

Cultural Competency in Hospice Care: A Case Study of Hospice Toronto

By

Maja Jovanovic

**A thesis
presented to the University of Waterloo
in fulfilment of the
thesis requirement for the degree of
Master of Arts
in
Sociology**

Waterloo, Ontario, Canada, 2008

© Maja Jovanovic 2008

Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Maja Jovanovic

Abstract

The population demographics of the greater Toronto Area are rapidly changing, with visible minorities comprising 43% of the GTA, and 10% of the total adult population of Canada. It is incumbent upon the health care sector to accommodate these changes in a culturally competent manner. Health care and culture intersect in the most delicate of ways during the last stages of life. The health care system must ensure that minorities have an equal access to end-of-life health care services and that their individual cultural beliefs and values are respected by culturally competent health care providers. Hence, this thesis examines the current state of cultural competence in hospice and palliative care in the Greater Toronto Area. This study will show the strengths and limitations of the current hospice care in terms of providing culturally competent care. To explore this topic in greater detail, my research is guided by the following questions:

- 1) What is the current state of culturally competent care in a hospice setting?
- 2) What are the challenges to providing culturally competent care in a hospice in the Greater Toronto Area?
- 3) What are some possible strategies for increasing competency within a hospice setting?

To explore my research questions fully, I provide a critical analysis of six cultural competency theories, while integrating a social determinants of health framework, focusing on the theory of social exclusion and minority health care. This case study analysis is enhanced by the 14 in-depth interviews of hospice volunteer participants and 1 administrator. There are six major findings in this research. First, volunteer participants encountered cultural clashes when their levels of cultural competency were weak. Second, volunteer participants revealed there was a lack of adequate cultural competency training with the hospice. Third, volunteer participants gave abundant suggestions for improving cultural competency training. Fourth, volunteer participants perceived the hospice to be unsupportive of some of their needs. Fifth, the lack of ethnic, cultural and linguistic diversity of the hospice volunteer participants was noted. Last, the lack of religiosity amongst the volunteer participants was surprising.

This research is significant for its Canadian hospice volunteer focus and the findings will be beneficial in practice for patients, their families, volunteers, and other health care providers, by providing the knowledge and tools necessary to enhance their level of cultural competency.

Acknowledgments

**Keep away from people who try to
belittle your ambitions. Small people
always do that, but the really great
make you feel that you, too, can
become great.
-----Mark Twain.**

Sometimes in life we are graced with the honour of having a mentor. I have had two.

When I struggled though my undergraduate degree at the University of Toronto, floundering, directionless and without ambition, Professor Lorne Tepperman told me I was talented. He believed in me before I believed in myself. He took me under his sociological wing of support, and year after year, I began to develop the confidence he had in me already, and when I finally confided my desire to attend graduate school. He only asked “what took you so long”?

When I arrived at graduate school, my supervisor, Professor Weizhen Dong said “Welcome”
When I visualized my goals to Professor Dong she said “Yes”.
When I explained my thoughts and feelings she said “Yes”.
When I dreamed of completing my M.A in a year, she said “Yes”.
Whenever I stumbled or had questions, she provided immediate answers and reassurance. She guided me towards the accomplishment of my goal and always illustrated the larger sociological picture for me.
When I accomplished my goal, she said “Of course you did”.

There are those who lead, not by demanding attention, but by quietly providing the example of dedication, and enthusiasm, and who strengthen those around them with their skills and talent. Professor Tepperman and Professor Dong have inspired me and this thesis is a direct result of their confidence in me, and their unwavering support and kindness throughout. I thank them both.

I would like to thank Professor McClinchey for his kind words of support during this year and for never doubting that I would finish the program in a year.

I would also like to thank Professor John Hirdes for agreeing to join my committee and his outstanding and helpful advice.

A sincere thank-you to Hospice Toronto, for their friendship, support and encouragement over the past decade. Through my association with Hospice Toronto and the clients I have served, I have realized the grace of patience, the vulnerability and heartache of the ill, and the complete honour in witnessing the dignity and grace of those that are dying.

Thank-you to all the hospice volunteer participants who gave their time, and entrusted their stories to me. You are all valued and appreciated and the work that you do is commendable.

Dedication

This thesis is dedicated to those who did not think they would succeed. For those who were afraid,--afraid of failing, afraid of making mistakes, afraid of questioning the status quo. This is also for those who have taken chances, and paved the way. For those who chipped away at the barriers, so that others would have an easier road. Life is better when you believe,--always believe in yourself, your vision and your dreams.

Our thoughts create our reality,-- and so we must believe.

Come to the edge, He said.
They said, We are afraid.
Come to the edge, He said.
They came. He pushed them
And they flew.

-----Apollinaire, Guillaume

Table of Contents

List of Tables.....	viii
List of Appendices.....	ix

Chapter 1: Introduction

1.1 Statement of the research problem.....	1
1.2 Objective of the research.....	2
1.3 Methodology.....	3
1.4 Significance of the Study.....	5
1.5 Organization of the paper.....	6

Chapter 2: Theoretical framework

2.1 Culture: Definitions and Importance	8
2.2 Cultural Competence: Definitions and Importance.....	10
2.3 Canada's Ethnic and Cultural Diversity Trends.....	14
2.4 Culturally Competent Organizations.....	18
2.5 Hospice and Palliative Care: Definitions and Importance.....	22
2.6 Importance of Cultural Competency in Hospice and Palliative Care.....	26
2.7 Examples of Cultural Competence in Health Care.....	32
2.8 Theoretical Framework.....	37
2.9 Cross's Cultural Competence Continuum.....	38
2.9.1 Cross's Culturally Competent System of Care.....	43
2.10 Isaac's Culturally Competent Care.....	46
2.11 Leininger's Culture Care Diversity and Universality Theory.....	48
2.12 Camphina-Bacote's Process of Cultural Competence Model.....	54
2.13 Giger and Davidhizar's Transcultural Assessment Model.....	58
2.14 Purnell's Model for Cultural Competence.....	61
2.15 Role of Multiculturalism in Canada.....	64
2.16 Social Determinants of Health Theory.....	65
2.17 Social Exclusion Theory and Minority Healthcare.....	66

Chapter 3: Methodology

3.1 Characteristics of Qualitative Research.....	74
3.2 Qualitative Research Design.....	76
3.3 Role of the Researcher.....	77
3.4 Data Collection Procedures.....	80
3.5 Data Recording Procedures.....	83

3.6 Data Analysis Procedures.....	84
3.7 Strategies for Validating Findings.....	85
3.8 Narrative Structure.....	87
3.9 Anticipated Ethical Issues.....	87

Chapter 4: Findings and Analysis

4.1 Hospice and Palliative Care Volunteers Profile.....	89
4.2 Women and the Role of Caregiving.....	92
4.3 Participants.....	95
4.4 Presentation of Findings.....	97
4.5 Analysis.....	97
4.6 Theoretical Sociological Contribution.....	120

Chapter 5: Conclusion

5.1 Recommendations to increase cultural competency in health care.....	122
5.2 Future Trends of the research.....	127
5.3 Limitations of the Study.....	131
5.4 Conclusion.....	132

Appendices.....	135
------------------------	------------

References.....	171
------------------------	------------

List of Tables

1. Table 1: Top 10 Source Countries for Permanent Residents in 1961-2006.....	16
2. Table 2: Top 10 Source Countries for Permanent Residents in 1991 and 2006.....	16
3. Table 3: Breakdown of Silver’s 1994 analysis of Social Exclusion.....	69
4. Table 4: Permanent Residents by Top Source Countries.....	140
5. Table 5: Permanent Residents by Top Source Countries in Percentages.....	141
6. Table 6: Purnell’s List of Primary and Secondary Characteristics of Diversity	158
7. Table 7: Meta-Paradigm Macro Aspects of the Purnell Model.....	159
8. Table 8: Micro-Aspects of the Purnell Model – The 12 Domains of Culture.....	160
9. Table 9: Explicit Assumptions upon which the Purnell Model is based.....	161

List of Appendices

Appendix A. Recruitment Poster.....	135
Appendix B. Letter of Information.....	136
Appendix C. Consent Form.....	138
Appendix D. Participant Feedback Letter.....	139
Appendix E. Participant Demographic Information.....	142
Appendix F. Dominant Cultural Traits for 19 Different Cultures.....	144
Appendix G. 14 National Standards on Culturally & Linguistically Appropriate Services...	155
Appendix H. Volunteer Participant’s Questionnaire.....	162
Appendix I. Volunteer Participant’s In-Depth Interview.....	165
Appendix J. Hospice Administrator’s Interview.....	168

Chapter 1: Introduction

1.1 Statement of the research problem

The growing diversity of Toronto necessitates that its health care system be culturally competent and responsive to each individual's needs. Toronto's increasing visible minority populations bring unique challenges to the community in general, and the health care sector specifically. The medical and health care services community must meet the growing demands of a diverse and multi-cultural, multi-lingual and multi-faith population. Canada has a responsibility as laid out in the Canadian Multiculturalism Act to identify and remove barriers that negatively impact visible minorities. The ethnic composition of the Greater Toronto Area is rapidly changing and the medical community must respond in kind.

Canada accepts more immigrants per capita than any other nation. (Statistics Canada, 2006). Close to 10% of the current adult population are visible minorities and this is expected to double by 2016 (Ibid). The growth rate of specific ethnic groups have differed significantly as immigration patterns shift from a reliance on Western Europe to a focus on Asian, and South Asian populations (Ibid). Statistics Canada's release of the 2006 Census on Language, Immigration, Citizenship, and Mobility/Migration data reveals some important information regarding the cultural and ethnic composition of the Greater Toronto Area. Currently, 43% of Toronto's population (1,051,125) people reported themselves as being part of a visible minority, up from 37% (882,330) in 1996. The top four visible minority groups in Toronto were: Chinese (10.6%), South Asian (10.3%), Black (8.3%) and Filipino population (3.5%). Currently, 49% of

Toronto's population was born outside of Canada, up from 48% in 1996. The top regions of origin for recent immigrants settling in the City of Toronto were: South Asian (26%), East Asian (22%), European (14%), Middle Eastern and West Central Asian (11%), Caribbean, Central and South American (10%), African (6%), American (6%) and Oceanian (less than 1%). Half of Toronto's population have a mother tongue in a language other than English or French. The top five mother tongue languages spoken in 2006 were: Chinese, Italian, Punjabi, Tagalog/Filipino, and Portuguese. With a plethora of languages spoken in the GTA there are also numerous dominant religions comprised of: Catholic, Protestant, Christian, and Christian Orthodox, Jewish, Buddhist, Hindu, Sikh, and Eastern religions (Statistics Canada, 2006). As culture can influence someone's health decisions, it is incumbent upon health care practitioners to be as culturally competent as possible when dealing with a diverse population. Culture and health care intersect in the most delicate of manners particularly with end-of-life issues. Cultures vary in how they perceive illnesses, medication, the role of physicians, hospitals, and their views on palliative care. Cultures also vary in how they approach hospices, perceived support and or barriers in accessing or accepting hospice care. The health care system must be able to handle the ethnic and cultural diversity of the community by ensuring that minorities have equal access to end-of-life health care services.

1.2 Objective of the research

The main objective of this paper is to analyze the current status of cultural competency in hospice and palliative care in the Greater Toronto Area. This study will show the strength and

limitations of current hospice care in terms of providing culturally competent care. The review of the challenges in providing culturally competent care as hospice care providers, and policy recommendations, are aimed to increase the awareness of cultural competency within hospice and palliative care settings in particular and health care agencies in general.

1.3 Methodology

My interest in this subject area derives from my ten years of experience as a hospice volunteer working for Hospice Toronto (formerly known as Trinity Home Hospice). I worked with patients who were diagnosed with a terminal, incurable disease with six months or less to live and who wished to die at home. I worked with these clients on a weekly basis for a four hour shift and saw first hand all the complexities involved in death and the dying process. Issues such as family dynamics, sexism, fear of death, and denial were present in many of my client cases. Working in such a diverse city as Toronto, I frequently took care of people who were culturally, ethnically and religiously quite different than that of mine. I was intrigued by the multi-lingual, multi-faith and multi-cultural aspects of being a hospice volunteer and wanted to pursue the matter in greater detail. I narrowed my focus to the cultural competency aspect of being a hospice volunteer, and decided on a case study because of my extended history in hospice care, and my connections, relationships and friendships I had built in the community over the years.

I take a social determinants health perspective in my research process, focusing on the theory of social exclusion and minority health care. In this perspective, exclusion is the central problem that impedes the health care of minorities in the Greater Toronto Area. Social

determinants of health care demonstrate how minority members “face institutionalized racism in the health care system, which is characterized by language barriers, stereotypical views held by some health professionals, lack of cultural competencies, barriers to access and utilization, and inadequate funding for community health services” (Galabuzi, 2002: 4). Although there are many intervening factors involved in social exclusion theory and minority health care, this paper will focus on the aspect of cultural competency within end-of-life care.

To explore this topic in greater detail, my research is guided by the following questions:

- 1) What is the current status of culturally competent care in a hospice setting?
- 2) What are the challenges to providing culturally competent care in a hospice in the Greater Toronto Area?
- 3) What are some possible strategies for increasing competency within a hospice setting?

I will be using the terms “hospice”, “palliative”, “hospice palliative care”, and “end-of-life care” interchangeably in this paper to indicate the type of care required by people who have an incurable illness with six months or less to live who are seeking comfort, not cures. I will also be using the terms “patient” and “client” interchangeably to mean someone who needs health care services from different agencies or providers such as hospices, long-term care facilities and hospitals. Patients and/or clients receive this care free of charge, unless otherwise specified. Hospice Toronto has a language history of using the term ‘client’, although the term is usually reserved for paying clients, all the services provided through the hospice are free. Health care “services providers”, “agencies” and “institutions” are all comparable terms, to suggest places such as hospitals, long term care facilities, hospices and palliative care wards. The term ‘visible

minority' are, according to the *Employment Equity Act* “persons, other than aboriginal peoples, who are non-Caucasian in race or non-white in color” (Statistics Canada, 2005).

To explore my research questions, I look at the overall nature of cultural competency first, such as the definitions and importance of this issue in health care in general and hospice palliative care in particular. I then explore the theoretical frameworks of cultural competency theories, the role of multiculturalism and social exclusion and I list examples of how culture can have an effect on health care situations. Next, I introduce my case study of Hospice Toronto, including interviews with volunteers and an administrator who give their opinions about working with different cultures, and the challenges they have encountered. I discuss the typical hospice volunteer profile and compare it to the results from my research. I also analyze the role of gender and the burden of caregiving which arose as an interesting issue. Finally, I conclude the paper with recommendations for increasing cultural competency in hospice care specifically and health care in general and I list several future trends of the research.

The data used in this research are primarily first-hand accounts given by volunteers and an administrator from Hospice Toronto. I also incorporate previously published work on hospice and palliative care research and volunteers.

1.4 Significance of the Study

There is a lack of research on Canadian palliative care issues in general and hospice volunteers specifically. Therefore, this research is significant for its Canadian hospice volunteer focus. Although there are some studies analyzing cultural competence in health care, there are no

studies that look at cultural competency in hospice care from a volunteer perspective in Canada. This paper's major concern deals with the scope of cultural competency in hospice palliative care and the research findings will be beneficial in practice for patients, their families, volunteers, and health care providers such as nurses, doctors, social workers and personal support workers by providing the knowledge and tools necessary to enhance their level of cultural competency. By initiating the discussion on the importance of cultural competency in healthcare, and specifically end-of-life care, this research uncovers challenges of providing culturally competent care in palliative care settings, which will be useful for relevant agencies to take measures for the improvement of care giver training, and the patient-caregiver relationship.

1.5 Organization of the paper

There are five chapters in this paper. The statement of the research problem, the objective of the research, methodology, and significance of this research comprise Chapter One. The remaining chapters are organized as follows: Chapter Two presents a theoretical framework that informs the remaining chapters. It discusses the definitions and importance of culture, cultural competency in health care and in hospice care in particular. A literature review on six cultural competency theories and the role of multiculturalism, social determinants of health and social exclusion and minority health is given. This is followed by a section on the examples of cultural competency issues in health care. Chapter Three focuses on methodology and discusses the characteristics of qualitative research, the research design, such as rationale for the case study.

Data collection procedures, organization and coding of the data are followed by a brief listing of the participant characteristics and anticipated ethical considerations. Chapter Four analyzes the findings, giving a general profile of hospice volunteer participants, a demographic profile of the hospice volunteer participants in this study and an analysis of the role of gender and the burden of caregiving. Following this, is a brief description of the participants of this research project. The six major themes that emerged throughout the data will also be discussed. The final chapter, Chapter Five, discusses recommendations to increase cultural competency in health care, and hospice care in particular. Also discussed in the chapter are the future trends of the research, and the limitations of the study, followed by the conclusion.

Chapter 2: Theoretical Framework

2.1 Culture: Definitions and Importance

Canada is a nation filled with a plethora of different cultures, races, ethnicities, languages, religions, customs, folklores, and ways of being. Culture, in particular, helps to form our individual personalities, our belief systems, our values, behaviors, attitudes and perceptions. Culture informs how we see ourselves, but more importantly, how we see, interpret and judge others. Culture influences and shapes our individual preferences and helps us make sense of, or understand the community we live in, the society we inhabit and the people around us.

Culture is also an integral part of our health, and health care system. It is a tool that can be used to break down old conditioned stereotypes and biases of the past, or it can reinforce ethnocentric viewpoints. Many intervening components can influence or affect someone's culture.

For instance, the American Medical Association compiled a list of factors such as: "educational level, income level, geographic residence, identification with community groups (e.g. religious, professional, community service, political), individual experiences, place of birth, length of residency in the [country], and age" that can affect someone's culture (AMA, 2003, p.1).

Attempting to define culture is not a simple task, as every agency, institution, and discipline defines it differently. For instance, the on-line Merriam-Webster dictionary defines culture as:

The integrated pattern of human knowledge, belief, and behavior that depends upon the capacity for learning and transmitting knowledge to succeeding generations. The customary beliefs, social forms, and material traits of a racial, religious, or social group; the characteristic features of everyday existence shared by people in a place or time. The set of shared attitudes, values, goals, and practices that characterizes an institution or organization (<http://www.merriam-webster.com>).

On-line Britannica defines culture as:

(1) Integrated pattern of human knowledge, belief, and behavior that is both a result of and integral to the human capacity for learning and transmitting knowledge to succeeding generations.

(2) Culture thus consists of language, ideas, beliefs, customs, taboos, codes, institutions, tools, techniques, works of art, rituals, ceremonies, and symbols...Every human society has its own particular culture, or sociocultural system. Variation among cultures is attributable to such factors as differing physical habitats and resources; the range of possibilities inherent in areas such as language, ritual, and social organization; and historical phenomena such as the development of links with other cultures. An individual's attitudes, values, ideals, and beliefs are greatly influenced by the culture (or cultures) in which he or she lives. Culture change takes place as a result of ecological, socioeconomic, political, religious, or other fundamental factors affecting a society. (<http://www.britannica.com>)

The Penguin Dictionary of Sociology defines culture as:

(1) Culture is contrasted with the biological. Anthropologists...use 'culture' as a collective noun for the symbolic and learned, non-biological aspects of human society, which include language, custom and convention, by which human behavior can be distinguished from that of other primates. Human behavior is seen as culturally and not genetically or biologically determined.

(2) Culture as a way of life. Social groups may be differentiated from each other by their differing attitudes, beliefs, language, dress, manners, tastes in food, music or interior decoration, and a host of other features which comprise a way of life. (Abercrombie, et al., 2000, p.83)

Robert Brym defines culture in his *New Society* (2008) as "...all socially transmitted ideas, practices, and material objects that people create to deal with real-life problems...Culture...is the sum of the socially transmitted ideas, practices, and material objects that enable people to adapt to, and thrive in, their environments" (p.31-32). In another undergraduate sociology textbook by John J. Macionis (2005) culture is: "...the values, beliefs, behavior, and material objects that constitute a people's way of life...culture includes what we think, how we act, and what we own. But, as our social heritage, culture is also a bridge to the past as well as a guide to the future" (p.55). He continues on by stating that culture "shapes what we do, helps form out our personalities—what we commonly describe as human nature" (p.56). The U.S. Department of Health and Human Services developed a handbook on cultural competency and defines culture as

“shared values, traditions, norms, customs, arts, history, folklore, and institutions of a group of people”(www.aoa.gov/prof/addiv/cultural/addiv_cult.asp). Purnell and Paulanka (2003) define culture as the “totality of socially transmitted behavioral patterns, arts, beliefs, values, customs, lifeways, and all other products of human work and thought characteristics of a population of people that guide their worldview and decision making” (p.3). They believe that these cultural patterns are inherited by family and passed down to others and are usually learned through the family and can be either explicit or implicit (Ibid).

