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University of New Hampshire
School of Health and Human Services
Department of Nursing

TWO CULTURES OF CARING: A COMPARATIVE STUDY
A COMPARATIVE STUDY OF NURSES' PERCEPTIONS AND EXPERIENCES OF
CARING FOR PEOPLE WITHIN A HOSPICE CONTEXT IN THE
UNITED KINGDOM AND THE UNITED STATES

BY

LISA ARMSTRONG & CHRISTINA POLITO

Baccalaureate Candidates in Nursing

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Honors Thesis Committee

Dr. Gerard Tobin, PhD, RN, RMN, Director of RN Baccalaureate Program
Hewitt Hall – Room 249

Honors Thesis Sponsor

Dr. Carol Williams-Barnard, PhD, RN, Associate Professor in Nursing
Hewitt Hall – Room 239

Honors-in-Major-Coordinator

Dr. Georgeann Murphy, PhD, Coordinator, International Research
Hood House – Room 217

Coordinator, International Research

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Dedication

This manuscript is dedicated to Lucy Holroyd, grandmother of Lisa Armstrong, and Carol Scannell, aunt of Christina Polito. Their journey with hospice at the end of their lives was both the impetus to join nursing school and the drive behind this unique research project.

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Preface

Both researchers involved in this study had relatives who died. One received hospice care in the United States, and the other received hospice care in the United Kingdom. Upon sharing their experiences of the many services hospice provided to their families, they discovered that these life-changing experiences had driven them both towards working in the palliative care arena. In the context of their nursing education, they compared experiences of the end-of-life nursing care provided to their loved ones, and discovered that there were many differences in the caring models; some significant, others small intangible nuances that contributed to the overall picture.

These findings sparked a collaborative literature review, and a report entitled “The Quality of Death: Ranking end-of-life care across the world” by the Economist Intelligence Unit (2010) was discovered. This landmark survey identified key differences in end-of-life care standards between nations globally, citing the United Kingdom as number one overall, with the US ranking 9th, behind Australia, New Zealand, Germany, Austria, and Ireland amongst others. Curious to learn more about these highlighted differences firsthand, the researchers embarked upon their own comparative study of nurse’s perceptions and experiences of caring for people within a hospice context between the United States and the United Kingdom.

ABSTRACT**TWO CULTURES OF CARING: A COMPARATIVE STUDY OF NURSES' PERCEPTIONS AND EXPERIENCES OF CARING FOR PEOPLE WITHIN A HOSPICE CONTEXT IN THE UNITED STATES AND THE UNITED KINGDOM**

By

Lisa Armstrong and Christina Polito
University of New Hampshire

Hospice is often considered the “gold standard” of optimal end-of-life care (Hill, 2005). The United Kingdom was recently cited world number one leader in providing end-of-life care; the United States ranked 9th (Economist Intelligence Unit, 2010). One article suggests that “There is much that the UK and the US could and should learn from each other to understand the quality of end-of-life care, through comparison of practice, analysis of care patterns and via original research” (Higginson, 2005). Although comparisons between end-of-life care in the United States and United Kingdom have demonstrated similarities and disparities in many contexts, there is little evidence of research that directly compares nursing perspectives between the two Atlantic partners. Using a descriptive qualitative approach, the research explores nurse’s perceptions and experiences of caring for people within a hospice context; and identifies themes of commonalities and disparities in theory and practice, as well as presents some of the diverse challenges and achievements that hospice nurses encounter in their role in caring for patients at the end-of-life.

Keywords: **hospice, end-of-life, nursing, palliative care**

INTRODUCTION

In the US, there are approximately 2.5 million deaths per year (Centers for Disease Control and Prevention, 2010). Over 60 percent of these deaths are related to diabetes, heart and respiratory disease, stroke, cancer, or Alzheimer's. The majority of dying patients will receive some level of end-of-life care as they progress toward the final stages of their illness trajectory. Hospice is often considered the "gold standard" of optimal end-of-life care (Hill, 2005).

REVIEW OF THE LITERATURE

There is an abundance of comparative research globally regarding general end-of-life care, and several research articles that directly compare the United States with the United Kingdom in the hospice field. Many authors (Chapman, 2000, Harper, 2000, Cambron & Cain, 2004, Higginson, 2005, Clark, 2008, O'Connor, 2009, Remington & Wakim, 2010, Economist Intelligence Unit, 2010) have compared the process of end-of-life care in different countries. A report entitled "The Quality of Death: Ranking end-of-life care across the world" (Economist Intelligence Unit, 2010) identified key differences in end-of-life care standards between nations globally, citing the United Kingdom as number one overall, with the US ranking 9th, behind Australia, New Zealand, Germany, Austria, and Ireland amongst others.

Other research comparisons between the United States and the United Kingdom have also demonstrated similarities and disparities between the two countries. Remington and Wakim (2010) suggested that "Despite similar foundations, the provision of hospice care differs in the US and the UK with regard to financing and access" (p. 16). Some research comparisons focused on one or two key variables, such as Chapman and Bass's conclusion that "In each country, the primary physician serves as the gatekeeper to services," (2002, p. 176) whereas other research studies extended across the continuum of variables, as outlined in Higginson's

(2005) research which covered everything from disparities in length of stay to framework for euthanasia. Although there appeared to be an abundance of comparative research globally regarding end-of-life care, and several research articles directly comparing the United Kingdom with the United States in this field, a comprehensive literature review did not reveal any research focusing directly on nursing perspectives in hospice care between the two countries.

