

Dying with Dignity: A Comparative Phenomenological Pilot Study of Hospice Nurses' Perceptions of Dignity in the Final Weeks of Life in Rural Ireland and Connecticut

**Introduction/Statement of the Problem/Deliverables:**

My interest in hospice began with the expected deaths of several of my family members. I became intrigued by a medical system unlike any other – that promoted quality, not quantity, of life. Hospice is a multidisciplinary care program that treats symptoms, rather than etiology, of a disease when a patient is within the last six months of life. The program aims to provide dignity, pain relief, and peace of mind to patients when cure-oriented care is no longer appropriate (NHCPO, 2008).

This is especially important in the U.S., where the dying population is deprived of dignity due to the value society places on productivity. The dying are made to feel like a burden on society. Much of hospice nurses' time with patients and family members is spent attempting to promote dignity, yet few studies explore the effectiveness of these interventions. By studying interventions of hospices in other countries where patients potentially feel more dignified at death, it may be possible to incorporate more effective interventions into hospice programs in the U.S.

I plan to conduct a comparative phenomenological pilot study of home hospice nurses in rural Ireland and in Connecticut. I have chosen to do research in Ireland because of family connections and ability to gain entrée into this population. This population also offers an interesting contrast to modern American culture because views in rural Ireland are more traditionally Catholic and older people tend to be more respected than in the U.S. I will be going to Ireland in May 2009 to interview nurses about perceptions of patient dignity during the dying process. Nurses will be asked to comment on beliefs and interventions regarding dignity in the final weeks of patient life.

After accumulating data, I will prepare a research article to be shared with participating hospice agencies. This study may also serve as a basis for future research if I choose to pursue a

graduate level education. Through my experiences with hospice both as a family member and as a nursing student in my clinicals, I believe I am well qualified to conduct this research study.

## **Review of the Literature:**

The word *hospice* has been used since the 11<sup>th</sup> century to mean “place of rest for weary travelers” (Connor, 1998). However, modern hospice is a relatively new concept. The first hospice facility, St. Christopher’s Hospice, was created in 1967 in London, and the first US hospice was created in 1973 in New Haven, Connecticut. Modern hospice care is holistic, patient-driven, and focused on comfort of patient and family. The aim is to alleviate symptoms, including physical, emotional and spiritual, in order to improve quality of life of dying patients (Poor & Poirrier, 2001).

The hospice philosophy is practiced in homes, nursing homes, hospitals, and skilled nursing facilities. This study will focus on nurses who provide home hospice care, because previous studies show that hospice accessibility is hampered by the biases of non-hospice health care providers (Parker-Oliver & Bickel, 2002; Hanson, Sengupta, & Slubicki 2005). These biases did not hold true in studies in Ireland, as shown by Sullivan, McLaughlin, and Hasson (2005), but home hospice will be studied in both countries to eliminate extraneous variables. Using home hospice also reduces risk of observing services provided by hospital and nursing home staff that may impact dignity but do not reflect hospice interventions (Stevenson, Huskamp, Grabowski, & Keating, 2007).

In home hospice, patient dignity is further enhanced by relief of caregivers. In a study by Raleigh, Robinson, Marold and Jamison (2006), caregivers frequently noted that hospice workers had a major impact on ability to keep the patient home and provided considerable emotional support to family members. Another study by Hanson, Danis and Garret (1997) showed similar results. By relieving some of the stress of

family members, hospice care may make patients feel less like a burden, and therefore maintain greater dignity while dying.

Other interventions may be spiritual or administrative. According to a study by Belcher and Griffiths (1993), a majority of participating hospice nurses admitted to being “personally spiritual,” and expressed this to patients in the form of encouragement and hopefulness, and sometimes prayer or meditation. In Ireland, a recently developed Hospice Friendly Hospital Program is being implemented to make hospitals more conducive to dying patients (Murray, 2008; Taylor 2007). The program aims to improve patient dignity, autonomy, communication, and integrated care through interventions such as increasing number of family rooms and ensuring that no patient dies alone.

One study by McClement, Chochinov, Hack, Kristjanson, and Harlos (2004) dissected the factors contributing to patient perception of dignity while dying and found that influential factors include illness-related concerns (e.g., dependency), a patient’s dignity-conserving repertoire (e.g., coping strategies), and social dignity inventory (e.g., privacy). Based on findings, researchers suggest interventions to promote patient dignity, the majority being psychological interventions.