2.2 Cultural Competence – Definition and Importance

One of the first people to discuss cultural competency was Cross (1989) in his groundbreaking monograph on child welfare and he defines it as:

Cultural and linguistic competence is a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or among professionals that enables effective work in cross-cultural situations. ‘Culture’ refers to integrated patterns of human behavior that include the culture is an integrated pattern of human behavior that includes the language, thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. ‘Competence’ implies having the capacity to function effectively as an individual and an organization within the context of the cultural beliefs, behaviors, and needs presented by consumers and their communities.

The U.S. Department of Health and Human Services, OPHS Office of Minority Health, in their executive summary for the National Standards for Culturally and Linguistically Appropriate Services in Health Care (2001, p.2) defined cultural competence as:

The thoughts, communications, actions, customs, beliefs, values, and institutions of racial, ethnic, religious, or social groups. Culture defines how health care information is received, how rights and protections are exercised, what is considered to be a health problem, how symptoms and concerns about the problem are expressed, who should provide treatment for the problem, and what type of treatment should be given. In sum, because health care is a cultural construct, arising from beliefs about the nature of disease and the human body, cultural issues are actually central in the delivery of health services treatment and preventive interventions. By understanding, valuing, and

incorporating the cultural differences of America's diverse population and examining one's own health-related values and beliefs, health care organizations, practitioners, and others can support a health care system that responds appropriately to, and directly serves the unique needs of populations whose cultures may be different from the prevailing culture (Katz, Michael, Personal communication, November, 1998).

The Cultural Landscape

It is a growing necessity for health care providers to become culturally competent in order to effectively, professionally and sensitively deal with a variety of different cultures and to diagnose, recommend and implement health care strategies that coincide with a clients' cultural preferences. A proficiency in cultural competence is important for all health care providers at all levels, in all types of agencies, institutions and disciplines. From doctors to nurses, social workers, volunteers, staff members, administration, morticians, nutritionists, home health care workers/aides, and technicians—everyone must take personal responsibility for ensuring their own level of cultural competency (Purnell and Paulanka, 2003, p.1).

Diversity is everywhere, from the airports, to the schoolyards to the corner stores in community neighborhoods. The demographics of North America are changing rapidly. With people moving, relocating, immigrating, migrating, intermixing, and inter-marrying, -- races are blurring together, cultures are mixing and diversity is growing more complex. A natural progression of this diversity is that different cultures will eventually intersect with the health care system that may or may not be cognizant or respectful of their differences. All health care providers must acknowledge their own internal belief systems, values, assumptions, judgments, potential stereotypes and biases in order to begin addressing the larger issue of cultural competence in healthcare. Internal assessment or personal/self-awareness or self-exploration are

interchangeable terms meant to describe the process of reflecting on one's own personal views and beliefs. Specifically, *self-awareness* as it relates to cultural competency is the:

...deliberate and conscious cognitive and emotional process of getting to know yourself: your personality, your values, your beliefs, your professional knowledge standards, your ethics and the impact of these factors on the various roles you play when interacting with individuals who are different from yourself" (Purnell and Paulanka, 2003, p.3).

Understanding yourself implies a level of recognition of your current belief systems (both positive and negative), and the need for more competent information or knowledge on diversity and cultures. This in turn leads to accepting and respecting the cultural differences of others (Ibid). Personal cultures are stimulated by and react to other cultures; they have an impact on what you say, how you say it, what you think, and what you believe in. All of these factors influence how you take care of yourself, your outlook on health and well-being, and how preventive you are in your health care regime.

When discussing culture and cultural competency, terms such as beliefs, attitudes and ideologies are frequently mentioned and need to be properly defined. *Attitude* is "a state of mind or feeling about some matter of a culture [and] attitudes are learned" (Purnell and Paulanka, 2003, p.3). A *belief* is "something that is accepted as true, especially as a tenet or a body of tenets accepted by people in an ethnocultural group" (Ibid). An *ideology* is "the thoughts and beliefs that reflect the social needs and aspirations of an individual or an ethnocultural group" (Ibid). There is no doubt that culture has important influences on how people view their health and illness. When defining cultural competency, terms such as cultural awareness and cultural sensitivity are used interchangeably, when in actuality, they are dissimilar. *Cultural awareness* is "the appreciation of the external signs of diversity (arts, music, dress, and physical characteristics), while *cultural*

sensitivity is the personal attitudes and not saying things that might be offensive to someone from a different cultural or ethnic background” (Ibid). When health care providers increase their own cultural competency, health care procedures and experiences for patients can only be enhanced. Purnell and Paulanka (2003) have developed the most comprehensive and inclusive definition of cultural competency to date, encompassing seven essential components including:

1. Developing an awareness of one’s own existence, sensations, thoughts, and environment without letting it have an undue influence on those from other background.
2. Demonstrating knowledge and understanding of the client’s culture, health-related needs, and meanings of health and illness.
3. Accepting and respecting cultural differences
4. Not assuming that the health-care provider’s beliefs and values are the same as the client’s.
5. Resisting judgmental attitudes such as “different is not as good”.
6. Being open to cultural encounters.
7. Adapting care to be congruent with the client’s culture. Cultural competence is a conscious process and not necessarily linear. (Ibid. p.3-4).

When dealing with cultural competency, issues of stereotyping and biases can arise and usually stem from an ethnocentric viewpoint. *Ethnocentrism* is the “universal tendency of human beings to think that their ways of thinking, acting, and believing are the only right, proper, and natural ways and can be a major barrier to providing culturally competent care” (Purnell and Paulanka, 2003, p.4). *Values* are “principles and standards that have meaning and worth to an individual, family, group, or community” (Ibid). *Worldviews* are “the way individuals or groups of people look at the universe to form values about their lives, and the world around them. It includes cosmology, relationships with nature, moral and ethical reasoning, social relationships, magicoreligious beliefs and aesthetics” (Ibid). How ingrained one’s values, beliefs and worldviews are, will “influence the tendency towards ethnocentrism” (Ibid).

The changing demographics of North America are one of the most important reasons for instituting cultural competence in health care organizations. With immigration increasing every

year in both Canada and the United States, the health care system is dealing with patients that are culturally and linguistically different and “providing culturally competent care is no longer a luxury but a necessity” (Tsai et al., 2004, p.3). In fact, by 2023, the racial and ethnic minority population in the United States will be the majority (Galambos, 2003, p.3). Currently, in the U.S., “African-Americans, American Indians, Alaska Natives, Asian Americans, Pacific Islanders, and Hispanic Americans account for 30% of the population, and by 2025, these population groups will account for 40% of the population” (Ibid).

There are varying perceptions of health, illness and disease according to each client’s culture, ethnicity, religious or spiritual affiliation, family dynamics and environment. Therefore, “to succeed in changing an individual’s behaviors to promote her or his health, the information and approach ought to be culturally relevant and competent” (Ibid). Many ethnic and racial minorities (Asian American, African Americans, and Hispanics and Latin groups), in both the United States and Canada, tend to underutilize the health care services available. This usually stems from “cultural insensitivity and inappropriateness of formalized services to culturally diverse groups” (Ibid, p.4). To alleviate the uneasiness ethnic minorities feel when accessing health care services, it is essential that health care providers in all levels of health care institutions become culturally competent.

2.3 Canada’s Ethnic and Cultural Diversity Trends

In Canada, the immigration trends have dramatically changed, with visible minorities now accounting for 16.2% of the total population (Statistics Canada, 2006, p.5). Statistics Canada

defines *visible minority* as “persons other than aboriginal peoples, who are non-Caucasians in race or non-white in color” (Ibid). Currently, the top ten visible minority groups in Canada are the Chinese, South Asian, Black, Filipino, Latin American, Southeast Asian, Arab, West Asian, Japanese and Korean groups (Canadian Social Trends, 2005, p.18). Between 2001 and 2006, the visible minority population in Canada increased by 27.2%, which was five times faster than the 5.4% growth rate of the total population (Statistics Canada, 2006 p.5). The 2006 Canadian Census also reveals that over 200 ethnic origins were reported which differs from the 25 ethnic origins reported in the 1901 Census (Statistics Canada, 2006). The rate of people claiming multiple ethnic ancestries is also rising (Ibid p.6). With each new increase of ethnic and racial minority immigrants, Canada’s cultural diversity increases. By 2006, eleven ethnic and racial origins had passed the 1-million mark (Ibid).

Table 1 reveals the differences in the top ten source countries of permanent residents in 1961 and in 2006. In the past, most of Canada’s immigrants were from Europe and the United Kingdom, whereas in 2006, the majority came from China and India. Table 2 lists the differences in the mother tongues of permanent residents in 1997 and 2006.

Table 1. Top Ten Source Countries for Permanent Residents in 1961 and 2006

Source Country 1961		Source Country 2006	
1. United Kingdom	25.5%	1. China	13.2%
2. Italy	15.3%	2. India	12.2%
3. Germany	10.2%	3. Philippines	7.0%
4. Netherlands	8.4%	4. Pakistan	4.9%
5. Poland	5.5%	5. United States	4.4%
6. United States	4.3%	6. Iran	2.8%
7. Hungary	3.1%	7. United Kingdom	2.6%
8. Ukraine	2.6%	8. Korea	2.5%
9. Greece	2.0%	9. Colombia	2.3%
10. China	1.7%	10. France	1.8%

Source: Citizenship and Immigration Canada (2006).

Source: www.cic.gc.ca/english/resources/statistics/facts2006/permanent/28.asp

also adapted from (Brym 2008, p.37).

Table 2. Top Ten Mother Tongues in Canada by Permanent Residents in 1997 and 2006

Mother Tongue in 1997	Mother tongue in 2006
1. Cantonese	1. Mandarin
2. English	2. English
3. Mandarin	3. Arabic
4. Arabic	4. Punjabi
5. Punjabi	5. Spanish
6. Urdu	6. Tagalog
7. Chinese	7. Urdu
8. Tagalog	8. French
9. Russian	9. Russian
10. Spanish	10. Korean

Source: Citizenship and Immigration Canada (2006).

Source: www.cic.gc.ca/english/resources/statistics/facts2006/permanent/28.asp

Note: Although Cantonese and Mandarin are both Chinese dialects, Mandarin is the official dialect. There are 76 distinctive dialects in China, therefore, Mandarin is used to communicate for people from different regions. The language itself should be referred to as “Chinese” only, and not “Mandarin” or “Cantonese”.

Tables 3 and 4 (see appendix) list the top sixteen source countries for permanent residents of Canada from 1997 through until 2006. These tables are given in both numerical and percentage distributions. There were “more than 200 different languages reported in 2006 in response to the census question on mother tongue” (Statistics Canada, 2006). People whose mother tongue is neither English nor French (allophones) now account for 20.1% of the population (or one-fifth), which has increased from 18.0% in the past five years (Ibid). Canada’s foreign-born population increased by 13.6% between 2001 to 2006, which represented the largest growth yet, and was four times higher than the growth rate of 3.3% for the Canadian-born population during the same period (Statistics Canada, 2007). Also of note, is that “mixed unions (marriages or common-law unions) involving a visible minority person with a non-visible minority person or a person from a different visible minority group have been increasing, and represents 3.9% of all unions in Canada” (Statistics Canada, 2006, p.16). As these tables make clear, Canada’s cultural, ethnic, racial and linguistic population is changing rapidly and becoming more complex with each passing Census.

Creating culturally competent health care organizations that can effectively deal with this cultural variety is an absolute necessity. Cultural competency in healthcare is about:

Respect for and understanding of diverse ethnic and cultural groups, their histories, traditions, beliefs, and value system in the provision and delivery of services. In practice, culturally competent public administration emphasizes the capacity of public organizations and their employees to effectively provide services that reflect the different cultural influences of their constituents or clients (Baily, 2005, p.177).

2.4 Culturally Competent Organizations

The National Center for Cultural Competence, affiliated with Georgetown University for Child and Human Development, (2006), in Washington, DC, define culturally competent organizations as ones that:

1. Have a defined set of values and principles, and demonstrate behaviors, attitudes, policies and structures that enable them to work effectively cross-culturally.
2. Have the capacity to (1) value diversity, (2) conduct self-assessment, (3) manage the dynamics of difference, (4) acquire and institutionalize cultural knowledge and (5) adapt to diversity and the cultural contexts of the communities they serve.
3. Incorporate the above in all aspects of policy making, administration, practice, service delivery and involve systematically consumers, key stakeholders and communities (www.11georgetown.edu/research/gucchd/nccc/foundations/frameworks.html)

The authors of California Tomorrow (2006) believe that organizations must follow five steps to be culturally competent:

1. Being intentional in recruitment and hiring to assemble a diverse staff and board;
2. Investing in professional development about issues of culture, cultural competence, diversity, and equity;
3. Creating the structure, time, and norms of productive dialogue;
4. Ensuring attention to cultural issues in outreach, programming, and service delivery;
5. Setting expectations that practices will be adapted to address the needs of the agency's diverse constituents and clients (p.7).

Este (1999) establishes six skill competencies that health care organizations must possess to become culturally competent:

1. The ability to develop a trusting relationship with clients and to show empathic understanding;
2. Assessment and consideration of how cultural factors may influence clients' behaviors, including an evaluation of clients' world views and levels of acculturation, particularly if they are immigrants;
3. The desirability of being able to use a second language;
4. The ability to utilize culturally appropriate interviewing techniques, taking into consideration the level of intrusiveness and directness, social distance, formality, and ways of addressing clients;
5. Awareness of and sensitivity to the verbal and nonverbal communication imparted by clients; and

6. The ability to recognize and manage defensiveness and resistance in clients when necessary (Este, cited in Bernard, 2007, p.3).

The Canadian Mental Health Association (2002) lists eight culturally competent systems and supports needed by health care service organizations:

1. Developing, implementing and regularly evaluating organizational policies and practices to ensure cultural competence
2. Ensuring effective cross-cultural communication with diverse clients;
3. Providing regular and frequent professional development opportunities and resources in order to build the cultural competence of staff;
4. Developing, implementing and evaluating strategies to recruit, retain and integrate people from diverse backgrounds and culturally competent staff throughout the organization;
5. Designing, implementing and evaluating services to meet the health care needs of the community;
6. Ensuring active and meaningful participation and representation of community members in organizational processes, including governance, by identifying and implementing innovative strategies;
7. Regularly evaluating results of efforts and monitor progress toward cultural competence; and
8. Establishing mechanisms to develop meaningful research and evaluation methodologies, knowledge and data.
(www.cmha.ca, cited in Canadian Nurses Association – position statement)

As cultures shift, change, intermix and intermarry, new cultures form and adjust. With as many cultures, ethnicities and languages that exist in North America, it would be impossible to be completely proficient in them all, but there should be a commitment from health care professionals, agencies, and institutions to be as up to date with their cultural knowledge and education and as competent as possible. Becoming culturally competent should not be viewed as a destination or endpoint, but rather a continuous journey. In fact, the “...process of becoming culturally competent is an ideal state, but one with no end point. It is conceived as a developmental process that requires life-long learning” (Este, 2007, p.2). Once proficiency is attained in one aspect of cultural competency, there will always be new cultures, traditions or skill sets that require learning or updating, so that the learning process never stops.

The National Center for Cultural Competence in the United States lists six reasons why cultural and linguistic competency is necessary in healthcare organizations:

1. To respond to current and projected demographic changes:

The changing landscape of North America is documented above, and the increasing diversity of people and the growth of visible minorities and immigrants present challenges to the health care community to adequately service and treat everyone in a culturally proficient manner.

2. To eliminate long-standing disparities in the health status of people of diverse racial, ethnic and cultural backgrounds:

Racial and ethnic minorities utilize health care services less often than the native born (Yang and Kagawa-Singer, 2007, p.533). Reasons for this include “ethnicity, years in the host country, labor force activity, immigration status, and type of health insurance” (Ibid).

Institutional barriers such as “a lack of bilingual and bicultural health professionals” are another reason for the underutilization of health care services by minorities (Ibid).

Programmatic barriers include the “lack of translator services, absence of culturally and linguistically appropriate health materials, and absence of cultural competence and sensitivity training for staff” (Ibid).

3. To improve the quality of services and health outcomes:

Health care delivery should be “...accessible, effective and cost-efficient” (Ahmann 2002, p.134). The most crucial factors in providing culturally competent health care services include: “beliefs, values, traditions and practices of a culture; culturally-defined, health-related needs of individuals, families and communities; culturally-based belief systems of the etiology of illness and disease and those related to health and healing; and attitudes toward seeking help from health care providers” (Ibid, National Center for Cultural Competency).

4. To meet legislative, regulatory and accreditation mandates:

The Healthy People 2000/2010 mandated an increased emphasis on cultural competency. The U.S. National Health Promotion and Disease Prevention Objectives also include cultural competency as part of their delivery of health and nutrition services (Ibid). State and Federal agencies have joined to create task forces, Joint Commission and National Committees to improve the situation. Title VI of the Civil Rights Act of 1964 “mandates that no person in the United States shall, on grounds of race, color, or national origin, be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance” (National Center for Cultural Competency).

5. To gain a competitive edge in the market place:

As health care options are increasingly being driven into private insurance, the ‘managed-care’ contracts need to rethink their positions and remain relevant by adjusting to the new demographics and provide services for people of different cultural or ethnic backgrounds (Ibid).

6. To decrease the likelihood of liability/malpractice claims:

Lack of cultural competency or awareness can easily lead to a misdiagnosis, lack of consent, or lack of informed consent, misinterpretations with translators, and a breach of trust with professionals who then become at risk for liability and malpractice claims. The most frequently sued physicians in a 1994 study revealed that poor communication was the primary reason for the lawsuit. To avoid legal hassles by increasing communication by cultural competency is a win-win situation for both patients and health care providers (Ibid).

Adapted from the National Center for Cultural Competence:

www.11georgetown.edu/research/gucchd/nccc/foundations/nned.html

2.5 Hospice and Palliative Care: Definitions and Importance

Proficiency in cultural competence allows for a pluralistic worldview where there is more than one truth, more than one way of viewing or understanding an issue, person or perspective. Being culturally competent also reveals the similarities (along with the differences) amongst us all. Every human being wants to be healthy, everyone wants their children to be safe-- these are commonalities that link us together across all cultures (Braun, Pietsch, and Blanchette, 2000, p.6-7). Cultural competency also improves our interactions with others, allowing for enhanced communication techniques and a diminishment of preconceptions or misjudgments. Culture infiltrates every single aspect of our lives, from birth to death, from pre-natal care to end-of-life care; --culture affects and influences the environment around us and how we respond to these issues. One of the most sensitive of health issues concerns end-of-life care, otherwise known as hospice or palliative care. This is a delicate arena where fear and uncertainty intersect with vulnerability and stress. Culture undoubtedly plays a major role in how people handle death, dying, and bereavement, and being surrounded by health care professionals who are culturally competent can alleviate the burden of such a sensitive time (Kemp, 2005, p.52). Palliative care is defined by the World Health Organization (WHO) as:

An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative care:

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process

- Intends neither to hasten nor postpone death
- Integrates the psychological and spiritual aspects of patient care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement
- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy, or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications
(Sepulveda et al. 2002, pp.94-95; also see Kaasa and DeConno 2001)

The term 'palliative' is derived from the Latin "palliare" which mean to cloak, while the Latin origin of the term 'hospice' means hospitality or hospitable (www.chpca.net). In Canada, hospices were originally a grass-roots organization, run by small communities or church groups on a volunteer and non-profit agreement, whereas palliative care was associated with larger health organizations such as hospitals and long-term care facilities (CHPCA, 2002, p.17). During the mid 1980s, the terms 'hospice' and 'palliative care' were used interchangeably and 'hospice palliative care' was soon coined and aimed at "relieving suffering and improving the quality of living and dying" (Ibid). According to the Canadian Hospice Palliative Care Association (CHPCA), hospice and palliative care strives to help patients and families:

- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears
- prepare for and manage self-determined life closure and the dying process
- cope with loss and grief during the illness and bereavement

Hospice palliative care aims to:

- treat all active issues
- prevent new issues from occurring
- promote opportunities for meaningful and valuable experiences, personal and spiritual growth, and self-actualization

- Hospice palliative care is appropriate for any patient and/or family living with or at risk of developing, a life-threatening illness due to any diagnosis, with any prognosis, regardless of age, and at any time they have unmet expectations and/or needs, and are prepared to accept care.
- Hospice palliative care may complement and enhance disease-modifying therapy or it may become the total focus of care.