Higginson (2005) stated that: “There is much that the UK and the US could and should learn from each other to understand the quality of end-of-life care, through comparison of practice, analysis of care patterns and via original research. The problems faced by the two countries are sufficiently similar, and the imperfect solutions both have found to date, would make such comparison timely” (p. 170).

The study highlighted emerging themes of commonalities and disparities in theory and practice which may provide the premise for stimulating new, focused research studies in key areas of end-of-life policy and practice that can be modified to improve end-of-life care for patients in both countries.

SIGNIFICANCE OF STUDY

A significant increase in the aging population is expected over the next two decades. No current evidence exists that examines nurses’ perceptions surrounding the provision of hospice and palliative care, yet: “Nurses are potentially the most informed and persuasive group to move forward on strategies to improve access and utilization to hospice” (Hill, 2005, p. 222).

STATEMENT OF PURPOSE

The purpose of the research was to explore nurses’ perceptions and experiences of caring for people within a hospice context between the United States and the United Kingdom.

APPROACH & METHODOLOGY

A qualitative descriptive method formed the basis of the research, and is the “method of choice when straight descriptions of phenomena are desired” (Sandelowski, 2000, p. 339). Such a research design accommodates a comprehensive summary and presentation of nurse’s perceptions and experiences as they relate to hospice care, providing a forum for “straight and largely unadorned answers to questions of special relevance to practitioners” (Sandelowski, 2000, p. 337). A small purposive sampling of nurses working in a hospice environment was the foundation of the sample population (refer to participant characteristics in List of Tables).

Nurses at each hospice location were invited to participate in the research study via a letter of invite (Appendix F), which was distributed by the Director of Nursing at each hospice location. Researchers arranged a convenient interview schedule at the Director of Nursing’s discretion.

AGENCY AND PARTICIPANT DESCRIPTION

Special administrative permission to pursue the hybrid SURF USA/Abroad project was granted by the Hamel Center for Undergraduate Research and IRB approval was granted (Appendix A). The research project was conducted over an eight-week period at a hospice house in Bristol, England and two hospice locations in New Hampshire, USA (Appendix B and C). Eighteen nurses participated in the study, ten from the United Kingdom and eight from the United States (Appendix H).

DATA COLLECTION, STORAGE, AND MANAGEMENT

Semi-structured interviews were recorded using a digital recording device and the resulting digital audio files were downloaded onto the researcher’s laptop. The audio files were password-protected, and only the researchers had access to the audio files. The qualitative

narrative responses were transcribed into word documents and all participant identifiers were removed prior to computer entry. Per the UNH IRB policy, all data will be stored for a period of three years from the completion of this study.

Informal, semi-structured interviews using guiding questions were the primary sources of data generation. Interview discussion was introduced with an open-ended primary research question such as “What are your experiences of hospice nursing care” in order to obtain detailed information in the participants own words. Additional guided interview questions were prepared (Appendix E) to augment discussion. Twelve hours of interviews held with 18 participants culminated in 98,461 words which were transcribed verbatim. Nurses were encouraged to share their individual perspective of perceived challenges and rewards in working within a hospice care environment, in order to identify common themes and work towards achieving a direct comparison between the experiences and perspectives of nurses on both sides of the Atlantic.

DATA ANALYSIS AND DESIGN

The objective of the analytical process was to use the emerging data themes to accurately account and summarize nurses’ perceptions of hospice care by highlighting key concepts, experiences, and perceptions of significance.

The researchers used a narrative analysis format to view the data that “focuses on a story as the object of inquiry, to examine how individuals make sense of events in their lives...linking an inner world of desire and motive to an external world of observable actions” (Polit & Beck, 2012, p. 504). The researchers read and re-read transcribed interviews, and an extensive data categorizing and coding exercise allowed the researchers to cluster similar data responses by classification of theme for indexing purposes. Polit and Beck describe this process as an “essentially reductionistic...data must be converted to smaller, more manageable units that can

be retrieved and reviewed” (2012, p. 558). Using this reductionist approach, the data was ultimately reduced from 78 distinct categories that had been initially sub-categorized under the guided interview question headings, into three major themes: Nurse as a Professional, Nurse as an Individual, and Nurse as a Care-Giver (refer to appendices H, I, and J).

The reduction period of collapsing 78 separate themes into a more manageable number and size was challenging. The researcher’s goal was to better understand what constituted themes as significant when discussing importance to the research, and what themes were truly significant as being a similarity or disparity between the two nations. After reviewing each of the 78 themes for statistical significance, it was determined that if a mean difference of 3 or greater occurrences was highlighted between the United States and the United Kingdom in regards to how often the topic was discussed in the interviews, it was deemed noteworthy. With this formula in place, the researchers were able to collapse the list of themes down to 18 categories, which was still considered too abundant. With input and guidance from both the honors thesis sponsor and honors coordinator, the 18 themes were further subcategorized to a more holistic and encompassing understanding of the data, which illuminated the fact that the data could be separated into the three primary themes of Nurse as a Professional, Nurses as an Individual, and Nurse as a Care-Giver. With these umbrella terms established, the 18 subcategories were able to be further lineated. In accomplishing this, the data was once again redirected back to the epicenter of the original research aim, placing the Nurses’ opinion at the center.