In contrast, in a study assessing availability of psychological support in hospices in the UK and Republic of Ireland, Price, Hotopf, Higginson, Monroe, and Henderson (2006) found a lack of accessible psychological care. Researchers noted that as many as 45% of hospices responding did not have access to either a psychiatrist or psychologist, and only a small percent had service level agreements with local mental health trusts. Another Irish study assessing communication at end of life found a positive correlation between hospice use and problematic communication (Higginson & Constantini, 2002). A study by Kealey and McIntyre (2005) showed psychological distress as most problematic at end of life as rated by both patients and caregivers in Ireland, though physical, functional and social symptoms were well maintained. This discrepancy between hospice programs and psychological therapists implies either a severe lack of effective care or a difference in the population being treated. For example, Price et al. also found that a majority of hospices use spiritual advisors. Perhaps, due to more well-defined national religions or different societal

values, patients in these countries may be less in need of psychological counseling at the end of life, or perhaps other physical and spiritual interventions reduce the need for psychological interventions.

My study will aim to compare dignity-promoting interventions in both Ireland and in Connecticut to better understand their effectiveness from the perspective of hospice nurses.

## **Methods:**

A sample of home hospices will first be selected from both Connecticut and from rural Ireland. The inclusion criteria for interviewees will be based on registered nurses having worked in home hospice in Connecticut or rural Ireland for at least one year. Further research must be completed to define “rural Ireland” to create inclusion criteria for this population. Counties will be restricted to include small population sizes and homogenous racial and religious demographic populations (predominantly native to Ireland and Catholic) due to recent immigration to Ireland from Eastern Europe (Garner, 2007). I wish to limit these mixed-ethnicity populations because changes are still new, so nurses have not likely been well trained in cultural acceptance at this stage, and racism, stereotyping and misunderstanding may influence care.

After selecting appropriate target populations, letters will be emailed or mailed to each facility explaining the nature of the study and asking for permission to display fliers to advertise for recruitment. Volunteers will be asked to contact me via email to participate in a 30 to 60 minute interview. Contact information for international hospices will be found through family connections as well as through Internet sources, such as Web sites for home hospice agencies. Local sites will be contacted through connections with Dr. Lynn Allchin, who has worked in hospice care in Connecticut for many years, and through connections made during clinical experiences with Mansfield Visiting Nurse Association this semester.

IRB approval must be achieved before interviews can begin. My IRB application will be submitted in the month of November, and will include positive response letters allowing advertisement for recruitment

from several hospice facilities, which will be forthcoming if not available at the time of application. Because this study poses no risks to participants and involves interviewing professionals rather than patients, I anticipate approval by May 2009. If this is not achieved, travel plans will be adjusted to accommodate approval as needed.

Besides basic demographic information, such as age, race, religion, gender, and level of training, respondents will be asked to answer four open-ended questions relating to patient dignity at end of life (see appendix). All other questions will be probing questions. Interviews will take place at the hospice facility or at a neutral area that will guarantee privacy close to the facility to be decided by the nurse and will be audio tape-recorded. Participants will be asked to talk until they have nothing more to say on the topic. Three to five nurses from each population will be interviewed, subject to change based on saturation of new information, and depending on response rate, for an anticipated total sample of six to ten nurses. Though small, this sample size is appropriate because this is a pilot study and because phenomenological studies tend to require smaller sample sizes.

Responses will be transcribed from recordings and coded to determine trends. Definitions of dignity will be compared between populations to detect goals of care, which will be compared between countries. Interventions discussed will be placed into categories of physical, psychological, spiritual, and any other thematic categories that become apparent based on responses, and then compared between populations. Specific attention will be given to interventions mentioned in one country and lacking in the other country. Trends in importance of interventions will also be compared.

Interviews in Connecticut will occur before interviews in Ireland if allowed by timing of IRB approval. Interviews in Ireland will occur in May 2009 pending IRB approval by this time. I plan to stay with relatives when possible, and to otherwise stay in hostels and bed-and-breakfasts. Travel throughout Ireland will include use of the Eurail train, as well as bus and taxi use when necessary. Stay will likely be three weeks. As a Presidential Scholar at UConn, I hope to use my enrichment grant to fund traveling. I will also apply for a SURF grant for further funding if necessary. Other funding will be from personal savings.

## **Plan of Study:**

My plan of study will not change drastically if I am accepted as a University Scholar due to the professional-program design of the School of Nursing. I am required to take courses for clinical experiences each semester, which are complemented by related courses based on clinical location. Other courses are requirements for all Nursing majors and are preparation for the NCLEX-RN exam and for a career as a registered nurse. All general education requirements have previously been met. Due to the number of credits and intensity of course load, it will be difficult to alter or add classes to this schedule. It is also difficult to plan courses around clinical experiences because these rely on placement at facilities with varying times of availability and are not assigned until just weeks before the start of each semester.