While hospice palliative care is the nationally accepted term to describe end-of-life care aimed at relieving suffering and improving quality of life, individual organizations may continue to use “hospice”, “palliative care” or another similarly acceptable term to describe their organization and the services they are providing. Hospice palliative care is most effectively delivered by an interdisciplinary team of healthcare providers who are both knowledgeable and skilled in all aspects of the caring process related to their discipline of practice. These providers are typically trained by schools or organizations that are governed by educational standards. Once licensed, providers are accountable to standards of professional conduct that are set by licensing bodies and/or professional associations (Ibid, p.18). The CHPCA (2002) lists seven values that are intrinsic to hospice palliative care:

1. The intrinsic value of each person as an autonomous and unique individual.
2. The value of life, the natural process of death, and the fact that both provide opportunities for personal growth and self-actualization.
3. The need to address patients’ and families’ suffering, expectations, needs, hopes and fears.
4. Care is only provided when the patient and/or family is prepared to accept it.
5. Care is guided by quality of life as defined by the individual.
6. Caregivers enter into a therapeutic relationship with patients and families based on dignity and integrity.
7. A unified response to suffering strengthens communities.
(CHPCA, 2002, p.19).

Authors Hawthorne and Yurkovich (2004) define hospice as:

- a program of care for the dying
- a type of care synonymous with palliative care
- a location of care in the community
- a reflection of scientific thinking regarding the end of life
- a place of refuge, a sanctuary, where human relationship prevails and science is an

- invited guest (p.416).

Harrison and Ford (2007) define hospice care as:

providing support to patient and family when the patient no longer responds to treatment and prognosis is six months or less to live. The goal of hospice care is to provide comfort and dignity that improves the quality of a patient's last days. Care is control of pain, and attention to the patient's psychological and spiritual needs. This contrasts with curative care because it's not designed to cure an illness and it's not designed to lengthen life, but it focuses on managing pain and enhancing quality of life (p.119).

Hawthorne and Yurkovich give one of the most beautiful descriptions of what hospice care is by stating that:

Hospice as a place of refuge means a place of reflection and hope, where the journey through the final days is not made alone but with another, where the patient, family and health professional need each other and understand each other beyond words. They are touched by the warmth of human relationship to the depth of their souls, sharing the mystery of dying and death (p.416).

To summarize, hospice and palliative care are used interchangeably in the literature and the Canadian Hospice and Palliative Care Association (CHPCA) permits the usage of either terms. Although the newest terminology incorporates both terms into "hospice palliative care", many organizations continue to use the term hospice or palliative or a combination of the two. This paper will use either term interchangeably to mean the same thing - end of life care for patients with a terminal illness, seeking to provide comfort and dignity, not to prolong or hasten death, not a curative treatment, but an outlet of support for the patient and their family and loved ones.

2.6 Importance of cultural competency in Hospice and Palliative care

The significance and value of cultural competency escalates when dealing with hospice palliative care because of the sensitive and stressful nature involved in the process of death and dying. In particular, cultural competency is imperative in hospice care for five main reasons; (1) there is a paucity of research in the field of cultural competency and palliative care; (2) the changing demographics of North America demand it; (3) ethnic minorities under-utilize hospice palliative care services; (4) for basic human decency and empathy reasons, and (5) to diminish the fear and stigma of death and dying.

1. Lack of research in the field of cultural competency and palliative care

The current state of research in palliative care is unbalanced at best and completely lacking in vital Canadian data. Most research to date has focused on American data except for research done by Claxton-Oldfield (2004a; 2004b; 2005; 2007) which looks at hospice and palliative care in Canada, but does not discuss the cultural competency aspect. There is significant room for future research to focus on cultural competency in Canadian end-of-life care. Culture and cultural competency are transformative terms that adjust and refine themselves to the changing environment of a multicultural country such as Canada. Cultural competency research must therefore be re-invigorated to reflect the most current demographics, and must consistently be amended to stay relevant to the current demographics. Unfortunately, only 1% of palliative care research focuses on the actual experiences of dying, so the urgency to further research this area is apparent (Jubb, 2002, p.344-345). In fact, some researchers have argued the lack of data in palliative care is attributable to the “ethical challenges that allegedly distinguish dying patients as

a special client class” (Ibid, p. 342). This type of research raises questions about free choice, and whether dying patients feel pressured to participate, and whether they believe their quality of care will be affected by their decision to participate in the research or not.

Cultural competency training for health care providers dealing with dying patients can only enhance sensitivity towards their patients’ needs, and create an awareness of their fears and anxieties while decreasing any misconceptions about certain cultural beliefs. Being culturally competent while working with patients who are dying allows for a greater sense of comfort and ease because health care providers will be equipped with the knowledge to handle almost any cultural situation that presents itself (Giblin, 2002, p. 238). Volunteers, health care providers, family members, and patients themselves, who give their time and expertise in palliative care research not only benefit directly from the research outcomes and recommendations, but they also assist future volunteers, family members and patients who will benefit from the expertise of previous research (Jubb, 2002, p. 342). Although palliative care research is limited, cultural competency in palliative care is almost non-existent in Canada, and any future research in this area will allow us to see the commonalities that link different cultures and peoples together, and will improve our communication and understanding of other people and cultures (Braun, Pietsch and Blanchette, 2000, p.7).

By studying cultural competency in palliative care, health care providers from all levels and institutions will be equipped with the communication tools to accommodate and understand a variety of cultures. Health care providers will be knowledgeable and respectful of the diversity of their patients’ needs, and develop the communication skills necessary to manage the health care of

all their culturally diverse patients (Braun, Pietsch and Blanchette, 2000, p.5). As Jubb (2002) states “there is no justification for not endeavoring to improve the quality of palliative care through research” (p.342). In fact, in 2000 a report of the Canadian Senate listed “improved support for palliative care research as one of their 14 recommendations for improving the quality of end-of-life care” (Fainsinger, 2002, p.173). Increased research and funding is just the beginning for becoming culturally competent in hospice care.

2. Changing demographics

The second reason cultural competency is important in palliative care deals with the changing demographics of North America in general and the Greater Toronto Area (GTA) in particular. We are an aging population with approximately 220,000 Canadians dying every year, and 160,000 Canadians needing hospice palliative care services (www.hospice.on.ca). Currently, over 13,300 hospice volunteers provide 630,000 hours of service in 450 different communities in Ontario (Ibid). The Hospice Association of Ontario (HAO) released a fact sheet detailing the following information:

- 90% of Canadians wish to remain in their own homes during the final stages of life, yet 75% of deaths still take place in hospitals and long-term care homes
- 94% of Canadians feel they could not adequately care for a dying loved one without outside support
- HAO has seen a 1000% growth in membership over the past decade
- HAO originated with 9 hospices in 1989 to over 150 hospices today which reflects the demand for end-of-life care in communities across Ontario
- Hospice volunteers have become the largest direct service providers within Ontario’s voluntary health care sector reflecting the growing need for compassionate support in the home
- Over 13,300 volunteers dedicated 630,000 hours of service each year to assist clients and families throughout Ontario, which represents an investment of \$6 million in local communities (www.hospice.on.ca).

Statistics Canada projects that by 2020 over 330,000 Canadians will die every year, which is an increase over the 259,000 who died in 2007 (Statistics Canada – Projections for Canada). People are living longer and are surviving through multiple illnesses and diseases to the point where some researchers claim, “we have created a medical culture that cures disease and prolongs life but fails to provide support during the death process” (Harrison and Ford, 2007, p.119). In 1994, there was only one known hospice in the United States, and in 2004, that number jumped to over 3640 registered hospices across the U.S. (Myers-Schim and Doorenbos, 2006, p.404). The challenge now is to make the existing hospice and palliative care services culturally competent and responsible to their culturally diverse community of patients. This leads up to the third reason why cultural competency is important for palliative care research.

3. Ethnic minorities under-utilize hospice and palliative care services

It has been reported that ethnic minorities under-utilize hospice palliative care services (Myers-Schim and Doorenbos, 2006, p.404). In fact, the National Hospice and Palliative Care Organization (NHPCO) reported that in 2004: 77% of hospice patients were Caucasian, 8% were Black/African-American, 6% were Latino/Hispanic, 2% were Asian/Pacific Islander, 6% were multi-racial (Ibid, p.404).

Since ethnic minorities under-utilize hospice palliative care services they are also “under-treated which leads to unnecessary suffering and poorer outcomes for minorities, especially Foreign-born and non-English speaking” people (Kemp, 2005, p.44). Ethnic minorities are confronted by a variety of barriers that may prevent or limit their chances of using hospice care services. Barriers such as language issues, lack of translators, issues of transportation, feelings of

being misunderstood or prejudged, racism and discrimination are all factors that will be explored further in this paper. Suffice to say, ethnic minorities face challenges when dealing with hospice care services.

The demographics of Canada are changing with a plethora of ethnicities, languages, religions and cultures co-existing together creating a diverse landscape of people. There is an urgency for health care professionals in end-of-life care to be able to effectively and sensitively communicate with their patients to create the best health outcomes (Myers-Schim and Doorenbos, 2004, p.31). For instance, “what is acceptable or appropriate for one group may be seen as problematic or dangerous for another” (Hallenbeck and Goldstein, 1999). It is crucial for health care practitioners at all levels (social workers, nurses, doctors, volunteers) to be cognizant of the cultural beliefs and traditions of their patients so that the correct recommendations are made in accordance with their own specific cultural or religious belief systems (Kemp, 2005, p.52).

When dealing with end-of-life issues, it is important to know from a cultural standpoint of view, what the patient believes in regarding pain medication, last rites, burial options, disposal of the body, and organ donations (Braun, Pietsch and Blanchette, 2000, p.2). Also of relevance is the decision making locus, and many times, it is not the patient who makes the most important health care decisions. In many cultures, that power is handed over to the eldest in the family or the family decides as a group (Ibid). As people are increasingly multi-lingual, multi-faith, and multi-cultural, it is necessary to be sensitive, patient and accepting of all types of religions, cultures, languages and belief systems, which is part of the fourth reason cultural competency is important in palliative care.

4. Sense of decency and sympathy for palliative care patients

From a structural functionalist perspective, we are all connected, and if ignore the needs of the dying community then we have failed as a society in general. If one part of the whole structure is weak or impaired, we are all weaker because of it. We are only as strong or as unified as our weakest and most vulnerable segments of the community. How we value or treat those who are dying speaks volumes about our tolerance and patience as a whole. The dying are simply at the opposite end of the life spectrum: just as those who are born deserve our kindness and patience, so to, do those who are dying. We must have a common sense of decency, or sympathy, and an ability to understand and relate to those who are dying, but who still deserve our attention. This distancing of those who are dying from the living leads us to the final reason why cultural competency is of utmost importance in palliative care research, which is to decrease the fear and stigma of death and dying.

5. Decrease the fear and stigma of dying

There is a sense of hostility towards issues that are frightening, such as the process of death and dying in our society. Most people dislike speaking about matters such as organ donation, burial plots, and life support or list rites. People find such discussion to be morbid, unpleasant and depressing, hence the avoidance of these issues altogether. People would rather not think about the dying process and most are uncomfortable around those who are dying, simply because of a lack of communication skills. When the usual exposure to death derives from television and movie screens, the reality of death seems intangible. Most Canadians still die in hospitals and palliative care wards even though they would rather die in the comfort of their won

homes (Fainsinger, 2002, p.173). If Canadians continue to shield themselves from what the dying process is really like, the negativity surrounding death will never dissipate.

In hospitalizing the dying and isolating them from society, physicians have fostered cultural taboos about death. Viewing death merely as a negative clinical outcome also trivializes the event, stripping it of significance for patients and their families. Ultimately, a vicious circle is established, in which cultural attitudes towards death influence clinicians to further shield society. Palliative care specialists have an important role in overturning this misguided philosophy by affirming death as a natural process (Jubb, 2002, p.343).

We must be aware of the tendency to “medicalize the dying experience”, and realize that death is as natural as birth, it is not something to be feared, but should be discussed, anticipated and dealt with, with the proper tools, resources and knowledge, to help diminish the stigma and fear of death and dying. Death awaits us all, at some point, so it makes sense to fear something that will eventually happen, something over which we have no control.

Cultural competency is fundamental in palliative care for five main reasons: first, because of the lack of research in the field of palliative care; second, the changing demographics demand it; third, ethnic minorities under-utilize hospice and palliative care services because of the many barriers they face; fourth, for reasons of basic human decency, kindness and sympathy; and last, to help diminish the stigma and fear of death and dying.

2.7 Examples of Cultural Competency Issue in Health Care

The following twelve examples are case studies of situations that caused anxiety and stress for the patients and confusion for the health care professionals because of a lack of cultural competency. Each situation is an example of misunderstandings, misjudgments, misinformation or misdiagnosis, caused by insensitivity to different cultures and a lack of cultural competency.

There is a culturally competent solution for every situation that presents itself, and continuous education and learning are part of that solution. Becoming culturally competent is not a destination, but a continuous journey, where each situation has the potential for learning to occur. Each patient situation differs from the next and each forms new experiences and builds upon that knowledge to create awareness, sensitivity and culturally competent health care solutions.

Example #1

An elderly Bosnian woman being admitted with terminal cancer may present the following challenges for health care staff and organizations: She and her family do not read, speak or understand English; her Muslim faith requires modesty during physical examinations, and her family may have cultural reasons for not discussing end-of-life concerns or her impending death. A culturally and linguistically appropriate response would include interpreter staff; translated written materials; sensitive discussions about treatment consent and advanced directive forms; clinical and support staff who know to ask about and negotiate cultural issues; appropriate food choices; and other measures (Chin 2000, p.28).

Example #2

A physician prescribes medication without knowing about the patient's use of an herbal medicine that has adverse interaction effects (Chin 2000, p.29).

Example #3

A Cambodian refugee uses "*cao gio*", or coin rubbing, to dispel the "bad wind" and restore the natural balance between hot and cold elements of the universe when her daughter is feverish. The bruise left by this remedy is reported as a sign of abuse by the provider (Ibid).

Example #4 – African-American Woman

An African-American woman from a Southern United States rural area was wearing a cord with knots around her abdomen when admitted for the delivery. The nurse removed the cord without the client's consent and was putting it in a garbage container. The client, however, grabbed the cord and put it back on her abdomen saying, "I need this (cord) to have a safe deliver". After the mother was given the anesthesia, the nurse removed the knotted cord and destroyed it. Unfortunately, the infant died during the delivery, and the grieving woman attributed the death of her child to the fact that the nurse "took her cord and killed the child".

When the woman left the hospital she was very upset and kept saying “You killed my baby and destroyed my cord—I lost both of them”. The nursing staff did not understand why this dirty cord with knots was so important to this African woman. Staff cultural ignorance and hurtful actions were evident. (Leininger, 2002b, p.63)

Example #5 – Chinese Man

A recent Chinese immigrant had major bladder surgery. He was told by the nursing staff to “force fluids”. The client did not understand the “forced fluid” order. He refused to drink the glasses of cold water from the big pitcher left on his bedside table. Each time the nursing staff entered the client’s room, they reminded him that he needed to force fluids and drink many glasses of water. They threatened that his physician would order intravenous fluids if he did not drink more water. He still refused to drink the cold water on his bedside. The staff said he was “uncooperative”, “strange”, and a “noncompliant” client. When the client’s daughter came to see him she told the nursing staff that he would drink hot herbal tea but not cold water. Finally, the nurses gave him the hot tea and he drank several cups. The nurses did not understand why the hot tea was culturally acceptable and why he had refused to drink tap water. A transcultural nurse came to explain the clinical “hot” and “cold” theory of the Chinese and its importance in nursing care. What other cultural factors and principles in this nursing situation were evident that needed to be addressed? (Leininger, 2002b, p.63-64).

Example #6 –Navaho Mother

A Navaho mother gave birth to a baby girl in a large urban hospital. The nurses assisting with the delivery put the placenta and umbilical cord in a delivery room pan and had the nursing assistant dispose of it. When the Navaho mother got ready to leave the hospital she asked for the placenta and umbilical cord. She learned that the nursing staff had destroyed it. The Navaho mother and her family were very upset and were shocked that the nursing staff did not understand the significance of the umbilical cord and that it should have been saved for the mother. To the nurses this woman’s request was a very strange one as “No other patients would want a bloody placenta and cord to take home”. The Navaho mother and her kinsmen cried as they left the hospital and said, “We have no hope for our child. We must not return again to this hospital”. What happened here and what concepts and principles were violated by the nurse? (Ibid. p.64).

Example #7 – Arab Muslim Man

An Anglo-American senior baccalaureate nursing student was assigned to care for an acutely ill, dying client who had recently come from the Middle East. Unfortunately, the student had no courses or preparation in transcultural nursing, but was told by the head nurse to “care for a newly admitted client who spoke another language”. When the student entered the client’s room, she found eight people around the male client’s bed. She asked all of the visitors to leave the room as she was to give “morning

care to him”. The visitors refused to leave the room and continued to talk to the client. The nursing student returned to the head nurse expressing her frustration as not being able to “get those visitors who speak a strange language to leave the room”. The head nurse told her to return to the room and “to be firm”. However, this time when she came into the room, the visitors had moved the bed so it faced an east window. The visitors, whom she realized later were close relatives, were praying loudly and calling for “Allah”. The student became more upset and felt it was impossible to care for the client. She firmly told the relatives that, “This bed has to be returned to its proper place as it is a hospital regulation”. One relative who spoke some English said, “It must be in this place to pray to Allah”. The nursing student did not know who Allah was and tried to clarify this with the male relative, but she thought the explanation was strange. The student then returned to the head nurse and emphatically refused to give any care. She said, “It is impossible to give him care”. Later in the day, the student learned that the client had died and that he was an Arab Muslim. This incident baffled her because the situation was so bizarre and the client with all the family was so different from Anglo-American clients she had cared for in the past. She felt so incompetent and unsuccessful in her nursing care. The “why” of the Arab Muslim behavior was never understood by the nurses and other Anglo-American health personnel. Later, when this critical incident was discussed in a transcultural nursing course, the student was so surprised about what had occurred with her and how she should have handled the situation. She said, “I did not understand this client and his culture”. And to the faculty she said, “Why was I cheated in my nursing program without knowledge of these different cultures we are expected to care for in nursing?” The faculty explained they never had transcultural nursing and never thought students would need it today. This clinical incident makes students very eager to enroll in courses in transcultural and to learn a new body of knowledge.

Later this student became a transcultural nurse expert through graduate study, and nursing had become totally new meanings and goals for her (Leininger, 2002b, p.65-66).

Example #8 - HIV + Hispanic Male

“Hector” is originally from El Salvador and only speaks Spanish. He goes to his health clinic to see a physician for HIV care. The physician needs a translator in order to treat Hector, so he calls in the Spanish-speaking receptionist to help. Hector is taken by surprise: The receptionist is related to his boss at work. Now, he fears that she will tell his boss that he is HIV positive and that word will spread through the small Latino community in his town. He leaves the clinic upset and afraid (www.hab.hrsa.gov/publications/august2002.htm)

Example #9 - Rosa from Puerto Rico

“Rosa”, who recently came to New York from Puerto Rico, goes to her local clinic and is relieved to find that the clinic provides an interpreter, because her English is poor. She explains to the doctor that she has fatiga, but she is perplexed when she is counseled to “get a little more sleep” to deal with her illness. Fortunately, she persists in describing her ailment, and discovers that the interpreter, who is from Spain, has been transcribing fatiga as “tired” in Puerto Rico, however, the word fatiga is used to describe wheezing from asthma (Ibid).

Example #10 - 16 year old Jennifer

“Jennifer”, who is 16 years old, goes to her family physician because her period has stopped. As the physician is taking her medical history, Jennifer tells her that she is “not sexually active”. During the physical examination, the physician notes signs of pregnancy. Upon further discussion, it becomes clear that Jennifer believes premarital sex is a grievous sin and that she is simultaneously in denial about her sexual behavior and terrified that her family or fellow church members will find out. The physician, who is not especially religious, can provide medical advice but has no idea how to reach Jennifer on the emotional level or spiritual level, although she can provide referrals. Both patient and doctor end the encounter unsatisfied (Ibid).

The following two case studies are examples of how cultural competency within health care agencies really start as soon as the patient enters the building, room or places a phone call.

Example #11 - Hispanic mother renewing prescription

Ms. G. speaks very little English. She finds it difficult to make appointments and gets prescriptions renewed at her child’s doctor’s office. She chose her child’s pediatric practice because one of the doctors speaks Spanish. There is another person in the office who speaks Spanish, but is often interpreting for patients who are seeing other doctors in the practice. Thus, Ms. G. feels very hesitant about calling her doctor’s office and often has to wait for a friend or for one of her older children to make the calls (Bronheim, -NCCC)

Example #12 - Woman with Hispanic surname

Ms. L. has a Hispanic surname and speaks with an accent. She is often upset when she calls a health provider’s office or goes in for a visit, and staff assume she does not speak or understand English. Sometimes, this assumption leads staff to speak slowly and loudly. Other times, they will have a Spanish-speaking staff person interact with her. Although she is pleased that some health care providers make an effort to have Spanish speakers on staff for families who require this level of language assistance, she wishes they would ask about her specific needs (Ibid).