Using this selective analytical approach, the researchers “highlight or pull out statements or phrases that seem essential to the experience under study” (Polit & Beck, 2012, p. 567). As key phrases were identified and emphasized, they were appropriately coded according to a

specific assigned category. The identified patterns and themes were then compared, contrasted, and related to each other to illicit meaning and relevance.

FINDINGS

1.1 Nurse as a Professional

It became clear early in the research that hospice nurses referred to themselves in their professional role, separating their personal lives from their professional responsibilities. This is perhaps a reflection of an intrinsic self-protection coping mechanism, in order to do the challenging work of hospice. As one nurse explained:

“I think it’s absolutely incredible how intimate we become with families and patients in such a short period of time, and then they die. And the next day if not the same day, we’re admitting a new person. We do some heavy duty work, physically, emotionally, spiritually, psychologically, all levels, and sometimes we do it in less than 24 hours...we’re constantly faced with death”

1.1.1 The Referrals

A challenge both countries recognized was the timing of hospice referrals. In the United States (Appendix H), nurses found that patients were being referred too late in the disease process to benefit from optimum symptom management, or take advantage of the hospice services, such as the bereavement team, chaplain, social worker and so forth:

“So that people really benefit from the hospice program and the team approach as opposed to having them on for 3 days and not really getting the benefit of the services”

“Even our oncologists have a hard time saying, okay, enough is enough. I’m to the point now where, with my patients, when they say, Dr. so and so said it would be 3-6 months, you can walk in and your gut is telling you more like 3-6 days”

“We absolutely get late referrals. I mean, we are well below the national average for length of stay”

“You can’t do the work with them to symptom control them better and maybe if they’d been referred earlier, they wouldn’t have developed such horrible symptoms”

Conversely, in the United Kingdom (Appendix I), nurses found that referrals were often too early or inappropriate, and patients were sometimes discharged much before their end-of-life process:

“The referral wasn’t appropriate, and this was someone who had had curative surgery and had a very traumatic post-operative recovery, but wasn’t going to die”

“It just wasn’t his time”

Both counterparts agreed that hospice services need increased exposure at a community level, so that physicians, patients, and families understand what services hospice can provide and when it is appropriate for them to seek help (Appendix J):

“I think there are still a lot of people that know the word, but don’t really know the full way that hospice services work”

1.1.2 The Communication

Looking inwardly into their organizational culture, United States hospice nurses (Appendix H) stated that they felt well supported by management and peers, benefitting from good communication through clinical supervision:

“We meet with our consultant, where we bring any difficult, either symptom control issues or whatever, we can take things that are difficult generally, and say look, I’m not sure what I’m doing with this, where can I go with it, how can I deal with it, so we support each other a lot within our team”

“One of the things about working with this team of people I work with is that people do listen to each other, and actually you can have that important conversation with somebody, so everybody’s view is important”

However, United Kingdom nurses (Appendix I) reported that communication with management and peers was sometimes strained, rushed, or time-constrained, leaving them feeling unsupported in their roles:

“We don’t have any kind of clinical supervision in place, which I think is a shame. We have monthly team meetings where there is an opportunity to share things, but I do think it’s hard to cope”

“What we actually lack at the moment, and it is something that since I have gone out on hospice at home which is more isolating than working with a team all the time, is we don’t have proper clinical supervision”

“So it’s difficult, it can be kind of lonely. My husband used to say, don’t you have someone to talk about this with, so I think trying to get people to talk more, you know. We’re geared towards being productive and because it’s a business too, so people are really supportive, they’ll leave messages for one another and they seek each other out, but it is hard, some people, it takes a toll on them”

A similar finding between the two countries (Appendix J) on the issue of internal communication is that both nursing parties assert that excellent communication skills are paramount in hospice care, both internally within the culture of the organization, as well as externally when caring for patients and families, and that the internal support extends itself into the external realm of support too, reflecting on patient outcomes.

1.1.3 Other Findings

Additionally, nurses from the United Kingdom felt that it was important for hospice nurses to have some level of previous experience either general experience or specifically working in oncology. United States nurses felt that no experience is necessary and that they have had success with training nurses straight from graduation into the role.

Another key difference highlighted related to the question of euthanasia. The United Kingdom team often had to have discussions related to euthanasia with patients and families, who were not understanding of the extent of hospice services. This was not an issue that the United States team encountered.

1.2 Nurse as an Individual

Hospice nurses have a keen sense of their inner-sanctum and discussed the many ways that they felt supported in their role.

1.2.1 The Support

United States nurses (Appendix H) utilize the support of work colleagues and counselors as a coping strategy, as opposed to family and friends. They feel that it is important to separate their professional role from their home lives, and have a positive view of their support network.