An honors independent study is included each semester to complete this hospice research study, which will also be used as my honors thesis. Independent study will be with Dr. Lynn Allchin.

In the summer of 2009, it is my hope to be accepted into an internship program through the Eastern Connecticut Health Network (ECHN), which involves a ten-week job opportunity at Manchester Hospital. If accepted, I would work on an oncology floor, which will likely intersect with some hospice experiences. This program also requires students to enroll in a three-credit summer course, and summer tuition fees apply. If not accepted into the University Scholar Program, where summer tuition would be waived, this internship would not likely be a possibility for me for financial reasons.

In Fall 2009, I will take "Aging in American Society" to enhance my understanding of my research done in Connecticut, and to better understand the context of my research. Since this class gives priority to HDFS majors, I may not be able to enroll in this class unless I am a University Scholar.

## **Appendix:**

### Questions for hospice nurses

- 1) How do you define “dignity”?
- 2) How do you define “dignified death”?
- 3) Please describe your interventions in promoting patient dignity in the final weeks of a patient’s life.
- 4) Of these interventions, which do you view as most important in promoting patient dignity in the final weeks of life?

## References:

- Belcher, A., & Griffiths, M. (2005). The spiritual care perspectives and practices of hospice nurses. *Journal of Hospice & Palliative Nursing*, 7(5), 271-279.
- Connor, S. R. (1998). *Hospice: practice, pitfalls, and promise*. Washington, D.C.: Taylor & Francis.
- Garner, S. (2007). Ireland and immigration: Explaining the absence of the far right. *Patterns of Prejudice*, 41(2; 2), 109-130.
- Hanson, L. C., Danis, M., & Garrett, J. (1997). What is wrong with end-of-life care? opinions of bereaved family members. *Journal of the American Geriatrics Society*, 45(11), 1339-1344.
- Hanson, L. C., Sengupta, S., & Slubicki, M. (2005). Access to nursing home hospice: Perspectives of nursing home and hospice administrators. *Journal of Palliative Medicine*, 8(6), 1207-1213.
- Higginson, I. J., & Constantini, M. (2002). Communication in end-of-life cancer care: A comparison of team assessments in three European countries. *Journal of Clinical Oncology*, 20(17), 3674-3682.
- Kealey, P., & McIntyre, I. (2005). An evaluation of the domiciliary occupational therapy service in palliative cancer care in a community trust: A patient and carers perspective. *European Journal of Cancer Care*, 14(3), 232-243.
- McClement, S. E., Chochinov, H. M., Hack, T. F., Kristjanson, L. J., & Harlos, M. (2004). Dignity-conserving care: Application of research findings to practice. *International Journal of Palliative Nursing*, 10(4), 173-179.
- National Hospice and Palliative Care Organization [NHCPO], (2008). Advancing care at the end of life. Retrieved October 28, 2008, from NHCPO Web site: <http://www.nhpc.org/>
- Parker-Oliver, D., & Bickel, D. (2002). Nursing home experience with hospice. *Journal of the American Medical Directors Association*, 3(2), 46-50.
- Poor, B., & Poirrier, G.P. (2001). *End of life nursing care*. Sudbury, MA: Jones and Bartlett Publishers, Inc..
- Price, A., Hotopf, M., Higginson, I. J., Monroe, B., & Henderson, M. (2006). Psychological services in hospices in the UK and republic of Ireland. *Journal of the Royal Society of Medicine*, 99(12), 637-639.
- Raleigh, E., Robinson, J. H., Marold, K., & Jamison, M. T. (2006). Family caregiver perception of hospice support. *Journal of Hospice & Palliative Nursing*, 8(1), 25-33.
- Stevenson, D. G., Huskamp, H. A., Grabowski, D. C., & Keating, N. L. (2007). Differences in hospice care between home and institutional settings. *Journal of Palliative Medicine*, 10(5), 1040-1047.
- Sullivan, K. A., McLaughlin, D., & Hasson, F. (2005). Exploring district nurses' experience of a hospice at home service. *British Journal of Community Nursing*, 10(11), 496-502.
- Taylor, M. (2007). The hospice friendly hospitals (HfH) programme. *Working with Older People: Community Care Policy & Practice*, 11(3), 29-31.