2.8 Theoretical Framework

Cultures vary in how they handle their own health care and well-being. Cultures also differ in preventive health care measures, what they eat, how they eat, who is involved in the health care decision-making process, how they communicate, how they wish to be communicated with, and how they handle issues related to death and dying and bereavement processes. All these issues are dealt with differently according to culture, faith, family-dynamics, linguistic competencies and language issues. Culture is a complex term that encompasses "...many hidden and built-in directives as rules of behavior, beliefs, rituals, and moral-ethical decisions that give meaning and purpose to life" (Ibid, p.9). The influence of culture extends into every single aspect of one's life, especially in terms of health care and well-being, and it is incumbent upon health care providers to bridge the gap between patients and practitioners in a caring manner. Leininger (2002b) defines care as "those assistive, supportive, enabling, and facilitative culturally based ways to help people in a compassionate, respectful, and appropriate way to improve a human condition or lifeways or to help people face illnesses, death or disability" (p.11). Leininger developed a new way of thinking about cultural differences in her *Transcultural Nursing* theory that will be discussed in this chapter. She outlines the critical importance of having health care providers be culturally competent:

For human care to be meaningful and therapeutic, professional knowledge needs to fit with the cultural values, beliefs, and expectations of clients. If professional knowledge and skills fail to fit the client's values and lifeways, one can anticipate that the client will be uncooperative, noncompliant, and dissatisfied with nursing efforts. Clients from different cultures are generally quick to show signs of conflict, discontent, distrust, resentment, and general dissatisfaction with [health care providers] who do not know how to provide culturally based care (Leininger, 2002b, p.6).

This paper will review the most important theoretical frameworks related to cultural competency from a variety of disciplines (social work, mental health, child welfare and nursing). First, Cross's (1989) pivotal monograph on the *Cultural Competence Continuum* and his *Culturally Competent System of Care* will be discussed. Second, is Isaac's *Culturally Competent Care Model*, which is a continuation of Cross's monograph, found in Volume Three of the series. Third, is Leininger's transformative *Culture Care Diversity and Universality Theory*, which includes a discussion of her *Transcultural Nursing Administration* standpoint, and her *Sunrise Model of Care*. Fourth, is Campinha-Bacote's *Process of Cultural Competence in the Delivery of Healthcare Services Model*. Fifth, the Giger and Davidhizar's *Transcultural Assessment Model* is analyzed, and fifth, the *Purnell Model for Cultural Competence* is looked at. Following this, a section on the role of multiculturalism in Canada will be discussed, and then an analysis of the social determinants of health care focusing on the social exclusion and minority health theory will be elaborated on. Finally, a new theoretical model by the author, on the 'Hospice Palliative Care Model for Culturally Competent Healthcare' will be offered as an alternative education tool to assist health care providers in dealing with diversity in hospice and palliative care.

2.9 Cross's Cultural Competence Continuum

The term 'cultural competency' was coined by Cross et al, (1989), who defined the concept in the first volume of a pivotal monograph on the subject. Cross originally developed his theoretical framework for minority children in the United States. Cross conceptualized his cultural competency framework from a mental perspective as an aid for emotionally disturbed

minority children. These minority children at the time included four groups: “African Americans, Asian Americans, Hispanic Americans and Native Americans” (Cross et al., 1989, p.iii)

This document was used as an aide for agencies and professionals to develop a culturally competent system of care when dealing with minority children. However, this monograph should not be viewed as limited or inadequate in scope, since it can be seen as the foundation for a culturally competent model of health care delivery services in varying aspects of the health care industry. The cultural competence continuum model as developed by Cross (1989) is defined as “a set of congruent behaviors, attitudes, and policies that come together in a system, agency, or amongst professionals and enables that system, agency, or those professionals to work effectively in cross-cultural situations” (Cross et al., 1989 p.iv). Cross (1989) defines culture as “the integrated pattern of human behavior that includes thoughts, communications, actions, customs, beliefs, values, and institutions of a racial, ethnic, religious, or social group” (Ibid, p.iv). Cross also defines a culturally competent system of care as one that “acknowledges and incorporates— at all levels - the importance of culture, the assessment of cross-cultural relations, vigilance towards the dynamics that result from cultural differences, the expansion of cultural knowledge, and the adaptation of services to meet culturally-unique needs” (Ibid, p.iv-v & p.13).

Cultural competency is an evolutionary journey towards the ultimate goal of proficiency, and this continuum has six different levels of competence ranging from cultural destructiveness to cultural proficiency. These six levels include: cultural destructiveness; cultural incapacity; cultural blindness; cultural pre-competence; cultural competence; and cultural proficiency (Ibid). Every agency, institution or health care delivery system is responsible for gauging or evaluating

its own level of cultural competency so that it can continuously have a reference point for specific improvements, future directions and implementation programs to effectively enhance the delivery of cultural competency (Cross, 1989, p.13)

1. Cultural Destructiveness

This is the most harmful and damaging level, where “...programs, agencies and institutions actively participate in cultural genocide—the purposeful destruction of a culture” (Cross 1989, p.14). This level consists of bigotry, racism, intolerance, extreme stereotyping and biases that effectively treat the minority population as undeserving of the same rights and respect as the dominant culture, or non-minority culture. An example of this would be the Exclusion Laws of 1885-1965 in the United States, which prevented or banned Asians from resettling where they wanted to, and where their basic civil liberties were terminated on both state and federal levels (Cross,1989, p.14).

2. Cultural Incapacity

This level does not actively aim to impoverish or deprive different cultures of their rights, but lacks the wherewithal to support minority communities. This is still a level of bias and racism that supports segregation, exclusionary policies and discriminatory stereotyping. There is also a genuine distrust or apprehension about visible minorities including ignorance. Characteristics include: “discriminatory hiring practices, subtle messages to people of color that they are not valued or welcomed, and generally lower expectations of minority clients” (Cross,1989, p.15).

3. Cultural Blindness

This level has a specific mandate to be unbiased and reduce stereotyping within its agencies and institutions. It believes that a blanket approach should work for all cultures regardless of their individual differences. Unfortunately, ethnocentrism exists in this level, because services become ineffectual when they are applied to all cultures, since the rate of assimilation is different for all cultures. Culturally blind agencies lack the resources and funds necessary to institute truly unbiased procedures and community outreach services. The consequences of this level are that agencies “ignore cultural strengths, encourage assimilation, and blame the victim for their problems. Institutional racism restricts minority access to professional training, staff positions and services (Cross, 1989, p.15). Although these agencies view themselves as helpful and open-minded or objective, their “ethnocentrism is reflected in attitude, policy and practice” (Cross, 1989, p.16).

4. Cultural Pre-competence

This level is the first to suggest true growth and progress towards competence. It acknowledges its inadequacies and seeks to rectify prior injustices. It experiments with training staff in cultural competency and hiring minority staff members (Cross, 1989 p.16). The risk in this level is from over-confidence or a “false sense of accomplishment or of failure that prevents the agency from moving forward along the continuum” (Cross 1989, p.16). If the first attempt at cultural competence is unsuccessful, there is the chance that they will not try again. Alternatively, they may feel that the hiring of some minority workers represents the fulfillment of their entire cultural competency agenda. This is the first level where agencies make a sincere effort to

become culturally competent and simply need the proper information and/or resources to move forward towards cultural proficiency.

5. Cultural Competence

This level is essentially about “acceptance and respect for difference, continuing self-assessment regarding culture, careful attention to the dynamics of difference, continuous expansion of cultural knowledge and resources” (Cross,1989, p.17). Minorities are viewed as having distinct cultures that differ not only from the mainstream culture, but also differ amongst themselves. (Cross,1989, p.17). Agencies “work to hire unbiased employees, seek advice and consultation from the minority community and actively decide what they are and are not capable of providing to minority clients” (Ibid). This stage is committed to strengthening its policies and procedures to accommodate cultural competency in all facets of care. They regularly assist staff members with information and support to improve their understanding and recognition of cultural competency.

6. Cultural Proficiency

This is the final stage where a heightened awareness of cultural competency thrives and is highly valued and respected by all. These agencies also take a step further by administering their own research on the subject, trying to develop further knowledge and engaging the community of health care providers. Cultural competency is a mandate that is enforced at all levels of the agency or institution, and specialists are hired to disseminate the information. Relationships improve between minority clients and the health care providers as “attitudes, policies and practices” regarding cultural competency are continually re-assessed and implemented to ensure evolution (Cross, 1989, p.17).

What these six levels of the cultural competence continuum show are how cultural competency is a developmental progression and cannot be solidified in one-step or one policy change. It is a journey where each individual health care practitioner, agency and institution must take responsibility for acknowledging their own internal biases and stereotypes, and then taking steps towards rectifying inadequacies, by continually educating themselves, hiring specialists, implementing changes and encouraging growth.

2.9.1 Cross's Culturally Competent System of Care

Associated with Cross's (1989) cultural competence continuum are five principles that assist varying levels of agencies, institutions, and practitioners in implementing cultural competency and ensuring its success. This culturally competent system would: 1) value diversity; 2) have the capacity for cultural self-assessment; 3) be conscious of the dynamics inherent when cultures interact; 4) have institutionalized cultural knowledge; and 5) have developed adaptations to diversity (Cross, 1989, p.v & p.19). For cultural competency to be fully implemented there must be a level of self-reflection within all individuals at all levels of the system. This is necessary so that personal values, beliefs, and even misconceptions are thoroughly examined, so that the proper knowledge and educational tools can be disseminated. Without this internal assessment of people's ingrained beliefs, it becomes difficult to gauge success, and more importantly, to be supportive and accepting of all cultures and differences (Ibid). Cross's five main principles of his culturally competence system of care are discussed in the following section.

1. Valuing Diversity

People must accept and respect the diversity and plethora of differences amongst varying cultures that they interact with in a health care delivery system. Diversity is strengthened when there is a common level of acceptance that all cultures and ethnicities seek the same things in life--good health. Everyone seeks supportive and professional assistance from health care practitioners who will treat him or her with respect. Being aware of the differences styles of communication, belief systems and health values allows for the possibility of successful health interventions (Cross, 1989, p. 19).

2. Cultural Self-Assessment

Agencies and institutions must recognize that their internal cultures are reflected in their own biases, attitudes, behaviors and policies that could potentially increase cross-cultural antagonisms. In order to minimize or avoid these antagonisms, agency systems must continuously reassess their own values and perspectives so that the process of learning and growing towards cultural competency is continual (Cross, 1989, p.19).

3. Dynamics of Difference

When cultures collide, there is the potential for confusion to occur. Learned experiences and histories can engrain falsehoods and solidify stereotypes about certain cultures. Each culture or system has its own beliefs, values, attitudes, history and experience that has been entrenched over the years and can lead to “dynamics of difference” when interacting with different cultures or systems. When this occurs, misunderstandings, misjudgments and misinterpretations take place (Ibid, p. 20). Although this can happen with both the minority and non-minority culture, it is best to anticipate the “dynamics of difference” and have a system in place to effectively deal with any false impressions, or errors in judgments.

4. Institutionalization of Cultural Knowledge

The system must endorse the implementation of a culturally competent framework in the delivery of health care services. In order to enforce this policy, every single level within the agency or institution must be responsible for their own individual portion of cultural competence and must have access to competent and professional information and knowledge regarding the core values of culturally competent health care. Every player in the system, from the doctors to the nurses, the social workers, volunteers, board members, and general staff must be culturally responsible and work together to create an atmosphere of respect and acceptance. There must also be an awareness and understanding of the cultural minority communities served by the agencies. Integration with minority communities can help to open the lines of communication and initiate network building (Cross, 1989, pp.20-21).

5. Adaptation to Diversity

Each of the steps mentioned above builds upon each other to create a culturally competent system of health care delivery that services minority clients and communities. Building programs and instituting services that bridge the knowledge gap between minority cultures and health care professionals can create an atmosphere of acceptance and respect for all cultural differences. Without the implementation of culturally competent programs and services, the health care system cannot internalize the commitment to cultural competence. Agencies and institutions must continuously assess and reassess their internal values and programs to comply with the core paradigms of cultural competency (Cross, 1989, p.21).

Cross's (1989) work is significant because he was the first to coin the term 'cultural competence' but also for initiating a discussion on the importance of cultural competency and health related matters. His mental health perspective on cultural competence, although important,

is really the foundation for further research. Cross's theoretical framework is missing a conceptual analysis with practical solutions for individual and agency health care providers to access. The theoretical premise of Cross's 'Cultural Competence Continuum' and his five principles of a 'Culturally Competent System of Care', reflect the importance of internal responsibility and reflection. Individual health care providers, along with agencies of care must accept a certain level of responsibility for the dynamics of cultural competency that exist. This responsibility is the first step in realizing that cultural competency is a journey and not an end point. This continuum is reflected in Cross's emphasis on individuals and agencies personally assessing their own values and beliefs first, so that progress is made within each person, at each level, and that both success and growth can be measured. What is needed now is a more complex definition of the premises of cultural competency, which can be found in Isaac's 'culturally competent care' model.

2.10 Isaac's Culturally Competent Care

The characteristics of Isaac's (1991) cultural competence model, found in the third volume of the monograph on minority children and mental health, reveals a detailed explanation of the nine basic premises of cultural competency.

1. Every human being has a culture.
2. Culture determines the way we think, feel, act, perceive the world, respond to situations, etc. Therefore, culture consists of attitudes, behaviors, values & rules of conduct.
3. Culture is learned—it is not innate or biological.
4. A large component of culture is below the level of conscious thought & expression.
5. Culture is a "group" phenomenon—it must be shared. Culture reflects tradition, having passed from generation to generation.
6. Culture is dynamic—it changes over time. Culture is also stable—it persists over time.
7. Within a larger society, group, or nation sharing a common majority culture, there may be sub-groupings of people possessing different values, beliefs, etc., that set them apart and distinguish them from others.

8. Unless completely isolated, cultures do not remain “pure”, but tend to incorporate aspects of other cultures with whom they come on contact.
9. A society’s institutions reflect its culture and its underlying beliefs and values.
(Adapted from Isaacs 1998, p. 10).

The changing demographics and influx of ethnic and cultural minorities necessitates a culturally competent health care system. There must be a shift from “uni-culture, or assimilation to biculturalism or multicultural” within the health care system (Isaacs & Benjamin, 1991, p.9). Systems need reforming, policies need to be reformulated, and staff along with administrators and front-line health care providers (doctors, nurses, social workers, volunteers)-- need to be re-educated on the importance of cultural competency so that the entire health care system can perform at optimum efficiency and efficacy (Isaacs & Benjamin, 1991, p.8-9).

Isaac’s model is significant because of the varying layers of cultural competency that are introduced. Isaac’s notes the extreme value culture plays in our lives, and the way it impacts our way of thinking, behaving and feeling. Culture pervades every aspect of our lives, and influences our decision making processes. Culture from Isaac’s vantage point is a learned behavior and changes over time, incorporating the influences of other cultures, peoples and larger community. Isaac’s also distinguishes between the cultural variations between and within cultures. The differences within the same cultures can be as significant as the differences across different cultures, realizing that no one culture is essentially uniform across its members. This intra-cultural diversity of the subgroups can influence the broader cultural traits amongst the dominant culture of the group.

As with Cross’s (1989) theory, Isaac’s model is more of a theoretical premise, rather than practical concept that provides the necessary tools to implement culturally competent policies and monitor their progress. Similar to Cross, Isaac’s ‘culturally competent care’ model emphasizes the importance of training and re-educating health care providers in providing

culturally competent care. The changing demographics of the nation are once again, mentioned as the main catalyst for incorporating culturally competent health care systems. The emphasis on “uni-culturalism” or assimilation can no longer be sustained with the dramatic changes in population and immigration trends. Although both Cross and Isaac formulate adequate theories and lay the ground work for definitions and premises of cultural competency, a new framework is necessary, one that will garner ethnographic data from ethnic minorities and provide health care providers with examples of the vast differences amongst cultures and their health care needs. This is provided by the third theory, taken from an anthropological nursing perspective, by Madeleine Leininger.

2.11 Leininger’s Culture Care Diversity and Universality Theory

A holistic approach to care giving with respect and understanding for cultural differences was integrated into the ‘Culture Care Diversity and Universality Theory’ (otherwise known as the Culture Care Theory), by Madeleine Leininger (1996; 2002a; 2002b; 2006). Advocating from an anthropological nursing perspective, Leininger founded the ‘*Transcultural Nursing Administration Standpoint*’ that she defines as: “a creative and knowledgeable process of assessing, planning, and making decisions and policies that will facilitate the provision of educational and clinical services that take into account the cultural caring values, beliefs, symbols, references, and lifeways of people of diverse and similar cultures for beneficial or satisfying outcomes” (Leininger 1996, p.30). The ultimate goal of transcultural nursing administration is to respect and value different cultural outlooks when dealing with health care delivery issues, so that every culture or belief system receives professional, caring service (Ibid).

What is unique about Leininger's 'Culture Care Theory' is its' focus on both the generic (emic) and professional (etic) types of caring. Emic caring values would be traditional or indigenous in nature, while etic caring values would be institutionalized, bureaucratized, and medicalized. Leininger, advocates for a union of both indigenous and professional views of caring, healing, and health care management. Another unique feature of the theory is Leininger's specifically-designed research method, which is 'ethnonursing'. As a professional anthropological nurse, Leininger spent her entire career observing various cultural groups around the world, during their times of health and illness. Her forty years of research data has profoundly enriched the field of transcultural nursing, and allowed health care professionals to become educated in the complexities of diversity and culture. Leininger defines her 'ethnonursing' methodology as "a qualitative nursing research method focused on naturalistic, open discovery, and largely inductive (emic) modes to document, describe, explain, and interpret informants' worldview, meanings, symbols and life experiences as they bear on actual or potential nursing care phenomena" (Leininger, 2002, p.85). Leininger's culture care theory is one of the oldest, since it originated in the 1950s and is another unique feature. Her focus on the interrelationships between the cultural and social structural dimensions of care (technological, religious, kinship, cultural, political, economic and educational values) was ground-breaking and improved the awareness of how culture and healthcare intersect. Leininger's field research showcased not only the differences between cultures, but also the commonalities between the dominant American cultural values and those of other cultures (Leininger, 2002, p.190).

The culture care theory was developed by Leininger as a way to breach the gap in care and caring studies that was not being taught or researched at the time of development in the 1950s. Leininger's focus has been on the holistic nature of 'caring' and what care does for an

individual in need. Caring, for Leininger is paramount, and cannot be separated from culture, healing and the nature of illness. The impact of caring was thought by Leininger to be overwhelming “essential for human growth, survival and health’ (Leininger, 2002, p.192). The purpose of Leininger’s Culture Care Theory was to “discover and explain the diverse and universally culturally based care factors influencing the health, well-being, illness or death of individuals or groups” (Leininger, 2002, p.190). The goal of the theory was to use her ethnonursing research methods to “provide culturally congruent, safe and meaningful care to clients of diverse or similar cultures” (Ibid).

Although cost-cutting measures are usually favored in a complex global market, where budgets are constantly being slashed, Leininger urges nurses who make up the majority of health care practitioners to be culturally cognizant of all the different cultural beliefs, values, perspectives and histories that can affect a patient’s health care choices and decisions. Acknowledging that a gap still exists in the theory and research of culturally competent care, nurses must be mindful as demographics change, as more minorities enter the health care system- - to be culturally sensitive and competent (Leininger, 1996, p.28). As health care systems become more multi-disciplinary, it is beneficial to draw from all paradigms such as anthropology, biology, social work, and nursing to enhance the proficiency of cultural competence.

Written from a nursing perspective, Leininger discusses the need for the health care delivery systems and administrators to “shift from largely a uni-cultural to a multicultural mode of operation...which necessitates having substantive knowledge of cultural systems, professional cultures, and cultures and subcultures” (Leininger, 1996, p.28). ‘Transcultural nursing Administration’ values diversity and continuously seeks to upgrade personal and professional skills regarding cultural competence. When developing the theory, Leininger noticed that nurses

needed specific information regarding the various cultural factors influencing health care such as: “religion, politics, economics, worldview, environment, cultural values, history, language, gender, and others” (Leininger, 2002, p.190). She therefore developed the *Sunrise Model* which is not the culture care theory, but outlines the various features that can affect peoples’ level of care (Ibid). Since nurses outnumber other types of health care practitioners (doctors, volunteers, or social workers), in any given agency or institution, it only makes sense to have them be as culturally trained as possible to avoid health care disparities and to reduce anxiety from both the clients and the nurses themselves. When nurses are effectively trained in all levels of culturally competent care, they are naturally more confident and compassionate when dealing with clients of diverse backgrounds.