“They are an amazing group of people to work with, their ethics, the morale that they have, the education that they share, and the support that they give...this is by far an elite group of people”

“Hospice has helped me to become ten times the nurse I was when I started”

On the other hand, United Kingdom nurses (Appendix I) rely on the support of family and friends as a coping strategy, as opposed to work colleagues or counselors. When discussing the role of support, their feedback predominantly reflected feelings of under-support, or difficulty in dealing with situational outcomes:

“Then the doctor cried on my shoulder, and then the nurse cried on my shoulder, and I actually though, but who is there for me?”

“I had a hard time where we couldn’t get the patient’s symptoms under control and the only thing that makes you feel better is time, because it stays with you and it gradually doesn’t feel as bad, but it’s something that just takes time”

“Sometimes I’m just really quiet because it’s just disheartening, it’s hard. I allow myself to be sad. Sometimes I’m angry.”

“You need to have a good social life, and a good group of friends”

Both teams (Appendix J) identified their own personal support networks and the important role they play in helping them to undertake the challenging role of a hospice nurse.

1.2.2 The Role

United States nurses (Appendix H) consider the role of a hospice nurse as autonomous and independent, and often set professional boundaries with self, patients, and their families:

“We give the gift to people that have been abandoned by their family the chance for them to be cared and nurtured for at the end of their life”

“People are so grateful, they’re just grateful that you are there”

However, United Kingdom nurses (Appendix I) felt that the role of hospice nursing can be lonely and overwhelming, and discussed difficulties in setting appropriate boundaries:

“I think for me, the biggest challenge and the thing that I struggle with the most is the loneliness of the job. Because although I’m part of a team, working in someone’s house, I don’t see my colleagues, I don’t really have contact with other nurses. I’m obviously just completely alone”

“You’re going to the house as a complete stranger and yet you’re leaving the house part of something hugely intense. You’re made very welcome usually by the families that we look after. Incredibly welcome. And you become very close to them in a short period of time”

“Some patients just really strike a chord with you. There’s something about some people, just the same as in hospital setting really. You just get on so well with, whereas other families, yeah, you know you get along fine, but there isn’t that real spark between you all, so that can be really hard, when they die. Really can shatter you, even though you know that’s going to happen”

United States and United Kingdom nurses (Appendix J) equally discussed their aptitude for living in the moment, or being in the here and now, as a result of being surrounded by death on a daily basis:

“Being a hospice nurse has changed my thought process...there are two things you can say - I wish I had, or I’m glad I did. I’m on the side of “I’m glad I did” now”

“Live every moment until you die. I think that’s true for our patients, but it’s also true for the nurses as well”

“We try to really be in the moment. So if something’s going on today, we don’t necessarily wait to address it tomorrow. Let’s address it today”

1.2.3 Other Findings

United States nurses used physical activity to cope with the stress of the role of hospice nurse, such as walking their dog, going to the gym, or attending yoga classes. In the United

Kingdom, nurses were more apt to utilize psychological compartmentalizing skills, such as “shutting off” or “off-loading” as a coping mechanism.

Both teams agree that they feel more in tune with their religious and spiritual beliefs, and are more self-aware and reflective than in their roles previous to hospice nursing.

1.3 Nurse as a Caregiver

There were stark differences in the way that care was delivered between the two countries, based largely on funding strategies, but producing two very different nursing outcomes.

1.3.1 The Care

United States hospice care (Appendix H) is focused on achieving fast, effective, and cost-efficient symptom control, preferably in the home environment. The nurses are trained to provide education and support to families caring for their loved ones at home, empowering them with the medical resources and basic symptom management knowledge they need to provide care with minimal supervision or intervention. If this is not possible, home care cannot be accommodated and the patient would have to be transferred either to a hospital, a nursing home, or a hospice house depending on their acuity level.

Conversely, United Kingdom hospice nurses (Appendix I) expressed their nursing care as ‘relationship-centered-care’ or described using ‘back-to-basics’ authentic care principles. Twenty-four hour in-home care is guaranteed, regardless of acuity, resource funding, or family availability to care for the patient.

Both nursing teams (Appendix J) shared that effective symptom control was both the number one most rewarding and the number one most distressing experience for them.

“It’s the symptoms...when you get somebody’s pain under control, or the family really understands what’s going on so there’s more of an acceptance of what’s happening, and they’re not suffering anymore”

“Lots of my patients and their relatives say how can you do that job, but it’s so satisfying...all of us are going to die eventually. And when that time comes for whatever reason, we want our symptoms to be controlled, to be pain free”

“Hospice care allows you to give the type of care that you were taught to give in school, but often didn’t deliver in an acute setting”

1.3.2 The Barriers

The barriers to hospice care are perceived to be very different between the two countries. United States nurses (Appendix H) consider the issue of appropriate medical insurance a barrier to receiving hospice services. They also discussed that the acceptance of arriving at end-of-life is a significant barrier, both for the patient and they physicians:

“People just kind of ignore the fact that they are seriously ill and are facing their mortality. And people in the medical field are not helping them deal with that. It seems like people are tending to set it aside and not deal with it, and therefore when they do come to the end, they’re in complete crisis!”

