoms. All caregivers unanimously stated that they liked the individualized approach to the training because it gave them a chance to raise personally relevant issues and to focus the training on what they really needed to know. The flexibility of the scheduling process allowed most of the caregivers to participate in the training. All subjects agreed that the experience was worthwhile and highly recommended that the training be given to all cancer caregivers before hospital discharge of their loved ones. When asked how the training could be improved, one caregiver stated that patients should be invited to participate, citing that caregiving in home settings is a partnership between caregivers and patients. Furthermore, patient participation in the training simulates the milieu of home-based caregiving, making the context of training relevant and realistic. Other caregivers thought that the training was very good and offered no suggestions for improvement.

## Discussion

As the provision of cancer care shifts from acute settings to home settings, the impetus shifts to better preparing informal caregivers. Symptom management consistently has been identified as an essential component of effective home caregiving (Steinhauser et al., 2000); however, most caregivers do not feel confident and are ill-prepared to help their loved ones manage their cancer symptoms at home. The period after hospitalization appears to be one of the most critical periods in symptom management for patients with cancer (Laizner et al., 1993; Weitzner et al., 1999). Yet healthcare providers continue to neglect caregivers’ needs for formal education and training prior to hospital discharge.

Flexibility in scheduling training proved to be crucial when soliciting attendance from informal caregivers, because most of the subjects worked. This reflects the current characteristics of caregivers in the country: 59% either work or have worked while providing care (National Alliance for Caregiving & AARP, 2004). Work and perhaps driving distance had the most influence on caregivers’ decisions to complete training in one session. As anticipated, most training was on a weekend.

The biggest challenge was in recruiting caregivers through the patients themselves. The authors were surprised that, even when older patients viewed the training as potentially helpful to their caregivers, almost half were reluctant to have their caregivers participate. Most said that they worried about imposing additional burdens on their caregivers. Some cited that their caregivers had too much to do and would not have time to participate. However, the researchers did not find the

**Table 2. Demographic Characteristics of Participating Caregivers**

Caregiver	Relationship to Patient	Age	Race	Marital Status	Working
1	Sister	57	Caucasian	Married	No
2	Daughter-in-law	26	Caucasian	Married	No
3	Mother	72	African American	Widowed	Yes
4 <sup>a</sup>	Sister	47	African American	Married	Yes
5	Wife	76	Caucasian	Married	No
6	Wife	68	African American	Married	No
7	Wife	48	African American	Married	Yes

<sup>a</sup> This caregiver also was a healthcare professional.

same reluctance among informal caregivers contacted by phone. Rather, they all were eager to participate because they viewed the training as potentially helpful in preparing them to give the best care to their loved ones at home.

Although the institutional review board did not require the researchers to obtain consent from patients, the researchers solicited patients' permission to have their caregivers in the study because of the necessity to discuss their symptoms and homecare issues with their caregivers. The researchers were quite challenged with how to deal with patient-protected information. With the advent of the Health Insurance Portability and Accountability Act of 1996 and its mandate of strict protection of privacy, the problem is common among researchers in informal caregiving (Albert & Levine, 2005).

## Implications for Nursing Practice

Caregiving education and support are considered to be under the purview of the nursing discipline. Nurses always have taken the lead in assisting and educating informal caregivers as they prepare to care for their loved ones at home. The results of the initial pilot study support an innovative approach to caregiver training. The findings indicate that when given an opportunity for training on cancer symptom management prior to hospital discharge, informal caregivers were very interested in participating despite the fact that they had to travel long distances for the training (the nearest caregiver lived almost 60 miles away from the hospital). This underscores how important the training was to caregivers. The researchers' assumption that a one-on-one approach to training would be more advantageous than a group approach was supported by the caregivers' feedback. They were unanimous in stating that individualized training gave them an opportunity to have their particular needs met, unlike in group training, where caregivers often are left to decide on their own how to apply information to their situations. The researchers' other assump-

tion that older patients with cancer may be too fatigued or distraught to participate in training, however, was refuted. In contrast, patient participation was seen to simulate the milieu of home-based caregiving, making the context of training relevant and realistic.

For symptom management intervention that requires skills, the researchers purposefully gave caregivers an opportunity to practice the skills under the tutelage of an expert (the PI). The caregivers unanimously complimented the approach as effective and important in boosting their confidence that they could actually perform the interventions. This is an important finding of the study, because self-confidence is essential for any course of action. Even when individuals believe that particular actions will produce certain results, they will not act on that belief if they question whether they can take the necessary actions (Bandura, 1997). Most cancer caregiver education programs mainly consist of written or audiovisual modules that are insufficient in promoting self-efficacy in caregiving.

In summary, one-on-one, experiential training regarding cancer symptom management and home care given to informal caregivers at the bedside prior to discharge from acute care settings was feasible and received well by caregivers. To the researchers' knowledge, no studies have systematically looked at this type of training and its potential effects on caregivers. In addition, the authors believe that through the training, nurses have the potential to improve patient outcomes and ultimately enable older patients with cancer to remain as long as possible in the comfort of their homes.

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