The Sunrise model has been revised ten times since its inception over thirty years ago, and Leininger cautions that the model should only be viewed as a signpost to help guide nurses and other health care providers toward becoming culturally competent. The Sunrise model consists of four levels: the cultural care worldview, the cultural and social structure dimension, the health care systems, and roles and functions of healthcare providers. The seven dimensions of cultural competency that can potentially shape or influence a client’s expectation of health care are: technological factors; religious and philosophical factors; kinship and social factors; political and legal factors; economic factors; and educational factors (Leininger, 2002a, p.191).

The first step is for nurses to establish a baseline of cultural expectations of care from their patients. Leininger believes that every patient presents with their own cultural beliefs and expectations about health, well-being and care and how it should be managed or delivered. Therefore, assessing a client’s *emic* (or traditional) cultural care expectations are necessary to integrate into the *etic* (professional) management of care (Leininger, 2006, p.5). Emic care is

defined as “the learned and transmitted lay, indigenous, traditional, or local folk (emic) knowledge and practices to provides assistive, supportive, enabling and facilitative acts for...others with...health care needs in order to improve the well-being or to help with dying or other human conditions” (Leininger, 2006, p.14). Etic care is “the formal and explicit cognitively learned professional care knowledge and practices obtained generally through educational institutions (Ibid). After assessing a client’s cultural beliefs along with the professional guidelines, health care providers can use one of three modalities or decision modes to guide their actions about which treatment options best suits the patient. The three decision modes are: 1) Culture Care Preservation and/or Maintenance; 2) Culture Care Accommodation and/or Negotiation; and 3) Culture Care Repatterning and/or Restructuring (Leininger 2002a; Leininger 2002b; Leininger, 2006). This unique feature of Leininger’s model provides the health care provider with specific steps to practically deliver culturally competent levels of care. The first action mode “Culture Care Preservation and/or Maintenance” are measures that allow cultures to “retain, preserve or maintain care beliefs and values, or to face handicaps and death” (Leininger. 2006, p.8). The second action mode “Culture Care Accommodation and/or Negotiation” are measures that allow cultures to “adapt to or negotiate with others for culturally congruent, safe, and effective care for their health, well-being, or to deal with illness or dying” (Ibid). The last action mode is “Culture Care Repatterning and/or Restructuring” and allows for measure to “help people reorder, change, modify, or restructure their lifeways and institutions for better or (beneficial) healthcare patterns, practices, or outcomes” (Ibid).

The Culture Care theory by Leininger was envisioned as a way to “discover and explain diverse and universal culturally based care factors influencing the health, well-being, illness, or death of individuals or groups” (Leininger, 2002, p.190). Its main purpose was to stimulate

further research findings “to provide culturally congruent, safe, and meaningful care to clients of diverse or similar cultures” (Ibid). The theoretical assumptions of the Culture Care Theory:

1. Care is the essence of nursing and a distinct, dominant, central & unifying focus.
2. Culturally based care (caring) is essential for well-being, health, growth and survival and to face handicaps or death.
3. Culturally based care is essential to caring and healing. There can be no curing without caring, but caring can exist without curing.
4. Culturally based care is the most comprehensive and holistic means to know, explain, interpret, and predict beneficial congruent care practices.
5. Every human culture has generic, lay, folk or indigenous care knowledge and practices and professional care knowledge.
6. Culture-care values, beliefs, and practices are influenced by and embedded in the worldview, language, philosophy, religion (and spirituality), kinship, social, political, legal, educational, economic, technological, ethnohistorical and environmental contexts of culture.
7. Cultural conflicts, cultural stresses and cultural pain are the result of a lack of culture care knowledge and competency.
8. Ethnonursing qualitative research method provides a means to accurately discover and interpret emic (general and etic (professional) culture care data.
(Adapted from Leininger 2002, p.192.)

Care is an integral component of the Leininger Sunrise Model, transcultural nursing administration and the Culture Care theory. Leininger states that “human care is what makes people human, gives dignity to humans, and inspires people to get well and help others” (Leininger, 2006, p.3).

Leininger’s ‘Culture Care Theory’ and her ‘Sunrise Model’ have changed the landscape of cultural competent or cultural congruent research. Her innovative ‘ethnonursing’ methodology and practical action care models are unique in that they are less abstract than previous research, and focus on delivering constructive, realistic solutions to dealing with diverse cultures in a health care setting. Her focus on care and caring as integral health care components fuses the union between generic or folk (emic) healing methods and professional (etic) views of health, healing and illness. Leininger advocates for a culture care worldview that encompassed factors relating to technology, religion, kinship, culture, political, economic and educational factors that all influence individuals, groups and communities in how they perceive, interpret and handle

their health and illness concerns. Leininger's theories are significant for their practicality, usefulness, and focus on care as a humanistic tool for health care providers.

2.12 Camphina-Bacote's Process of Cultural Competence in the Delivery of Healthcare Services

Another model of cultural competence was developed by Camphina-Bacote (2002), which views health care practitioners as "becoming culturally competent rather than already being competent" (2002, p.181). A unique feature of Camphina-Bacote's theory is the combination of fields including: transcultural nursing, medical anthropology and multicultural counseling (Ibid). Cultural competence for Camphina-Bacote is the "ongoing process in which the health care provider continuously strives to achieve the ability to effectively work within the cultural context of the client-individual, family, & community" (Ibid). The 'Process of Cultural Competence in the Delivery of Healthcare Services Model' uniquely includes five constructs of cultural competence which are "cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desire" (Ibid). These five concepts are interrelated and must all be acknowledged and eventually experienced and are related to the theorists' assumption that health care providers are constantly in a state of 'becoming' culturally competent, rather than already attaining that competence. Another unique feature of this theory is the direct relationship between the level of cultural competence of health care providers and their service of care. Health care providers' abilities or inabilities in cultural competence have a commanding effect on the health care recipients. Camphina-Bacote's theory also highlights the differences within specific ethnic and cultural groups, not only the differences between various cultures. This is known as 'intra-ethnic variation' and is an important component in cultural competency education (Camphina-Bacote, 2002, p.181). The five significant constructs of Campinha-Bacote's model include

“cultural awareness, cultural knowledge, cultural skill, cultural encounters, and cultural desires” and are discussed below.

1. Cultural Awareness

Similar to Cross’s (1989) ‘self-assessment’ criteria, this construct deals with examining one’s own potential for cultural biases, stereotypes and misperceptions. It encourages health care providers on all levels to explore their own values, and beliefs, presumptions and prejudgments about cultures that are different from their own. Without acknowledging and then rectifying internal prejudices, there is an opportunity for ‘cultural imposition’ to occur. This is “the tendency of an individual to impose their beliefs, values, and patterns of behavior on another culture” (Camphina-Bacote, 2002, p.182).

2. Cultural Knowledge

Cultural knowledge is learning about different cultures and ethnicities through professional and specialized means. In order for health care providers to be culturally sensitive, they need to have the proper information and tools to assist them. Part of that process focuses on incorporating three key items: “health related beliefs and cultural values, disease incidence and prevalence, and treatment efficacy” (Ibid). Becoming culturally competent about: (i) *a ‘client’s health-related beliefs and cultural values’* through cultural knowledge helps health care providers understand the “worldview” of their patients. A worldview is a lens through which different cultures view their life, and in particular, how they view their health and/or illness and affects what they do, how they do it and what they think (Ibid). Secondly, *disease incidence and prevalence* must be addressed through bio-cultural ecology. Diseases affect different cultures differently, and health care providers need to have proper epidemiological data to effectively treat, disseminate health information, screen and recommend treatment programs to their clients (Ibid). Thirdly, *treatment*

efficacy involves acquiring information on such diverse subjects as “ethnic pharmacology” (Ibid). Part of cultural knowledge is the recognition that no one culture is identical internally. Not all people within cultures will be the same, have the same values and beliefs, experiences, history or presumptions. There is as much diversity across different cultures as there are within one culture. It is therefore necessary that the health care providers properly culturally assess each client to avoid misjudgments about them (Ibid).

3. Cultural Skill

Cultural skill is the “ability to collect relevant cultural data regarding the client’s presenting problem as well as accurately performing a culturally based physical assessment” (Ibid). A cultural assessment as defined by Leininger as “a systematic appraisal or examination of individuals, groups, and communities as to their cultural beliefs, values and practices to determine explicit needs and intervention practices within the context of the people being served” (Leininger, 1978, p.85-86). Knowing the patients biological, physical, physiological differences will help in properly diagnosing illnesses (Camphina-Bacote, 2002, p.182).

4. Cultural Encounters

Cultural encounters are the process where health care providers educate themselves on different cultures by integrating themselves into “cross-cultural” exchanges with clients from a wide variety of cultural and ethnic backgrounds. By continuously engaging in dialogue with other cultures, health care providers can simultaneously learn about cultures while diminishing any previous preconceptions about them (Ibid). Cultural encounters also recommend the use of trained and specialized interpreters for linguistic comprehension. Using family members or staff who may speak the language of the patient, but not be well versed in the medical terminology can lead to misinterpretations at best and misdiagnosis at worst (Ibid).

5. Cultural Desire

Cultural desire results from the health care practitioners truly *wanting* to rather than *having* to become culturally aware, culturally knowledgeable, culturally skilled and informed with cultural encounters. This desire stems from the notion of caring, which is also one of the main features of Leininger's Culture Care theory.

The significance of Camphina-Bacote's model on the 'Process of Cultural Competency in the Diversity of Healthcare' is the attention paid to the five progressive levels of 'cultural awareness, cultural knowledge, cultural skill, cultural encounters and cultural desire', which is reminiscent of Cross's (1989) cultural competency continuum. Each theory insists on a ladder of competency, where health care providers climb each successive step, incorporating further knowledge, experience, awareness and skill, that enable them to reach the next step on the ladder, until they have attained either 'cultural proficiency' for Cross, or 'cultural desire' for Camphina-Bacote. As with all theorists so far discussed, there is an agreement that cultural competency is a process, a journey, and a continuum. It is not something that can be achieved quickly; instead, it is an ultimate goal in health care that requires dutiful diligence and commitment to education, training and experiencing. Also of note, is Camphina-Bacote's development of a measurement tool to assess cultural competence that includes a "20-item instrument that measures the model's constructs of cultural awareness, cultural knowledge, cultural skill and cultural encounters" (Camphina-Bacote, 2002, p.184). These conceptual tools are a necessary segment to theoretical frameworks and add a practicality to the issue of cultural competence that allow health care providers to measure and track the progress and growth of cultural competency within their institutions. It would also be useful to record the opinions of the actual recipients of care, to assess whether or not they consider their health care providers to be culturally competent and

whether they can detect a difference in competence after health care providers have been trained on cultural competence. This is an area that requires further research.

The next model of cultural competency is once again from a nursing perspective, originally developed for undergraduate nursing students, but now has a broader appeal, as it is being accepted by numerous health care fields, is the Giger and Davidhizar ‘Transcultural Assessment Model’.

2.13 Giger and Davidhizar Transcultural Assessment Model

This model was developed in 1988 to allow nursing students to effectively care for their patients in a culturally competent manner (Giger & Davidhizar, 2002, p.185). The Giger and Davidhizar model attempts to simplify the issue of providing cultural competency in nursing care by providing a concise assessment tool. Within this model all individuals have distinctive cultural features and should be assessed in relation to six cultural phenomena: “communication, space, social organization, time, environmental control and biological variation” (Giger and Davidhizar, 2002, p. 185). Communication includes verbal and nonverbal forms and can potentially be one of the most problematic issues when dealing with diverse cultures who may not speak English well, or not at all. Learning different forms of communication (body language) can certainly assist health care providers when linguistic competence is lacking (Ibid). Space consists of the actual distance between the health care provider and the client. There are four zones of interpersonal space: intimate, personal, social and consultative and public. Knowing the preferences for interpersonal space with different cultures can alleviate unnecessary distress or awkwardness (Ibid). Social organization refers to “how a cultural group organizes itself...

[according to] family structure and organization, religious values and beliefs and role assignments, [which] may all relate to ethnicity and culture” (Ibid). Time is related to all past, present and future situation. Cultural groups vary on whether they are past, present or future aligned (Ibid). For instance, the use of preventive medicine would lead to a future alignment as the value in controlling or even preventing illness is accepted. Environment control is the “ability of the person to control nature and to plan and direct factors in the environment that affect them” (Ibid). Some individuals may believe that they can control nature or the environment around them, and that belief can influence their worldview. Biological variations include genetic variations that are known to differ according to racial and ethnic groups. For instance, some “races metabolize drugs in different ways and at different rates” (Giger & Davidhizar, 2002, p.187). For instance, Chinese people are more susceptible to the negative cardiovascular effects of the drug ‘Propranolol’ than White people are. Furthermore, heightened or diminished sensitivity to certain illness may be “genetically, environmentally, or gene-environmentally induced” (Ibid). For instance, African Americans are three times more likely to have tuberculosis than White Americans (Ibid).

The Giger and Davidhizar’s model of Transcultural Assessment includes five metaparadigms: importance of transcultural nursing that focuses on the client and is driven by a ethnocultural research design: culturally competent care, where the health care provider uses cultural competence to assist clients in delivering the most competent and respectful level of care; culturally competent individuals, remembering that each individual consists of their own unique cultural values, beliefs and attitudes, which are all a product of their experiences; culturally sensitive environment, in which all levels of care must be competent in cultural diversity and sensitivity training; and health and health status, which suggests that an individuals

experience, cultural values and attitudes all effectively influence their awareness of and internalization of their own health and well-being (Giger & Davidhizar, 2002, p.187).

The Giger and Davidhizar ‘Transcultural Assessment Model’ is based on six premises:

1. Culture is a patterned behavioral response that develops over time through social and religious structures and intellectual and artistic manifestations.
2. Culture is the result of acquired mechanisms that may have innate influences but are primarily affected by internal and external stimuli.
3. Culture is shaped by values, beliefs, norms, and practices that are shared by members of the same cultural group.
4. Culture guides our thinking, doing, and being and becomes patterned expressions of who we are. These patterned expressions are passed down from one generation to the next.
5. Culture implies a dynamic, ever-changing, active, or passive process.
6. Cultural values guide actions and decision-making and facilitate self-worth and self-esteem.

Adapted from Giger & Davidhizar (2002, p.185).

The Giger and Davidhizar ‘Transcultural Assessment Model’ is significant for its clarity and simplicity. This model has grown over the years to include a textbook detailing over twenty different cultures from around the world, based on their six cultural phenomena of biology, environment, time, social organizations, space and communication. Health care providers can assess their clients needs based on the six cultural phenomena and then decide which variables from each phenomena are the most applicable to their clients cultural needs. Health care professionals are encouraged to gain a general understanding of the culture of their clients first in order to perform an accurate assessment of their client’s cultural needs based on the six phenomena. The Giger and Davidhizar ‘Transcultural Assessment Model’ builds upon the work of Leininger (2002), and attempts to simplify previous models by centering on the six cultural phenomena.

2.14 The Purnell Model for Cultural Competence

This theory was developed in 1995 to provide nurses with a theoretical model to be used as a cultural competency tool. Although initially developed for nurses, this model is applicable for all levels of health care providers (Purnell 2000, p.40). The Purnell model for cultural competence is “an ethnographic approach to promote cultural understanding about the human situation during times of illness, wellness, and health promotion” (Ibid). This model, like previous ones, draws on multiple disciplines such as: “organization/administrative theories, anthropology, sociology, anatomy and physiology, philology, psychology, religion, history, linguistics, nutrition and the clinical practice settings in nursing and medicine” (Ibid). The Purnell model for cultural competence focuses on both emic (generic) and etic (community) perspectives, just as Leininger, Camphina-Bacote and Giger and Davidhizar models do. In this paradigm, there is a mutual obligation for health care service providers and administrators and patient and/or clients of that health care to share information, although the onus is on the health care provider to be diligent in establishing an open, sensitive and welcoming environment for cultural diversity to thrive. People’s viewpoints are often shaped by various factors such as religion, community, family, economics, education, age, culture, and ethnicity. Purnell (2000; 2002; 2005) categorizes these influences as primary and secondary characteristics of diversity (see appendix). Primary characteristics are not easily changed, unlike secondary characteristics, which can contain a certain amount of assimilation or acculturation (Purnell, 2005, p.14). Primary characteristics of diversity include: “nationality, race, color, gender age and religious affiliation” (p.14). Secondary characteristics include: “educational status, socioeconomic status, occupation, military experience, political beliefs, urban versus rural residence, enclave identity,

marital status, parental status, physical characteristics, sexual orientation, gender issues and reason for migration” (p.14). See appendix G for the table of primary and secondary characteristics of diversity from Purnell.

Beginning from a macro perspective, the Purnell model consists of the metaparadigm concepts of global society, community, family, and person (Purnell, 2000, p.41). Global society is one world composed of a diverse and multicultural population. Community is a smaller group of people having the same interest or identity. Family is an even smaller unit of two or more people emotionally invested in each other, and person is considered the ‘biopsychosociocultural being’, constantly adjusting to their community (Purnell and Paulanka, 2005, pp.9-10).

The micro aspects of the model are the overall conceptual framework, incorporating twelve domains and their concepts and their relationship to cultures. The actual model consists of four circles. The outer rim of the first circle is the global society, followed by the community, family and person. The inner core of the first circle represents the “unknown phenomena” (Purnell 2005, p.10). The inside of the circle is divided into twelve “pie-shaped wedges” that illustrate the twelve cultural domains and their concepts (Purnell 2000, p.41; Purnell, 2002, p.195). The bottom of the model has jagged lines representing the four stages of progression from unconsciously incompetent, to consciously incompetent, to consciously competent and lastly to unconsciously competent. Purnell’s Model for Cultural Competence (2000; 2002; 2005) shares some similarities with Cross (1989) since they both employ continuum scales. Purnell posits that “one progresses from (a) unconscious incompetence (not being aware that one is lacking knowledge about another culture); (b) to conscious incompetence (being aware that one is lacking knowledge about another culture; (c) to conscious competence (learning about the client’s culture, verifying generalizations about the client’s culture, and providing culturally

specific interventions), and finally (d) to unconscious competence (automatically providing culturally congruent care to clients of diverse cultures” (Purnell, 2005, p.9). The metaparadigm concepts consist of both macro (global society, community, family person, and health) and micro aspects (the twelve domains) and are defined in Table 6 in the appendix. The 12 domains and their concepts include:

Overview/heritage – origin, residence, topography, economic, politics, education, education, occupation, and reason for emigration.

Communication - dominant languages and dialects, contextual use, volume/tone and intonation, spatial distancing, eye contact, facial expressions, touch, body language, greetings, temporality, clock versus social time and use of names.

Family roles and organization - head of household and gender roles, family roles, tasks of children, child-rearing, roles of the aged and extended family, social status and views toward alternative lifestyles

Workforce - autonomy, acculturation, assimilation, gender roles, ethnic communication styles, individualism, and health care practices.

Biocultural ecology - ethnic and racial variations in skin color, physical differences in body stature, genetic, hereditary, endemic and drug metabolism

High-risk behaviors - use of tobacco, alcohol and recreational drugs; lack of physical activity, high-risk sexual behaviors.

Nutrition - meaning of food, food choices, rituals and taboos, food as health promotion or wellness.

Pregnancy and childbearing practices - fertility, birth control, views toward pregnancy, birthing and postpartum treatment.

Death Ritual - views of death, rituals and behavior to prepare for death, burial and bereavement.

Spirituality - religious practices, use of prayer, behaviors that give meaning of life and wellness.

Health care practice - acute or preventive measures; traditional, magicoreligious and biomedical beliefs; individual responsibility for health; self-medicating practices and views toward mental health, organ donation and transplantation. Barriers to health care and one’s response to pain and the sick role.

Health care practitioner - status, use and perceptions of traditional, magicoreligious, and allopathic biomedical health care providers. Gender of health care provider. (Purnell, 2000, pp.41-43; 2002, pp.195-196).

The Purnell model for cultural competency is by far, the most comprehensive and encompassing of all models. By providing an analysis of the twelve domains and how they relate to all cultures, this model allows health care providers to grasp the intricacies of different cultures and their values, taboos, beliefs and expectations regarding their health, well-being, illness and death. The Purnell model has advanced to include textbooks on dozens of different cultures, and their views on the 12 domains, which is instrumental to educating and training health care providers in all sectors. For an extensive discussion on the various aspects involved in culturally competent health care the Purnell model is all-inclusive and expansive, providing an intelligible analysis of the wide-ranging effects of culture.

The considerable amount of cultural diversity data linked to the twelve domains is what makes the Purnell model a great tool for health care providers in general, but its scope is not detailed enough for hospice and palliative care educators, who need an absolute development of the cultural diversity amongst cultures during the death, dying and bereavement stages exclusively. In fact, all the models discussed here focus on cultural competency as it relates to the living, but do not specifically address the patients' dying moments, either as process or event. This is where the gap in the literature exists and why it is imperative that a cultural competency model specifically for hospice and palliative care be developed. This gap is precisely what my research seeks to fill.