“I think that people don’t know what hospice is. And I think a lot of that has to do with reimbursement and Medicare”

Conversely, with funding not a patient issue in the United Kingdom, major barriers identified by the nurses (Appendix I) were cultural and stereotyping behaviors in ethnically diverse populations. It is assumed by much of the medical profession that certain religions, cultures, or ethnicities have no interest in hospice or palliative care based on their beliefs, but this is not true and while the hospice team have provided care for a diverse range of cultures, their services are still not well represented in the community:

“Ethnic diversity is certainly not represented in home care patients that we see. They’re mainly White, British, Christian”

“Sometimes there is a language barrier. There’s also the cultural and religious barriers as well. And the way different cultures view the dying person”

Both countries’ nurses (Appendix J) talked of the honor and privilege of being present in the final hours of a person’s life and how important hospice services are to their communities:

“And it was lovely, because after she died, the grandkids were sitting on the bed showing her pictures that they had done for her, and I was thinking, there isn’t another service that could have facilitated that to happen”

“It’s a gift, not just from you to them, but from them to you”

1.3.3 Other Findings

A key difference between the two Atlantic partners was their approach to care and support. The United Kingdom team felt that a collaborative approach was important, especially when providing 24-hour supportive nursing care in the home. However, the United States team considered being able to work alone and independently an important skill, as well as being able to educate and support the patient and family to be independent and self-sufficient in the home environment. This was a reflection of the different types of nursing care provided, but resulted in two very different views about the role of the hospice nurse.

DISCUSSION

The similarities and differences found between the Atlantic partners reflected significant cultural differences in support networks and work ethos. The United Kingdom team valued their colleague support from a professional and personal coping perspective, but did not feel that it was forthcoming, resulting in them feeling lonely and overwhelmed in their roles. Conversely, the United States team felt well supported, perhaps as they are required to work more independently and autonomously, and as a result, appeared better equipped in coping with the role of hospice nurse. Equally, when United Kingdom nurses work in family homes for such long periods of time, they appear to struggle with issues of detachment and maintaining personal

boundaries. As this is not the level of care that United States nurses provide, they do not face similar challenges and are more easily able to separate themselves professionally from the role.

Access to, and barriers preventing access to hospice services were very different, although it is difficult to sense whether cultural barriers would be apparent for the United States nurses, since the demographic of New Hampshire is not particularly culturally diverse, while Bristol, England has a significant multicultural population base. However, United States hospice nurses felt very strongly that Medicare and appropriate medical insurance coverage such as long-term care insurance is the primary barrier for preventing access to hospice services in the United States.

It is clear from both countries that there are still considerable issues surrounding the guidelines regarding the referral of hospice patients, from acuity level to appropriate timing, and that much education is required at a community and national level.

RECOMMENDATIONS

Further transatlantic research may be warranted into some of our more significant findings. Autonomous and independent nursing care versus collaborative nursing care is an interesting subject area, considering the stark differences between the two countries approaches. A study into the effect of patient outcomes in the home-care setting would prove beneficial.

Similarly, focusing on patient-centered-care versus system-managed care would also highlight some interesting differences and provide direction for future practice changes.

There are clearly misconceptions about referral timing and appropriateness. A study into how to educate physicians and patients at a community level would provide a timely and meaningful outcome.

Finally, the role of support and clinical supervision in hospice nursing is clearly beneficial to the United States team and lacking in the United Kingdom team. A study into how clinical supervision and support translates into patient outcomes would be advantageous to the hospice community globally.

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APPENDIX A
Institutional Review Board Approval

From: Simpson, Julie [julie.simpson@unh.edu]
Sent: Monday, May 09, 2011 11:12 AM
To: lcb29@cisunix.unh.edu
Cc: ctk5@unh.edu; lcb29@unh.edu; Tobin, Gerard; Akerman, Peter
Subject: RE: IRB #5170

Christina and Lisa,

Thank you for responding to the IRB's request. The IRB reviewed and approved your response with the following comment:

- In the second sentence in the penultimate paragraph on page 1 of the revised consent form, change “researcher’s” to “researchers.”

You are all set to start your study at St. Peter's Hospice. Upon receipt of letters of support from the other sites and written acknowledgement of receipt of such from the IRB, you will be able to conduct your study there.

Good luck with your research.

Julie

Julie F. Simpson, Ph.D.

Director, Research Integrity Services

University of New Hampshire

51 College Road, Room 103

Durham, NH 03824-3585

Phone: 603/862-2003 * Fax: 603/862-3564

Email: julie.simpson@unh.edu

APPENDIX B

Permission from UK Hospice Location

St Peter's Hospice

St Peter's Hospice
Charlton Road
Brentry
Bristol
BS10 6NL

Tel 0117 915 9400

Fax 0117 915 9473

Web www.stpetershospice.org

Gerard A. Tobin PhD RN RMN
Director of RN Baccalaureate Program
Assistant Professor
University of New Hampshire
College of Health & Human Services
Department of Nursing
Hewitt Hall - Room 249
Durham NH 03824

28th April 2011

Dear Gerard,

Re: "Two Cultures of Caring: A Comparative Study"

I am writing to confirm our willingness to participate in the above study and provide access to the student nurse (researchers) who will be working under the supervision and guidance of Dr Gerard Tobin.

I understand that you will liaise with me closer to the time to arrange a date and let me have copies of the letter of invitation for our staff. Please also let me know how many staff the students wish to interview.

I look forward to hearing from you.

Yours sincerely



Hazel Elliott
Director of Patient Care

APPENDIX C
Permission from US Hospice Location



Central New Hampshire
VNA & Hospice
 780 N Main Street
 Laconia, NH 03246
 603-524-8444

May 11, 2011

Dr. Gerard Tobin
 Re: Tow cultures of caring: A comparative study

It is with great pleasure and support that Central New Hampshire VNA & Hospice support a one hour taped interview of the hospice Registered Nurses for the above named study. I will work to make the hospice RNs available at a time mutually agreed upon.

Feel free to contact me with any further questions.

Sincerely,

Andréa R Huertas, BSN, MBA, CHPN
 Hospice Director
 Central New Hampshire VNA & Hospice
 603-524-8444 ext 323
ARHuertas@commhlth.org

Community Health & Hospice
 780 N Main Street
 Laconia, NH 03246
 Tel: 603-524-8444 / 800-244-8549
 Fax: 603-524-8217

VNA-Hospice of Southern Carroll County & Vicinity
 240 S Main Street
 PO Box 1620
 Wolfeboro, NH 03894
 Tel: 603-569-2729 / 888-242-0655
 Fax: 603-569-2409

APPENDIX D

Subject Demographic Questionnaire

1. Gender

Male

Female

2. Age

<21

21-30

31-40

41-50

51-60

61+

3. How many years have you been a nurse?

<1 year

2-3 years

4-5 years

6-10 years

11-15 years

16-20 years

21+ years

4. How many years have you practiced as a hospice nurse?

<1 year

2-3 years

4-5 years

6-10 years

11-15 years

16-20 years

21+ years

5. What is your highest level of nursing education?

Associate (or equivalent)

Baccalaureate

Masters

PhD

Other

APPENDIX E
Guided Interview Questions

1. Please begin by sharing with me what it is like for you, as a nurse, to care for people in the hospice program?
2. Can you give me an example of a situation when caring for your patient [client] that was particularly rewarding?
3. Can you give me an example of a situation when caring for your patient [client] was particularly distressing?
4. How has caring for hospice patients affected you emotionally and / or spiritually?
5. What way[s] have you found helpful in coping with the daily challenges inherent in hospice care?
6. What recommendations would you offer to future hospice nurses?
7. Is there any information that you like to share that we have not already discussed?

APPENDIX F
Letter of Invite to Participate in Interview

Attention Nurses of St. Peter's Hospice!

You are cordially invited to participate in a research study entitled:

TWO CULTURES OF CARING: A COMPARATIVE STUDY

**A COMPARITIVE STUDY OF NURSES PERCEPTIONS AND EXPERIENCES OF CARING
FOR PEOPLE WITHIN A HOSPICE CONTEXT IN THE UNITED KINGDOM AND THE
UNITED STATES**

The aim of the study is to compare and contrast the perceptions and experiences of nurses in hospice houses in the United Kingdom and the United States. The research hopes to illuminate some of the diverse challenges and achievements that hospice nurses encounter in their day-to-day care of patients experiencing end-of-life care.

The University of New Hampshire's Institutional Review Board for the Protection of Human Subjects in Research has approved the use of human subjects in this study.

Your consent to participate in this study is entirely voluntary, and no financial incentive or other direct benefit will be provided for your participation. If you decide to participate, you will attend an informal one hour interview which will be conducted during the course of your working day.

The interview will be recorded using digital audio technology, to allow the researchers to capture your personal experiences and perceptions of hospice care nursing. Your interview will not be directly attributed, but will form part of an overall data analysis of response reflections and summarization across all nurses interviewed in both countries.

Two researchers from the University of New Hampshire will be visiting St. Peter's Hospice House between June 6 and June 23, 2011 to undertake informal interviews at your convenience.

If you would like to participate in the study, please write your name in the space provided below, indicating the most suitable date and time for you to attend an interview, and return this form anonymously in a blank sealed envelope to the Director of Nursing no later than June 6, 2011.

You may also RSVP the researchers regarding your participation and availability directly via email at lcb29@unh.edu. Please type in the subject line: RSVP TWO CULTURES OF CARING and include your name and preferred date and time of interview availability.

If you have further questions about the research study, please feel free to contact the faculty professor overseeing the research project, Dr. Gerard Tobin PhD RN RMN at gerard.tobin@unh.edu or at telephone number: 001-603-862-3207.

Thank you for your interest in this research project. We appreciate your valuable insights and look forward to sharing them with nursing communities across the Atlantic.

APPENDIX G

Informed Consent Form

Project Title: Two Culture's of Caring: A Comparative Study

Project Leaders: Lisa Armstrong Phone 001-603-686-4937
Christina Polito Phone 001-617-543-1421

Research Facilitator: Dr. Gerard A Tobin Phone (603) 862-3207

Honors Coordinator: Dr. Carol Williams-Barnard Phone (603) 862-2281

PURPOSE

The purpose of this research aims to consider nurses' perceptions and experiences of caring for people within a hospice setting with hopes of identifying themes of commonalities and disparities in theory and practice between the US and the UK.

DURATION OF PARTICIPATION

Your participation in this study can range according to your responses to the interview questions. However, the majority of interviews are expected to be conducted within a 30-60 minute period.