2.15 Role of Multiculturalism in Canada

In 1988, Canada became the first country to establish multiculturalism as a national law by adopting the "Canadian Multiculturalism Act", which reiterates Canada's belief in the fundamental freedom of individual rights regarding culture, ethnicity, religion and language. As

part of Section 27 of the 'Canadian Charter of Rights and Freedoms', this act calls for the charter to be "interpreted in a manner consistent with the preservation and enhancement of the multicultural heritage of Canadians" (Canadian Heritage, 2002-03). According to the Canadian heritage website, this act was "designed to preserve and enhance multiculturalism in Canada, and the Act seeks to assist in preserving culture, reducing discrimination, enhancing cultural awareness and understanding, and promoting culturally sensitive institutional change" (Canadian Heritage, 2002-03). Multiculturalism paved the way for respect of diversity to erode previous views on uni-culturalism and assimilation. Diversity and multiculturalism are what makes Canada unique and what draws hundreds of thousands of immigrants on a yearly basis. In 2006, over eleven different ethnic origins have reached over one million people. According to Statistics Canada (2006), this increasing diversity is expected to continue, with visible minorities accounting for one-fifth of the total population of Canada by 2017. This diversity cannot be underestimated and the health care system needs to be able to respond in a culturally competent manner. The importance of multiculturalism has never been more urgent than it is today with the changing demographics of the country.

2.16 Social Determinants of Health Theory

According to Dennis Raphael (2004), "social determinants of health are the economic and social conditions that influence the health of individuals, communities, and jurisdictions as a whole" (Raphael, 2004, p.1). Social determinants determine whether a person is healthy and how they can stay healthy and avoid illness. Whether or not someone has the access to social resources to assist them in the maintenance of the well-being, or increase the quality of their care during times of illness, are all segments of the social determinants of health. Resources that

determine what type of social determinants affect certain people include some of the following: “conditions of childhood, income, availability of food, housing, employment, working conditions and health and social services” (Raphael, 2004, p.1). How a society organizes and dispenses the valuable resources of social and economic conditions have a direct link on peoples’ health care. The social determinants of health theory seek to address two questions: what are the social conditions that affect health disparities? Second, what are the social conditions that influence the quality of these social factors? (Raphael, 2004, pp.4-5). The attention paid to social and economic conditions as directly affecting population health, differs from the biomedical model which emphasizes issues as obesity, cancer history, smoking, high cholesterol or high blood pressure as negatively impacting people health (Ibid).

York University’s School of Health Policy and Management was funded through Health Canada’s Policy Research Program to study the social determinants of health, and according to their findings, there were eleven social determinants of health: “Aboriginal status; early life; education; employment and working conditions; food security; health care services; housing; income and its distribution; social safety net; social exclusion; and unemployment and employment security” (Raphael, 2004, p.6). One of those eleven determinants of health--social exclusion, will be analyzed in the section below, showing the links between social exclusion and minority health, and how these negatively impact end-of-life care issues.

2.17 Social Exclusion Theory and Minority Health

Social exclusion was first discussed in relation to the changing political landscape of Europe in the last three decades of the twentieth century, which witnessed massive demographic, political, social and cultural changes. The changing dynamics of unemployment, welfare-state

provisions, and the eligibility of citizenship and civil rights ignited the discussions on social exclusion. During the latter half of the century there were six major influences that impacted the field of social exclusion: “(1) changing patterns of work, both paid and unpaid; (2) changes in the demand for and supply of various labor forms; (3) changes to the welfare provisions; (4) changing patterns in interpersonal relations in the home, at work and in the locality; (5) new patterns in inter-relations between ethnically, nationally and culturally diverse groups; and (6) changes to the definition of juridical rights of those living within both national and supra-national boundaries” (Littlewood, 1999, p.2).

Alongside these six influences were an additional six emerging trends, according to Littlewood (1999) that shaped how social exclusion as a political, social, economic and cultural theory was developed. First, there are the massive population changes occurring across the European continent and the simultaneous resistance to these new minority demographics in certain countries. Second, there are high levels of unemployment and underemployment. Third, the fall of manual labor and rise of white-collar work. Fourth, the increasing participation of women in the paid labor force. Fifth, the role played by increasingly sophisticated technology and last, the demand for a variety of educational and technical qualifications in the labor market (p. 3). These global changes of immigration, migration, resettlements, unemployment, women’s increased labor participation and the dwindling of manufacturing and manual jobs has led to changes in how social exclusion and social inequality is framed. These economic changes, socio-demographic changes, segregation changes and the changing of the welfare state and provisions in Europe has focused attention on those who are excluded, marginalized and stigmatized and the consequences for their exclusion.

Definitions of social exclusion must take into account that the terminology is multi-dimensional, dynamic, fluid and is defined differently for each discipline. There are broad interpretations that focus on the macro aspects of general economic inequality for instance, and there is also the micro aspects of how specific groups become marginalized in the first place from the health, social, economic, political and cultural activities and benefits of the community they belong to (Littlewood and Herkommer, 1999, p.4). For the most comprehensive definition of social exclusion, Silver (1994) provides three paradigms to identify the various levels of social exclusion (pp.535-536).

Silver (1994) labels her three paradigms solidarity, specialization, and monopoly. Each paradigm focuses on the opposite side of exclusion by looking at the various meanings of inclusion and integration. For clarification, solidarity can be viewed as the Republican or Durkeimian functionalist perspective, specialization is tied to Liberalism or Pluralism, and monopoly can be viewed as belonging to Social Democracy or conflict theorists. Each paradigm differs in the conceptions of integration, the sources of integration, the terminology which most aptly expresses the paradigm and the key characteristics of social order and social exclusion. See table 3 below.

Table 3. Breakdown of Silver’s (1994) analysis of Social Exclusion

Paradigm	Solidarity (Republicanism – Durkheimian Functionalism)	Specialization (Liberalism – Pluralism)	Monopoly (Social Democracy – Conflict Theories of Marx & Weber)
Concept of Integration	Emphasis on social cohesion through group solidarity & cultural boundaries	Interdependence of separate, specialized spheres	Social Closure
Sources of Integration	Moral Integration	Exchange	Citizenship Rights
Terminology	Exclusion	Discrimination & underclass	Underclass – new poverty
Key Characteristics of Social Order	Viewed as external, moral, normative, not grounded in individual, group or class interests. National consensus, and collective conscience ties individual to larger society through mediating institutions. Integration through assimilation into dominant culture.	Networks of voluntary exchanges between competing individuals with their own interests & motivations. Exclusion results from inadequate separation of social spheres, barriers to free movement and exchanges between spheres.	Coercive and imposed downwards through hierarchical power relations. Those with class, status, & political power have monopoly on scarce resources— seek to preserve their interests by keeping out others against their will.

Source: (Littlewood and Herkommer, 1999, pp.5-6; Silver, 1994, pp. 540-543).

Solidarity refers to “social cohesion through group solidarity and cultural boundaries” (Littlewood and Herkommer, 1999, p.5). Solidarity views the social order as “external, moral and normative, rather than grounded in individual, group, or class interests” (Ibid). The greater national concerns always bind the individuals together to create cohesion. Specialization refers to “social structures comprising of separate, competing, but not necessarily unequal spheres, which leads to exchange and interdependence between them” (Silver, 1994, p.5442). These social groups “shift their alliances between them to reflect their various interests and wishes” (Ibid).

Monopoly focuses on the “conception of social closure” and views the social order as “coercive and imposed downwards through hierarchical power relations” (Silver, 1994, p. 543). Monopoly views the power struggle between those who have status and those who do not. Those

groups wielding power and class seek to preserve their status by excluding others out against their will (Ibid).

Various frameworks of social exclusion exhibit similar characteristics in their definitions of exclusion as discussed by Littlewood and Herkhommer (1999). They identify seven common themes in the social exclusion discussion: newness of social exclusion as a paradigm; social exclusion as the effect of economic and social restructuring; social exclusion as a process; social exclusion as multi-dimensional; social exclusion as cumulative; the spatial dimensions of social exclusion; and the 'underclass' as an effect of exclusionary processes (pp. 9-19). Social exclusion as a 'new' paradigm looks at the dynamics between competing groups for scarce resources, how certain groups become marginalized and excluded from the social, cultural, economic and political benefits of being active members of society. Social exclusion is most commonly referred to in economic terminology as the polarization between those who have money and resources and those who do not, and the economic consequences of poverty. Social exclusion as a process refers to experiences of feeling excluded. For instance, if someone loses their job and can not find another one, they lose their health benefits associated with their employment. Not being able to pay for medication, they may feel humiliated at their inability to be self-reliant or self-sufficient and those psychological ramifications manifest themselves into physical ailments such as high blood pressure and weight gain (Littlewood and Herkommer, 1999, p. 12). Of course, these conditions are magnified when dealing with the most affected and vulnerable groups in society: the unemployed, ethnic minorities, lone parents, the disabled, the elderly, and women (Shaw, Dorling and Smith, 2006, p. 212).

Social exclusion is also multi-dimensional as people can be excluded from the labor market (long-term unemployment); economic exclusion (poverty); cultural exclusion (the

dominant values exclude those who are different); exclusion by isolation (restricting social contacts); spatial exclusion (neighborhood confinement) and institutional exclusion (exclusion from public services such as schooling). There are many types of exclusion, but the most common focus on the social, economic, cultural and political forms of exclusion (Littlewood and Herkommer, 1999, p.15).

Social exclusion is also cumulative, as the effects of being stigmatized or marginalized at various points in life accumulate to affect every aspect of one's life. For example, a unemployed person might not have the ability to guide their children through schooling, or to know when their rights are being violated and how to defend themselves. Their children may be segregated in poorer neighborhoods, attending older less competent schools, using out-dated technology or infrastructures. These exclusions accumulate overtime to a point where stigmatized members may feel they are trapped within their misery and unable to escape. This cycle of exclusionary policies tend to affect certain groups more than others and can have disastrous health consequences.

Social exclusion limits access to fundamental health care benefits for the most vulnerable groups, specifically ethnic minorities. Nazroo (1988) claimed that "ethnicity does not exist in isolation, it is within a social context that ethnicity achieves its significance, and part of that social context is the ways in which those seen as members of ethnic minority groups are racialize" (p.8). One of the main reasons for studying ethnicity and health care exclusion according to Nazroo is "to extend our understanding of the nature and extent of the social disadvantages faced by ethnic minority groups. Not only is health part of the disadvantage, it is also a consequence" (Nazroo, 1988, p.8).

In Canada, social exclusion is the “inability of certain groups to participate fully in Canadian life due to structural inequalities in access to social, economic, political, and cultural resources arising out of experiences of oppression as it relates to race, class, gender, disability, sexual orientation and immigrant status” (Galabuzi, 2004, p.238). To be socially excluded in a Canadian context signifies that certain groups are isolated from social institutions such as “the school system, the criminal justice system and the health care system, as well as spatial isolation or neighborhood segregation” (Galabuzi, 2004, p.238). If social and economic conditions are weak, social inequalities increase, and the quantity and quality of resources to offset these conditions are further weakened, affecting particular groups. In Canada, those groups most disadvantaged by poor social and economic conditions and a lack of resources are: “Aboriginal Peoples, immigrants and refugees, radicalized groups, people with disabilities, single parents, children and youth in disadvantaged circumstances, women, the elderly and unpaid caregivers, gays, lesbians, bisexuals and transgendered people” (Galabuzi, 2004, p.235). Living on a daily basis with limited access to social resources significantly affects health status leading to stress and psychological effects which negatively effect these groups’ already fragile health and health care (Ibid). As Canada’s population continues to diversify, this exclusion of certain groups from the social and economic conditions to better their health care is unacceptable.

The Canadian Institute of Health Research identified four particular groups of people that have a heightened risk of social exclusion and negative health outcomes in Canada: women, new immigrants, radicalized group members and Aboriginal peoples (Galabuzi, 2004, p.238). Minorities in Canada as either racialized groups or new immigrants, face barriers when trying to access or take advantage of the health care system. This can be characterized as lack of cultural competency and language barriers, lack of translators and a lack of awareness of cultural

diversity. Minorities do not access health care services at the same rate as non-minorities in Canada, and their lack of health care service use has a direct, negative impact on their state of health, well being and illness.(Galabuzi, 2004, p.238). This is precisely why cultural competence in health care is so vital. By increasing the cultural competency of health care providers, the Canadian health care system can begin to fully include these minorities in all aspects of their care. By addressing long-standing disparities in access and use of health care services from minorities, the cultural competency model can aid educators and trainers at all levels within the health care system, to competently diagnose, and properly recommend a course of treatment that respects peoples' individual cultural beliefs.

Acknowledging that ethnic minorities face barriers when attempting to use either community or professional health care services, are the first steps in beginning the process of identifying which barriers are significant, and which areas need funding and further research. This is what my study seeks to uncover, specifically for hospice and palliative care. How can end-of-life services be more culturally responsive to our changing landscape, and how can healthcare providers be assisted in their attempts to educate and train on culturally competent techniques? As the findings of this study reveal, the lack of cultural competency among hospice volunteer participants impacted their ability to be effective hospice volunteers. These volunteer participants were cognizant of the need for culturally competent services and wished to receive further training and education on the topic.

Chapter 3: Methodology

3.1 Characteristics of qualitative research

The exploratory nature of this research necessitated a qualitative research design. When dealing with such sensitive topics as cultural competency in end-of-life care, it is imperative that science and detachment not take precedence during data collection. A qualitative research design was chosen because of its “human centered” approach, its use of multiple methods and the reliance on inductive approaches, where the theory emerges through the data (Palys, 2003, p.15).

Adopting a “human centered” approach allows for a closeness between participants (the hospice volunteers) and the researcher/interviewer, and contrasts with the quantitative method which favours distance, detachment and measurable data and quantifiers. While quantitative data seeks to “find a solution” or “fix a problem”, qualitative researchers seek to explore the meanings, feelings and actions of the participants (Hawthorne and Yurkovich, 2004, p.416). There is an emphasis on Weber’s concept of *Verstehen*, which implies understanding, specifically understanding the participants as they understand themselves. It is necessary to comprehend the behaviour, actions and feelings in the context applicable to the participant (Palys, 2004, p.11). *Verstehen* is the “intimate and empathic understanding of human action in terms of its interpretive meaning to the subject” (Ibid). Closeness with the participants is important for achieving this type of “connection and attachment”, necessary to garner rich, descriptive data (Hawthorne and Yurkovich, 2004, p.416). When participants are comfortable and trusting enough to open up about their most intimate feelings, experiences, beliefs and perceptions, then true *Verstehen* can occur.

A second advantage of qualitative research is the choice of multiple methods. Researchers can choose between “case studies, personal experience, introspection, life-story, interviews, artefacts, cultural texts and productions, observational, historical, interactional and visual texts” (Denzin and Lincoln, 2005, p.5). Being able to specify details such as the inclusion of open-ended interview questions, a focus group or individual case study, allows the researcher to coordinate the collection of data according to the best suited methods available.

The third reason qualitative research best suits my specific study relates to the inductive approach. This methodology allows theory to emerge through the data. The theory is not prefixed or prefigured, rather it flows from and through the data and may change depending on what questions are asked and who answers those questions (Creswell, 2003, p.181-182). Allowing the theory to emerge from the data stems is a process of conducting interviews, collecting the data, analyzing the data, coding the interviews, beginning to develop general themes, and eventually narrowing those themes into a broader theory (Creswell, 2003, p.181-183). Being able to constantly interpret the data at various stages allows for an “interactive process where researchers cycle back and forth from data collection and analysis to problem reformulation and back” (Ibid, p.183). This “simultaneous activity of collecting, analyzing, and writing up data” produces rich and descriptive data that then forms the core of qualitative research (Denzin and Lincoln, 2005, p.12). Interpretation is also required of the researcher, who naturally filters the data through their own personal lens, acknowledging one’s own interests, values and agenda from the onset is critical in qualitative research also. According to Denzin and Lincoln (2005), qualitative research “involves an interpretive, naturalistic approach to the world. This means that qualitative researchers study things in their natural settings, attempting to make sense of or interpret,

phenomena in terms of the meanings people bring to them” (p.3).

3.2 Qualitative research strategy

There are a variety of different research designs to choose from, in fact Tesch (1990) identified twenty eight various methods, while Creswell (1998) focused on five in particular: grounded theory, case study, ethnography, phenomenology, and narrative. For my particular research, the case study was best suited. In the following section I will define the case study, discuss the importance of incorporating this approach and how the case study will shape the collection of data and analysis.

A case study is the “empirical study of human activity” (Stake, 2005, p.250). A case study seeks to know more about one particular phenomena or individual, and to generalize broader themes from the particular by comparing the similarities and differences between the case study and other research findings (Ibid, p.454). Case study researchers seek to know: “the nature of the case, its activity and functioning; its historical background; its physical setting; other contexts, such as economic, political, legal and aesthetic; other cases through which this case is recognized; and those informants through whom the case can be known” (Ibid, p.447). By studying Hospice Toronto, and the status of cultural competency within the hospice, I hope to produce policy recommendations and strategies for increasing cultural competency training, not only for Hospice Toronto, but for health care providers and agencies in general.

The case study approach is important for my particular research because it allows me to gain an understanding of how the hospice volunteers feel about working with a diverse client base, their attitudes on cultural competency and to listen to their stories of cultural clashes, and

their suggestions for improving cultural competency training. Their stories are reflected in the narrative that weaves together the human testimony and eventually leads to certain findings, future recommendations and policy research. Stake (2005) believes there are five reasons why case studies are important: “they refine theory; suggest complexities for further research; establish limits of generalizability; set public policy; and reflect on the human experience” (p.460).

The case study approach influenced how the data would be collected and analyzed. I incorporated the use of in-depth interview questions along with a questionnaire that involved a face-to-face meeting for the majority of volunteer participants. The use of the interview was paramount to uncovering the status of culturally competent care within Hospice Toronto, and developing recommendations for increasing cultural competency. Being able to seek out the patterns within the narrative, allowed broader themes to develop, which eventually became the six main findings of the research. The case study method allowed me to draw particular generalizations from the study and apply those to future health care research with hospices and volunteers in particular.

3.3 Role of the researcher

My interest in end-of-life care stems from my 10 years experience as a hospice volunteer for Hospice Toronto. As a hospice volunteer I provided care to dying patients who had six months or less to live and who wished to die at home. I visited with patients once a week for a four hour shift and my duties included providing emotional and physical support. I would attend to their most intimate care, such as mouth care, feeding, dressing, and changing. I have been

involved in some of the most difficult client cases and have served as a spokesperson for the hospice, giving talks to new volunteers, fundraising campaigns and board members. As a hospice volunteer with a decade of experience, I understand the complexities involved in the death and dying stages and that knowledge helped guide my research questions and my probing during the interview process. It allowed me to engage the volunteer participants in dialogue that resulted in richer data sets. Having the experience of working with the dying, provided an intimate familiarity with the topic, and created an atmosphere of trust and understanding between the volunteer participants and myself. As a qualitative researcher, it is essential that I reflect on my role as a researcher involved in the primary data collection and analyze any prejudgments or biases from the onset. Although every effort was made to remain objective, there are inherent assumptions involved. I believe that being a hospice volunteer is a privilege that can be taxing on the emotional, mental and spiritual nature of volunteers, and that support from the hospice is vital in preventing caregiver burnout. I have dealt with a very diverse population base with numerous clients where linguistic barriers arose. I am interested in how cultural competency training can bridge that gap and prevent future cultural and linguistic clashes between client and volunteer.

Obtaining ethics clearance from the University of Waterloo was straight-forward, as there were no anticipated ethical concerns for the volunteer participants. The volunteers who participated were aware that they could choose to not answer any question or stop the interview or questionnaire at any point. Their decision to participate, or not participate in the study would have no bearing on them as hospice volunteers and Hospice Toronto would never know the identity of those who participated. Their anonymity was assured as no identifiers were used at all. The participants were allocated numbers and no names or personal information was recorded.

Establishing clearance with Hospice Toronto to research the agency as a case study was also made easier by my established relationships with fellow volunteers, the staff, administrators and board of directors. Many of the volunteers know me or have listened to my speeches during the yearly fundraisers. Some of my client cases have been turned into segments of the initial volunteer training, as case studies for how to handle difficult clients and situations. To initially obtain permission for the study, I contacted the Hospice Toronto directly and spoke to the client service coordinators and administrators. I was immediately given a warm reception, and proceeded to file the appropriate paperwork with the Ethics Committee at the University of Waterloo. I provided the hospice with an initial summary of my research questions, the volunteer participants questionnaire and interview for their viewing so that they could raise any questions or concerns beforehand. Once they were satisfied, Hospice Toronto then provided me with a letter agreeing to participate, which I sent to the Ethics Committee. Once I obtained full ethics clearance, I notified Hospice Toronto and the advertisement poster was placed in the electronic newsletter soon thereafter. I also attended volunteer get-together where I presented my research and asked for research participants.