PROCEDURE

The researchers anticipate interviewing up to ten nurses per location during the course of the study. As a participant, you will be asked to answer a few open ended questions, as well as some focused, specific questions concerning your perceptions and experiences experienced in your career as a Hospice care nurse. These questions will be recorded via digital audio device so that the data extracted from the interviews can be transcribed to help further identify themes that are present, or absent, in both hospice locations. This will help us to get a better understanding of the similarities and differences that exist between the two nations and how they offer end of life care.

Data extracted from the audio-recorded interviews will be downloaded onto a personal laptop of one of the two researchers. These files will be password-protected, to which the researcher's, faculty mentor and honors coordinator will have access only. Once the data has been examined and key themes identified and documented, all audio files will be permanently deleted.

As key concepts emerge from examination of the data, they will be labeled, coded and categorized to allow identified patterns and themes to be compared, contrasted, and related to each other to provide format and structure, and illicit meaning from the research data. The objective of the analytical process is to use the emerging data themes to accurately account and summarize nurses' perceptions of hospice care by highlighting key concepts, hypotheses, or other thematic suggestions of significance, which may warrant future Transatlantic comparative research.

The research will culminate in a joint honors thesis manuscript, and a presentation at the Mary Louise Fernald symposium and Undergraduate Research Conference in May 2012, at the University of New Hampshire. The student researchers will also work closely alongside their faculty mentor to publish at least one paper in an international peer reviewed journal, such as the American Journal of Hospice and Palliative Medicine.

RISKS

The possible risks associated with participating in this research study are minimal. The only challenge that this study will impose is the timing constraint it may cause on your daily work routine.

BENEFITS

There may not be any direct benefit to you as the research participant, but this study will help generate data that may give insight as to what differences exist between the US and the UK. This data may also help contribute to nursing research knowledge base and stimulate future comparative research studies into key topics of end-of-life policy, practice, and nursing interventions within a hospice context internationally.

PLEASE READ THE FOLLOWING STATEMENTS CAREFULLY AND RESPOND AS TO WHETHER OR NOT YOU AGREE TO PARTICIPATE IN THIS STUDY:

- 1.) I understand that the use of human subjects in this study have been approved by the UNH Institutional Review Board for the Protection of Human Subjects in Research.
- 2.) I understand the scope, aims, and purposes of this research study and the procedures that need to be followed, as well as the expected duration of my participation.
- 3.) I have received a description of any reasonable risks that may incur as a result of my participation in this research project, and have had these risks explained to me in a manner that I have understood them.
- 4.) I have received a description of any potential benefits that I may experience from this research and understand how they may affect me or others.
- 5.) The investigators seek to maintain confidentiality of all data and records associated with my participation in this research. I should realize, however, that rare instances may occur that can require the investigators to share personally-identifiable information. For example, in response to a complaint about the research, officials at the University of New Hampshire designated by the sponsor(s), and/or regulatory and oversight government agencies may access research data. I also understand that the audio recorded files will be password-protected on a personal laptop that only the researcher's will have access to, and after the data from these files is extracted, it will be permanently deleted.
- 6.) I understand that my consent to participate in this research is entirely voluntary, and my refusal to participate will involve no prejudice, penalty or loss of benefits to which I would otherwise be entitled.
- 7.) I further understand that if I consent to participate, I may choose before, during or after the interview process to no longer be a part of this research without penalty, prejudice or loss of benefits that I would otherwise be entitled.

- 8.) I confirm that no coercion of any kind was used in obtaining my participation in this research study.
- 9.) I understand that if I have any questions pertaining to the research, I have the right to call Lisa Armstrong at (603) 686-4937 or Christina Polito at (617) 543-1421 and be given the opportunity to discuss my concerns or questions in confidence.
- 10.) I understand that if I have any questions pertaining to my rights as a research subject I may call Julie Simpson at the UNH Research Integrity Services at (603) 862-2003.
- 11.) I understand that the University of New Hampshire will not provide financial incentive for participation.
- 12.) I certify that I have read and fully understand the purpose of this research study and the risks and benefits incurred as stated above.

I (name), _____ CONSENT / REFUSE (circle one) to participate in this study


I (name), _____ CONSENT / REFUSE (circle one) to be audio-taped during the interview

Date _____

APPENDIX H

Themes for the United States Interviews

Nurse as a
Professional




Feel it is not important to have experience in general/ oncology nursing prior to hospice nursing

Rarely have discussions with clients and families about Euthanasia

Have to correct misconceptions about timing of end-of-life care, as many patients are referred too late from physicians to receive effective symptom relief and future management

Feel supported by management and peers, and also benefit from clinical supervision

Nurse as an
Individual



US nurses use physical activity to cope with the stress of the role, such as walking the dog, going to the gym, and yoga


Utilize the support of work colleagues and organization counselors more than family and friends in coping

Feel that their own awareness of self-spirituality has grown in their role as a hospice nurse

Sets boundaries with self and client/families

Feel that the hospice nurse is autonomous and independent

Nurse as a
Care-Giver



US care is focused on achieving fast, effective, and cost efficient symptom control