Hospice Toronto was chosen for my case study because of my experience as a hospice volunteer with the agency, my established relationships and friendships with the staff, board of directors, and fellow volunteers. This study was non-disruptive in nature and the results will be presented to the hospice in an executive summary format, along with a copy of the final written report. Hospice Toronto will benefit from participation in my case study by acquiring the knowledge and resource tools necessary to improve their level of care by concentrating on the importance of cultural competency.

3.4 Data Collection Procedures

Bounding the Study

Setting:

This case study was conducted over a period of seven months from January to July 2008.

Interviews were conducted on a face-to-face basis, over the phone and through email. All the volunteer participants in this study work with Hospice Toronto, and provide support to patients who have a terminal illness and wish to die in the comfort of their own home. Advertisements were placed in the electronic newsletter circulated once monthly by Hospice Toronto and went out to all 169 hospice volunteers. Posters were also placed in the hospice and the study was mentioned during volunteer meetings and get-togethers. Interested participants contacted me through phone or email and a subsequent day and time was set up to conduct the interview.

Actors

I interviewed fourteen hospice volunteers and one administrator from within Hospice Toronto.

Events

Adopting a case study approach, the methodology used in this study included in-depth interviews and questionnaires with volunteer participants. The total time for both questionnaire and interview was sixty minutes. The focus of the study was on the current status of culturally competent care with Hospice Toronto, and the challenges that may arise in attempting to provide culturally competent care in a city as diverse as Toronto. The interview questions fell into the following categories: (1) socio-demographic questions, such as ethnicity, sex, marital status, income levels, employment, education and language ability; (2) motivational questions such as, history of volunteering for the hospice and reasons for becoming a hospice volunteer; and (3)

cultural competency questions such as, their knowledge of cultural competency, their experiences working with clients of different ethnicities, languages or culture, and their recommendations on how cultural competency training could be improved in the hospice.

Processes

Attention was paid to the personal reflections of hospice volunteers recounting their perceived lack of support from the hospice, their examples of cultural and linguistic barriers with their patients and the numerous recommendations for improving cultural competency training.

This case study incorporated the use of in-depth interviews with a self administered questionnaire. I interviewed fourteen hospice volunteers and one administrator from Hospice Toronto, over the course of six months from January 2008 to July 2008. Each interview lasted approximately 60 minutes and I met up with the volunteer participants at the location of their choice. Many volunteers invited me into their homes for the interview, and for those whose schedule did not permit a face-to-face interview, I was able to interview them over the phone, or for one participant I included the interview and questionnaire via email.

The in-depth interview style was chosen for its unstructured open-ended questions, that allowed me to probe for further detail when necessary and also encouraged the volunteer participants to tell their story, rather than simply answer questions. The interviews felt more like conversations between friends, because of my long history with Hospice Toronto, and my ten years of experience as a hospice volunteer. I was able to include my own stories of hospice clients, certain situations or difficulties I faced when volunteering and that knowledge helped to create a familiarity and comfort between interviewee and interviewer. The conversation-style of the interviews was enriched by my genuine interest in their stories, and in the subject matter at

hand.

The benefits of incorporating a self-administered questionnaire include the ability of volunteer participants to ask me questions or clarify any confusion during the interview time period. There were no ambiguities with responses for the questionnaire because I was there and able to answer their questions at the time. Questionnaires are also a great tool for getting a large amount of information in a limited amount of time with relatively little cost. The questionnaires provided me with my basic demographic profile of the volunteer participants.

The benefit of incorporating in-depth interview style questions are the rich narrative that resulted from the volunteer participants story telling. Their reflections were characterized by very detailed and thoughtful responses that allowed the reader to get an intimate glimpse into the lives of hospice volunteer working in a multi-cultural setting. As a qualitative researcher with experience in conducting in-depth interview of a sensitive nature, I knew when to appropriately probe for greater detail and for further explanation. The interviews were structured with the general demographic questions first, and then narrowed down into the status of cultural competency training within the hospice, their views on working with a diverse client base, and then concluded with their suggestions or opinions on how to increase cultural competency within Hospice Toronto. I began each interview with the definition of cultural competency and ended each interview by asking the volunteer participants if they had any questions or concerns they would like to address now, that perhaps did not arise during the interview.

The limitations of incorporating in-depth interview questions are the volunteer biases that can occur. As Palys (2004) states: “people who participate in social science research tend to be more highly educated, politically more liberal, less authoritarian, more in need of social approval,

more intelligent, and more interested in the issue being addressed than those who don't" (p.152). Another limitation of the interview is that people are not "equally articulate and perceptive" or forthcoming with information (Creswell, 2003, p.188). For this study though, the advantages outweighed the disadvantages of incorporating in-depth interviews.

3.5 Data Recording Procedures

Each interview began with the volunteer participants reading the information letter, detailing the goals of the research, the definition of cultural competency and the ethical considerations involved. Each volunteer was told that they could chose to decline answering any question or stop the interview at any time. Volunteer participants were also encouraged to ask questions if they were unsure about anything. Each volunteer participant was informed that a copy of the final written report would be made available for the hospice to keep and if they wished for a personal copy, they could indicate so on their consent form. Once volunteers read the information sheet and signed the consent form, with their permission the interview was tape recorded. Each interview began with an exchange of pleasantries and a transition of general conversational topics to the beginning of their experience with the hospice and then the interview began. I followed my interview questions and probed the appropriate areas for further detail. I took notes while interviewing, as a back up procedure in case the tape recorded stopped working. Immediately within twenty-four hours, I transcribed the tape recorded interviews, and began recording the data from the questionnaires.

I decided against the use of computer software (Nvivo, Nudist) because my case study contained a small number of volunteer participants. I personally transcribed the data so that I

could reflect once more upon the interview, analyze the responses from a distance, and in case the tape recorder had stopped working, my memory of the interview was still fresh and clear and enabled me to accurately reflect the views of the participants in the transcription of their data. Transcribing the data within twenty four hours also allowed me to figure out if there were any missed questions or vague answers that I needed further clarification on. In fact, there were three such instances, where I was able to contact the volunteer participant for further information. Another advantage of personally transcribing the data was its cost-effectiveness. The data was transcribed verbatim from the recorded interviews, with the exception of the words “um”, “ah”, “like” “oh”. These were omitted because they distracted from the overall essence or nature of the interview.

3.6 Data Analysis Procedures

Qualitative research necessitates the simultaneously activities of collecting the data, analyzing the data, reflecting upon possible themes, beginning to code the data and then back to recollecting more original data. This is an ongoing process of collection, analysis and reflection that eventually allows the theory to emerge through the data. There are numerous steps involved in the analysis process and I describe each step in the following section.

The first step was transcribing the tape recordings within twenty four hours so that my memory was still fresh and in case the tape recorder stopped working, I could rely on my memory and handwritten notes that I had taken during each interview. Second, after each transcription, I printed off the interview and read it in its entirety to reflect back on the narrative and see if there were any questions that I missed or needed further clarification on. After all the interviews were

complete, I read all the transcripts once more to get a general sense of the themes and ideas that were emerging. Third, I began going through each transcribed interview in great detail, coding and organizing the emerging themes. I color coded the major research questions and began linking the data or narratives into a story. I cut and paste all the answers to each question separately so that I could read all the answers together to get a greater sense of similarity and differences in tone and depth of answers. Fourth, I jotted down notes on themes that I thought were emerging, and on the surprising findings that I never expected to emerge. I made a list of the main themes, and then cut and paste all the answers and narratives to those particular questions involved. The coding allowed me to recognize the themes as they were developing in the study. Fifth, the themes ended up being represented by the personal narratives found in the embedded and italicized quotes in the analysis section. The final step in analyzing the data was presenting the material in terms of the sociological relevance and future implications of the findings. The data was filtered through my own personal sociological lens and my experience as a hospice volunteer with Hospice Toronto, and concluded with the recommendations for increasing cultural competency within the hospice and highlighting the challenges to providing culturally competent care in a multicultural setting.

3.7 Strategies for Validating Findings

Every research needs to be able to validate its findings, and this case study employed several measures to ensure that validity. First, during each interview, I asked the volunteer participants if I had captured their true feelings, and if they wished to view the transcripts of the interview. The majority of the volunteer participants stated that they would only be interested in

reading the final report or a summary of it. Second, I relied on the very detailed and descriptive responses by the participants to accurately convey their personal reflections about working with a diverse client base, their training in cultural competency and their opinions on how to increase cultural competency training within Hospice Toronto. I believe that a story was told in these detailed and vivid accounts that will resonate with readers and provide a glimpse into the lives of hospice volunteers, working with the dying in a multicultural setting. Third, I acknowledged my own biases as a previous hospice volunteer with Hospice Toronto, but view my experience as an asset in being able to elicit the most genuine, honest and reflective responses from the volunteers. Fourth, because of my ten years of experience in being a hospice volunteer, I have gained the immeasurable experience of knowing exactly what it feels like to take care of someone who is dying. I know the intricacies involved in entering a strangers' home who is vulnerable and in need of support. I have witnessed outrageous family dynamics, denial of disease and impending death, intolerable levels of pain, and complete devastation and sadness that can overwhelm even the strongest among us. This in-depth knowledge about death and the dying process has made me keenly aware of the value and importance of volunteers in the health care sector, their roles within the hospice and the upheavals a community based hospice agency goes through, and I believe this lends me credibility in the narrative process. Fourth, I made sure to include the negative or contradictory data garnered through this case study, even when they were contrary to what I expected to find-- it is a necessary component that adds to the credibility of qualitative research. Lastly, I made sure to situate my study within previous research and compare and contrast my research results with those of other hospice palliative care studies.

3.8 Narrative Structure

For this qualitative study, I chose the use of descriptive narrative or quotes to reveal the six major findings. This is a natural choice as a qualitative researcher since it allows the readers to capture the essence of what the volunteer participants are feeling. I have used a combination of long (indented and single spaced) and short quotes (italicized) and have included my own analysis of the interviews alongside the narratives. I also compare the volunteer participants' answers to those findings in previous research and look for the similarities and contrasts between the studies.

3.9 Anticipated Ethical Issues

At the onset of each interview, the volunteer participants read the information letter, detailing the goals of the research, the exact research questions the definition of cultural competency and the ethical consideration involved in participating. Volunteers were reminded that they may chose to not answer any question, or to stop the interview whenever they would like. Their decision to participate in the study, or not, did not impact their status as a volunteer with Hospice Toronto. No identifiers were used in this study, and the anonymity of the volunteer participants could be completely assured. Volunteers then signed the consent form, or verbally consented to the interview process over the phone. Those volunteers' who participated through email, received the information letter and consent form to read over before completing the questionnaire and interview.

Ethics clearance was received by the ethics committee at the University of Waterloo and the board of directors at Hospice Toronto before the study officially began. Volunteer

participants all agreed to have their interviews tape recorded with the understanding that the tapes would be transcribed within twenty-four hours and then erased. Volunteer Participants also agreed that their responses would be made available in the final thesis, future articles, presentations and conferences, with the understanding that their identities would not be revealed. Volunteer participants were also given the choice to read the final report and a copy would be made available to Hospice Toronto to be put on reserve, and a personal copy would also be available for the individual volunteer participants if they informed me of their preference. All the volunteers indicated their preference for reading a summary of the final report or the actual thesis itself from the hospice, and did not wish a copy for themselves.

As a researcher involved in interviewing people, there is an obligation first, to do no harm to these volunteer participants, and to respect their opinions, needs and wishes at all times. Volunteer participants need to be made aware of the research goals, questions, collection and storage of data, and confidentiality agreements. Volunteers in this study gave their informed consent to participate based on an honest representation of the requirements of this research, including what their participation entailed, how data was to be collected and analyzed, and the future use of the research findings. Volunteer participants were also informed of their rights regarding privacy and anonymity and ensured that no identifiers would be used in this research. No names or personal information was ever recorded, and the participants' identities were coded as VT1, VT2, VT3, etc. I took special care to never record any names, and only used their codes.

Chapter 4: Findings and Analysis

4.1 Hospice and Palliative Care Volunteer Profile

Those who volunteer for the dying in end-of-life care tend to be homogeneous, exhibiting similar demographic characteristics. In the few Canadian studies available on palliative care volunteers, Claxton-Oldfield et al., (2007), looked at twenty-three hospice volunteers from six different hospices in Atlantic Canada and concluded that 78% were women, 65% were married, 87% had college or university education, 61% were retired, 96% held religious affiliations, and 91% had previous volunteer experiences (p.260). Previous research (Caldwell, 1996; Claxton-Oldfield et al., 2005) also reveal similar attributes, with the majority of hospice volunteers being women who were married, middle aged or older, with some post-secondary education and religious affiliations. In Pearson's 1996 study of hospice volunteers, the overwhelming majority were women (87%), married (73%), Caucasian (95%), middle-to-upper income brackets (58%) and held religious views (91%) (p.24). Handy (2004) looked at the general demographic characteristics of hospital volunteers in thirty-five different hospitals in Ontario and once again, the results demonstrate that women who are white are the majority of volunteers, approximately 74% of the sample were females (p.33-35).

Women who volunteer for the dying are motivated because of their previous experience with the death of a loved one, whether a family member or friend. At times, this experience with the dying process can be traumatic and reveals to volunteers their hidden fears and anxieties about death. At other times, the dying process is inspiring and heartfelt, and people wish to give

back to the community, to help others, to feel as if they are making a difference in the community, and in people's lives. People volunteer in hospice palliative care out of a genuine desire to help others, to "feel useful" and to give back to society (Handy, 2004, p.33-35).

Hospice volunteers are a unique brand of personalities who willingly enter into the arena of death and dying, whereas most people fear, deny and ignore the inevitability of death. To be able to handle the stressful atmosphere of dying, sadness and grief, where the only guarantee is death itself for the clients, requires that volunteers possess certain attributes to be able to withstand the pressures. Volunteers must often handle varying situations ranging from difficult and unpleasant clients who may resist or deny their impending death with hostility and anger, to unsettling family dynamics where family members may place unrealistic expectations on the volunteers. Overwhelming emotions of sadness, anxieties and fears about the unknown factors of death and dying and bearing witness to uncomfortable levels of pain, are a common occurrence during shifts. Emotions from clients can range from genuine appreciation, to excruciating sadness and intolerable pain (Rokach, 2005, p.326). Volunteers can become engrossed in the emotional ramifications of dying and to expect them to be unscathed by their caregiving duties is unrealistic. The human experience of witnessing someone in the dying process and eventual death is staggering in its intensity and unimaginable for most people.

To be able to handle the demanding dynamics of end-of-life care, volunteers tend to exhibit similar attributes such as "acceptance of self", "acceptance of others" and "flexibility and patience" (Wilson, 2000, p.108). Accepting oneself entails understanding one's own beliefs, values, and experiences while acknowledging the impact of these experiences on oneself. Accepting others deals with respecting his/her clients for whom they are during the dying

process, not who you wish them to be. Being non-judgmental, courteous and attentive are mandatory characteristics of hospice volunteers. And lastly, volunteers must be flexible and accommodating to the various stages of dying, both emotional and physical changes of the client must be dealt with in a patient and tender manner (Rokach, 2005, p.327). Volunteers routinely display attributes of “compassion, empathy, faithfulness, justice, advocacy and practical wisdom” (Giblin, 2002, p, 237). They must also be able to exhibit “emotional maturity, tolerance, warmth and an ability to listen” (Lamb et al., 1985). Without these necessary characteristics, death would be stripped of its dignity and grace.

Volunteers are guided and supported in their benevolence through hospices and palliative care teams who provide in-depth training, typically lasting twenty to thirty hours. Volunteers are trained on a variety of topics, including but not limited to:

direct patient and family care, emotional and social support of the ill, respite care, non-direct tasks, therapeutic touch and bereavement support, philosophy and goals of palliative care, spiritual issues, communication dying process, grief and palliative care team roles, listening skills, funeral options, family dynamics, pain control, symptom management, legal aspects of hospice care, AIDS and Cancer information, and the roles and responsibilities of volunteers, hospice philosophy, roles of inter-disciplinary team members, physical aspects of death and dying and communication skills.
(Pearson and Cladwell, 1996, p.28; Claxton-Oldfield et al., 2005, p.112; Claxton-Oldfield et al., 2006, p.191)

Most hospice volunteers visit their clients once a week for approximately four hours. They perform a variety of tasks with their clients including “light housekeeping, running errands, light meal preparation, respite care, and providing emotional support” (Claxton-Oldfield et al., 2007, p. 464). Volunteers may also provide such intimate practices as provision of personal care (mouth-care, feeding, dressing, changing, assisting with bathroom or commode use), spiritual and emotional support and respite care which involves allowing family members to take a break

(www.hospicetoronto.com). When science and medicine reach a standstill, where the remedy is pain control and comfort rather than curing, it is an opportunity for “caregiving [which is] an experience of privilege, not of burden” for hospice volunteers (Giblin, 2002, p.239). Providing care, comfort and companionship to people in their last moments of life, is an honourable mission that nurtures both client and volunteer, while allowing the dying to have the grace of being looked after.

4.2 Women and the Role of Caregiving

One of the intriguing findings from this case study of Hospice Toronto volunteers and confirmed through previous palliative care research (Caldwell and Pearson-Scott, 1994; Auger, 2000; Gallicchio, et al., 2002; Kao and McHugh, 2004; Brannen, 2006; Crewe, 2007; Mellow, 2007; Walker, 2007) is the predominance of women in volunteering and caregiving roles. In fact, “gender is a strong predictor of becoming an unpaid caregiver in Canada” (Crewe, 2007, p.31). When women become caregivers, they suffer the social, economic and health consequences of this unpaid labour choice. Whether providing care in the family household, or the community, more women than men are unpaid caregivers, according to the Healthy Balance Research Program (HBRP), funded by the Canadian Institute of Health Research (Ibid).

As a social consequence of caregiving, women must balance the demands of child-rearing, family-care, work relationships, housework and the added dimension of elder care (Kao and McHugh, 2004, p.124; Mellow, 2007, p.452). The “sandwich generation” are people who must simultaneously take care of their children and aging parents, which raises stress and anxiety levels according to Statistics Canada (2004). Women are more likely to find themselves sandwiched

between child-rearing and elder care, spending upwards of 29 hours a month on elder care, which is twice as much as their male counterparts spend (Statistics Canada, 2004).

Since the majority of caregiving takes place in the home, whether it be for family members, or in the homes of others, caregiving remains concealed and its value is trivialized because it is seen as a “continuity of domestic labour”-- blurring the private and public spheres of women’s lives and caregiving roles (Mellow, 2007, p.452). The “sandwich generation” are typically women in the 40's and 50's that have to take care of their children and elderly parents, while maintaining a household, family responsibilities, and working outside of the home (Walker, 2007, p.32). It is assumed that caregiving is more appropriate or natural for women because it is an extension of what women already do at home. Caregiving is gendered since women provide the majority of the care, but also because the nature of caregiving embodies more feminine tasks such as: “tending to small children, nursing the sick; [providing] comfort” and emotional support and physical connection to those that need help (Mellow, 2007, p.453). Women also tend to volunteer for agencies that are socially driven because of the element of care involved, where as men tend to volunteer for “civic organizations” such as sports teams and associations (Mellow, 2007, p.453).

The economic consequences for providing unpaid caregiving entail a “change in work hours, refusal of a job offer, or a reduction in income” (Statistics Canada, 2004). Expenses incurred can include transportation costs, home maintenance, fees, grocery shopping, medical bills and medication. Since women perform the majority of caregiving duties, they are impacted economically by their reduced work hours, even though they assist the Canadian health care system by providing their “time, energy and love”, all for free (Crewe, 2007, p.32).

The health consequences for women who provide unpaid caregiving in a variety of

positions include: “increased stress levels, high blood pressure, elevated insulin levels, weak immune systems and cardiovascular diseases” (Suthers, 2006, p.4). Caregiving can also cause such negative health outcomes as “feelings of depression and helplessness, poor eating habits and disturbed sleep” (Brannen, 2006, p.13). Female caregivers suffer disproportionately more negative health outcomes because of the intense nature of their caregiving. Women provide both physical support such as personal care (bathing, mouthcare, feeding, dressing); and emotional support, such as listening, giving advice, and being a shoulder to cry on (Statistics Canada, 2004; Brannen, 2006, p.12-13; Crewe, 2007, p.32). Men, on the other hand, tend to assist with issues such as “home maintenance and transportation” (Statistics Canada, 2004), which is not emotionally taxing. As women’s personal identities are persistently tied to the nature of caregiving, mothering, nurturing and supporting, women will continue to feel the burden of stress and fatigue (Ibid). Increased stress levels for women escalate because of the multiple burdens of childcare, homecare, eldercare and caregiving. Trying to fulfil these roles heightens stress levels for women and creates unrealistic expectations that women can be all things for all people. Although it is beyond the scope of this paper to investigate the gender burden of caregiving, it is a perspective that deserves further research.