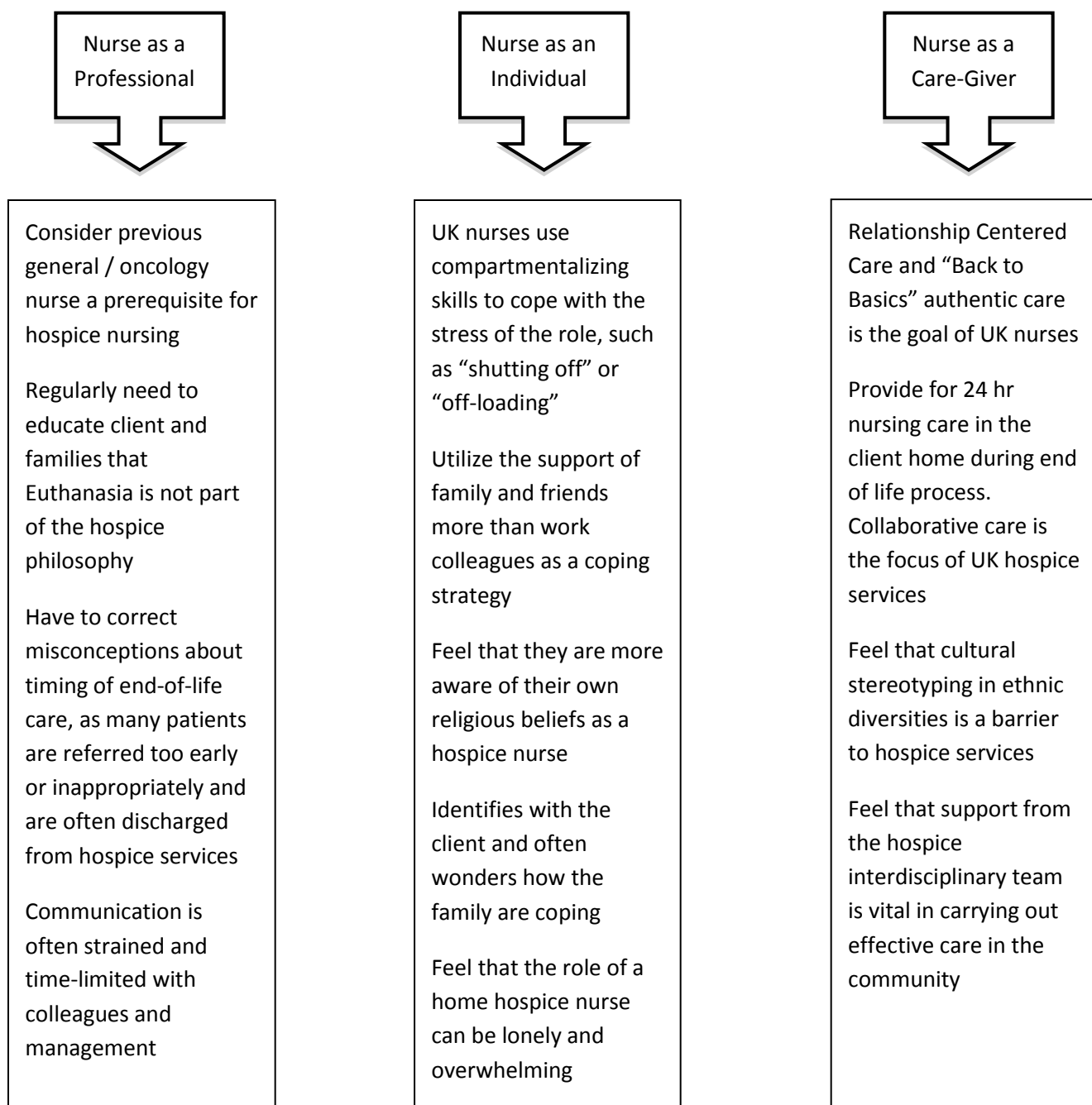
Educate the client and the family to be independent and self-sufficient at home during the end-of-life process. Autonomous care is the focus of US hospice nurses

Consider the issue of appropriate medical insurance a barrier to hospice services

Consider being able to work alone and independently an important skill in community hospice nursing

APPENDIX I

Themes for the United Kingdom Interviews



APPENDIX J
Themes for the United States and the United Kingdom Interviews

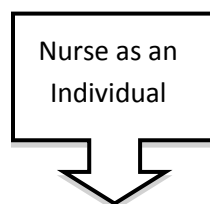


Public Knowledge and Education

Both teams share the opinion that hospice services still need increased exposure at a community level

Communication

Both teams agree that excellent communication skills are paramount in home hospice care, both internally within the organization and externally with patient and families



Living in the Moment

US and UK nurses equally discussed their aptitude for “living in the moment” or “being in the here and now” as a result of being surrounded by death on a daily basis

Using Colleagues, Friends, & Family to Cope

Both teams talked of their own personal support networks and the important role they play in helping them to undertake “the work of hospice”



Symptom Control & Privilege

Symptom control was the #1 reward for all hospice nurses. Many nurses talked of the privilege and honor of being present in the final hours of a persons life

Dealing with Anger and Grief

Inadequate symptom control was also the #1 distressing factor in hospice nursing, alongside managing client/family transference of anger and grief