On a positive note, the female volunteer participants in my study revealed an authentic desire to help others and to be of service to the community. These female participants were sensitive to the difficulties involved in the delicate nature of cross-cultural palliative care, and their responses proves that they enjoy volunteering, they believe they are making a difference and perhaps their nature allows them to be more sensitive especially when working with a culturally diverse clientele base that is dying. Although, women may suffer some consequences for their

choice in volunteering, they also reap the benefits of increasing their social contacts, social networking, learning new skills, and knowing that their community service is making a sustained difference in the lives of those who need it the most. By providing companionship and personal support to clients and their family members during end-of-life care, the value of these female volunteer participants is immeasurable (Handy and Srinivasan, 2004, p.40).

4.3 Participants

The participants of this study include 14 hospice volunteers and 1 administrator from Hospice Toronto. The following descriptions are of the hospice volunteers, the administrator interview will be dealt with separately. Among the volunteer participants, 2 of them were complementary care volunteers who provided patients with services such as massage therapy, reflexology, reiki or music therapy for free. The main differences between these volunteers are that they did not visit clients for the average 4 hour shift once a week. Complementary care volunteers generally visit clients once a week for one to two hours at a time. “Volunteer” used in this context means both regular volunteers and complementary care volunteers.

Age: The volunteer participants’ ages ranged from 31 to 75, with 3 volunteers each were in their 30s, 40s, 50s, and 60s, and 2 volunteers were in their 70s.

Birth place: All but 2 of the volunteers were born in Canada; the 2 foreign born volunteer participants were from Estonia and South Korea respectively.

Martial Status: 5 volunteer participants were married, 4 were divorced, 1 was widowed and 3 were single and never married and 1 was divorced but will soon marry.

Race: Every volunteer participant other than the South Korean (13/14 of the volunteers) were

White/Caucasian with European decent.

Language: Only 6 of the volunteers spoke a language other than English, and only 2 volunteers spoke languages other than English and French.

Religious affiliation: What was significant in this research was the lack of religiosity from the hospice volunteers. While previous research has stated that most volunteers tend to be religious, this research did not confirm that. In fact, the majority of the volunteer participants stated emphatically that they were not religious at all. This may be attributable to the growing trend for Canadians to not be as religious as they used to be (Statistics Canada, year?).

Education: The highest level of education achieved for the volunteer participants ranged from grade 8 to a PhD, with the majority (11/14) completed a university degree.

Income: Annual incomes fell in the middle-to-upper range (from \$41,000 to over \$70,000 annually), with the majority (9/14) making over \$41,000 a year.

Hospice care volunteer experience: For 11 of the volunteers this was their first palliative care volunteer job.

Main reasons for joining the hospice as a volunteer: It ranged from prior experiences with the death of a loved one and a desire to educate themselves on the processes of death and dying.

Distance traveled from home to hospice: The distance for the volunteer participants to travel from home to hospice ranged from 10 minutes to 2 hours.

A detailed description of the demographics of this sample can be located in the Appendix.

4.4 Findings

There are six major findings in this study: First, there are significant cultural and linguistic barriers amongst hospice volunteers when dealing with a diverse client population; Second, the current cultural competency training provided to the hospice volunteers is inadequate; Third, volunteer participants have valuable knowledge on how to improve cultural competency training; Fourth, volunteer participants felt the hospice was unsupportive of some of their needs. Fifth, the hospice volunteer team is not ethnically, culturally and linguistically diverse. Last, most hospice volunteers are not religious, which is different from previous studies on hospice volunteers.

4.5 Analysis

Finding #1 - Volunteer Participants encounter cultural and linguistic barriers when providing care.

Cultural Competency Examples

As previously discussed, cultural competency is crucial in end-of-life care because of the changing demographics of the country, the under-utilization patterns of minorities, and the need to diminish the fear and stigma of death, but also to allow patients the dignity of dying in a respectful manner where their cultural beliefs, traditions and customs are honoured and given the consideration they deserve. When volunteers are not adequately trained in cultural competency, situations can arise where there is a clash of cultures. A situation such as this can lead to awkwardness, confusion and embarrassment for both the client and volunteer. Worse yet, it can offend or disrespect the client in a way that negatively impacts their already fragile health.

Volunteers work with clients on an intimate basis once a week for a four hour shift, and it is imperative that volunteers not add any unnecessary stress and anxiety to a patient that is already dying. The role of volunteers in hospice care revolves around easing the pain and discomfort of patients by providing caring support during such an exhausting and difficult period of their lives. Therefore it is of utmost importance that volunteers are properly and adequately trained in the complexities of cultural competence. When discussing these issues with the volunteers numerous examples were given where there was indeed a clash of cultures between client and volunteer. One such example consisted of a Muslim family where the volunteer had been placed to take care of a 6 year old boy whose older brother was dying. On one of her visits with the Muslim family the young boy initiated a discussion on God and religion. This is her story.

When the little boy asked me if I believed in God, well, there was a long pause, and then he just kept looking at me, with such wide eyes, waiting. "I love God!", he said emphatically. "I love God". He was so excited about God and because his mother and aunt were both in the room, and a question like that obviously perks up people's ears. Well, at first I tried to tell him that there are many different things that people believe in, –but it wasn't computing, and it wasn't the answer he was looking for. So, finally I just said "yes", even though it was a lie. I mean, I'm an atheist, but I felt I needed to say it to make him happy. You don't want to provoke a philosophical debate on religion with a child. He was too young, especially when you're in the home of a devout Muslim family, so I just went along with it. He just wanted to hear his own beliefs reaffirmed, he was only 6, so it was totally appropriate to do so (VT1, p.4-5)

Another instance of a cultural clash also occurred with this same client and volunteer. This time the young boy, the volunteer and the grandmother, who spoke no English, went out to eat lunch at the Red Lobster restaurant. Hospice rules and procedures dictate that any and all meals should be paid for separately by the volunteers and client. It is not the job of the client, nor is it necessary, for the client to provide any type of meals for the volunteer. Many clients may feel obligated to show their

appreciation of the volunteer, and sometimes wish to pay for meals or certain expenses, but hospice volunteers are never allowed to accept any type of gift, reimbursement or token of appreciation for ethical reasons. Accepting such gifts sets up a precedent where clients may think that their level of service will depend on the types of gifts given to the volunteer. This is their example of what happens when there is not a clear understanding of the cultural traditions and customs of a particular faith or religion.

The Mom had to go to the hospital to go to be with the older boy and she asked me to take the younger boy and his grandmother to eat. So, off we go to the Red Lobster restaurant. The little boy was very excited about going to a restaurant, he was very enthusiastic. I remember taking the waiter aside and making sure he knew that I needed to pay for my own meal, because of hospice rules. Well, it was a very jubilant dinner, because he asked if I wanted to sing "O Canada". Well, he burst out singing "O Canada" at the top of his lungs, in the middle of Red Lobster. So, there I am, sitting at the Red Lobster, with a Muslim boy singing "O Canada" at the top of his lungs and his grandmother who speaks not a word of English. After he finished singing, he started to sing it again. I can just imagine what the rest of the restaurant was thinking. Well, the meal was good, they had crayons for him to draw with at the table. But the conflict came when the bill arrived with the waiter. The grandmother quickly got the gist of what I had asked for, of what I was trying to do, and started waving at me, indicating she wanted something. She said something to the little boy, and all of a sudden, she had physically grabbed my right arm, and the little boy grabbed my left arm, and actually restrained me. He's a solid boy, maybe I was 10 pounds heavier than he was. So, I needed to pay, I have to cover my own expenses, but the grandmother doesn't speak any English and I can not understand them. Now the situation is totally escalating in to a scene in the restaurant. So, finally I just thought "wrap it up". So the little boy paid for the meal because his grandmother had given him the money before hand. When we got back to their home, I slipped a \$20.00 bill underneath a Kleenex box for the mom. She obviously found it and was very upset about the whole situation. She was angry, and crying because I had insulted their culture because when 2 women go out the male is always the head of the family, and this 6 year old boy was technically the head of their household. So, I was insulting their culture by trying to pay for something that the head of the household was supposed to pay for. I tried to explain to the mother that I was just trying to cover my expenses and follow hospice guidelines, that I wasn't trying to insult their culture. I was in a situation that was completely new to me. When I told the hospice, they were very surprised about it. Well, in the end it got smoothed out, but it was a very dramatic scene in the restaurant, and it was a dramatic scene afterwards with the mom. The mom did not understand why they couldn't pay my meal. She felt that I was insinuating that they couldn't afford to pay, which insulted her even further. This family were fairly new to Canada, so this was a learning curve for both of us. What's neat is how interested she is in Canadian culture. She always wants to know about Canadian holidays. She was

very interested in Easter, and Halloween. She was quite anxious for her kids to participate in these activities. What I think would be helpful in this type of situation is to have on-line resources. You can't necessarily prepare yourself for every cultural situation, but once you know which culture your client and or their family belongs to, you can look up the necessary information and perhaps avoid a situation like mine from occurring (VT, p.4-5)

Issues have arisen surrounding linguistic competency when dealing with clients who speak little to no English and volunteers need to rely on body language, or family members as interpreters.

“Language is the biggest barrier, it was a problem for me, because it's difficult to communicate with someone when they don't speak English and you just have to rely on body language” (VT 6, p.1).

Language has been a barrier and made it difficult for me. My client was Japanese and spoke no English and as he progressively got worse, it became more difficult to try and read his body language. I had to rely on hand gesturing and I don't think I was doing what he asked me to do, so that was troubling (VT6, p.2).

Five of the volunteers expressed a desire to be able to better communicate with their clients whose English skills were lacking.

It's usually just a language issue. All of my clients have been able to speak English, even if it's just poorly, but I wish I could speak their language, especially with the older family members, you know the grandmothers, they usually can't speak English that well, and it would be nice to know a little bit more about the family, or what they were trying to say, to know what was going on with them (VT 8, p.2).

Another example of language barriers showcases the need for greater diversity of hospice volunteers themselves. It is a dilemma for the hospice organizations, because it is difficult enough trying to recruit volunteers to work with people who are dying, but then to find volunteers who are ethnically, culturally and linguistically diverse themselves can present a challenge.

I think the first time that I dealt with someone who only spoke Chinese because there's nothing that's remotely similar in English, so there's nothing to catch. You know, to make sure that someone translated the waiver form to the person, so that they understood, and to also have that person tell the client that if they're

uncomfortable in any way, to let me know. So, until that was organized, and also having the person's son there during my session, because he spoke English in the house, that was better. But the few times, with him not being there, his wife spoke a little more English, he didn't speak any English. I mean there would be times that I would see him and I would ask her "Is that uncomfortable for him?", and she would say "No, no,"...I'm a very patient, calm person, but it does give you a different level of respect for other people who are trying in their way, and it's challenging, that they're making the effort to communicate with you, and you have to respect that (VT4, p.2).

Another example of linguistic barriers and the extreme sensitivity involved when caring for clients who are dying and speak little or no English is discussed below.

The lady I'm seeing at the moment is Bulgarian and she has Alzheimer's, and she doesn't speak any English. I basically do it the same way as I did with my ESL students. I go into her room, I look at her, I smile at her, she always recognizes me, she pulls my face down for a kiss you know. She starts talking in Bulgarian, and I just smile and nod, and she's always pleased to see me, so she's happy to see me. I don't really know if she knows that I don't speak Bulgarian, you know what I mean? I really don't know what goes on in her head. What I generally do is, well, I would never walk into anyone's room if I didn't speak the language, like I wouldn't just walk into her room, do what I wanted to do, and walk out. You still have to acknowledge that you're in their room, while you're there. So, I would always say to her "I'm going to raise the head of the bed", and I'm sure she doesn't understand those words, but I'll show her what I'm doing by lifting up the buttons. We sort of understand each other with hand signals. She loves to talk, and sometimes she'll just talk away in Bulgarian and she thinks I understand and then it'll get to a point, where I can tell she's trying to tell me something and she knows that I'm not understanding her, and she gets frustrated, and starts wacking her finger at me. So, then I know I should leave, but I don't just walk out of her room without saying anything. I make an excuse, like I'll pick up her dirty dishes and show them to her to tell her that I'm going to go wash the dishes. Then she'll nod. Or, I'll take the garbage can, and show her that I'm going to empty out the garbage. So that she knows why I'm walking out of her room. I sense after a time that she's wondering why I'm not understanding her, or maybe she thinks I'm disagreeing with her, or giving her attitude or something. I don't want her to feel frustrated, so the longer I'm in her room, and the longer she tries to talk to me, she gets frustrated. So, I go out of the room, and then when I come back in, she's happy all over again, to see me (VT3, p.2).

Volunteers also discussed the need to be aware of their actions and behaviours while visiting clients from a different culture, so as not to accidentally upset or offend them. Volunteers had different techniques for trying to avoid cultural clashes, some choose to be reflective on the various cultures of illness, household, family dynamics and ethnicity, while others choose to steer conversations

away from controversial topics.

It made me more conscious about being aware, to stay on my toes, so to speak. Every person, every household has their own culture, and I have to be aware of that. It's a couple of layers really, –personal culture, household culture, ethnic culture, culture of dying, and working intimately with the family, trying to be aware of these different levels of cultures is important (VT10, p.1)

Volunteers expressed a real desire to be sensitive to their client's needs, even when their client's beliefs or needs contrasted with their own views; they try to always be respectful of their clients.

My outlook is about being present and aware, and this helps me when dealing with different cultures and when dealing with death and dying. I don't go into defining anything with people. I try not to get into certain discussions. I'm there to do what is necessary. Basically, all people are the same. We all have similar habits, and you have to be open to receiving whatever people are giving you. Even if I don't agree, you have to remember that nothing is personal, we may not all believe in the same things, or live by the same rules, but it's not personal (VT12, p.2).

Volunteers also shared stories where their level of awareness of different cultural traditions helped them in certain situations with their clients.

To make sure that I don't say something politically incorrect to someone is important. My last client was during the time of Chinese New Year, and I had helped her with some reiki, besides doing some reflexology, and I noticed the red envelopes, which the Chinese tend to give money in during New Years. So, she had come out with this red envelope, because she had really, really appreciated what I had done for her this particular day. And I knew enough that I didn't want to be insulting, because New Year's is a really big event, but I can't accept \$100.00 or \$50.00, or whatever. So, I was trying to find a politically correct way out of the situation. But, the thing is, I was aware enough to know what this meant. If I didn't accept, and had just said "No, I can't accept it", well, instead I said, "No, no, I'm very sorry, I can't accept any money, it's part of the hospice policy", and so, she looked around the place and found some candy, and I said "Yes, I would love to have some candy". So, I accepted a bag of candy instead, but she was trying to show her appreciation and I discussed it with Evelyn [volunteer coordinator at Hospice Toronto], and she said that I had done the right thing. But, that's just because I knew enough about the culture, but that's not necessarily true with every volunteer. So, the sort of thing can come up (VT4, p.5).

All the volunteers were innately aware of the importance of the client taking precedence.

Volunteers are there to assist and comfort the clients, basically to cater to their needs, so their

wishes need to be respected, it is not about making the volunteer comfortable as it is making sure the client is comfortable.

Being a volunteer, just remembering that it's all about them. It's basic, but that's how I've gotten through some of the most difficult situations, is to remember that it's all about them. For instance, one person that I was working on, performing reiki, felt uncomfortable and wanted to sit on a chair instead, so I said sure. Then it was too painful sitting down, so we did it standing up, then they wanted to lay down. I just followed them around and only did what they were comfortable doing. And I think one of the things I felt uncomfortable with at the beginning was, every time I go in I ask the person if it's o.k. that I can touch them to do the service. And when someone doesn't speak the language, and is also drugged, or you go in and the client is sleeping, well, I never touch a person who is sleeping, they need their rest more than anything. Listen, I've sat for half an hour before and if they've woken up, then I tell them who I am and I ask them if they'd like a treatment (VT4, p.6).

Finding #2 – Cultural Competency training provided by the hospice is inadequate

Nine of the volunteer participants in this study stated that they had not received any training on cultural competency or sensitivity; if they had, they could not remember what it entailed. Of the remaining 5 volunteers, they felt that the training was adequate, and could only remember vague details about the specifics of the training, but they were open to having more. In fact, Hospice Toronto does provide a segment on cultural competency in their initial intensive 30 hour training for volunteers; obviously the training was too brief or not detailed enough for volunteers to remember. The results point to need for greater training on cultural competency and even a need for re-fresher courses or materials that volunteers can take home with them. Responses to this initial question were very similar: *“No, Not that I can remember. We may have, but I don't really remember. Well, I can't exactly remember what the training was, so I guess I needed more of it (VT3, p.1). It's not very nice to say that I can't remember what the training on cultural competency was. Maybe it'll come to me during the interview” (VT3, p.1). “They do have*

one section of their training that has to do with dealing with people with different cultures” (VT4, p.1), “No, there was no training” (VT5, p.1), “No, but if I did, it was really brief, and not enough for it to stick in my mind, or nothing that I really remember” (VT6, p.1), “Yes, in the initial training, just a little bit, but I can’t remember it now. I don’t specifically remember what it was” (VT7, p.1), “Yes, in the initial hospice training, but I don’t really remember the training. I have some vague details that they mentioned we should be aware of other people’s religious backgrounds, but that was pretty basic stuff, common knowledge really” (VT8, p.1), “Yes, just about being respectful around different cultures, but we didn’t get specific” (VT9, p.1), “Ah, well yeah, it was part of the initial training, it was touched upon. What I recall of it was that it dealt with attitudes towards dying, and being sensitive to where these people are coming from” (VT10, p.1), “Yeah, it was a short, brief segment, maybe a 2 hour maximum seminar that was given in the initial volunteer training. I remember it being about being aware of other people’s beliefs, if we were to be matched up with someone from a different religious background for instance” (VT11, p.1).

There was an element in there called cultural competency, but I’m just trying to remember what it covered....I think that I should probably pull out my binder and remind myself what they trained us on, because I just can’t at the moment, I just don’t recall, I don’t remember it. What it actually covered, I can’t recall. Maybe it will come back to me while we’re talking (VT2, p.1)

2b. Volunteers’ desire for more training on cultural competency

All hospice volunteers expressed a genuine desire for more training on cultural competency. A few of the volunteers stated that training was a good idea in general, but they considered themselves quite culturally competent already, because of their vast travel experiences

and/or higher education, that exposed them to the diversity of cultures. For instance, *“For someone with my background [the training] was adequate. I come from studies in sociology and psychology at university, and also my life experiences, so I’m used to dealing with multi-faith and multi-ethnic people or issues” (VT13, p.2), “Yes, absolutely, I always want more to learn more. You can never learn everything about everyone, so more education is good”.*

No, culture isn’t an issue for me. Toronto is the most multi-cultural city in the world and I’m glad to be living in the city. We’re all essentially the same, so different cultures doesn’t mean anything to me. I feel like a citizen of the world, living in Toronto is a pleasure. I’ve done a tone of traveling and it’s fantastic to see that we have the largest percentage of Chinese people living in Canada, other than in Mainland China, or Hong Kong. I really don’t even know what a “Canadian” is (VT5, p.1).

The theme of experience, whether through traveling, education or internal reflection and spirituality arose, with many volunteers expressing the belief that their travel experiences led them to be more culturally aware of the growing diversity of cultures, and also increased their awareness of different cultures and ethnicities. They expressed their opinions quite thoughtfully in the following quotes.

I can’t really remember it [the training]. You know, I have my own ideas of what cultural competency means from my own experiences. I’ve traveled extensively. I’ve worked with the African-Canadian Legal Clinic. I’ve had various experiences from training. But, ultimately, it’s about people and human beings, and we’re all basically the same, and we all want the same basic things from life. But I guess for me it was adequate. You can teach principles, but ultimately, you learn from experience. A lot of stuff come out of ignorance, people cling to their cultural identities as a way of separating themselves from others. You must be sensitive and open to whatever is there from people. You can do what is required compassionately though (VT12, p.2).

I’m usually just interested in different cultures. I’m more skilled at it, because of my traveling. I’ve lived outside of Canada for 10 years. We can get into that later. I’ve also taken a great course with Evelyn McKay on death and dying and she taught me about the “Universal Prayer”, that has no ethnicity attached to it. I had a client that asked me to pray for him, and I didn’t know how. But after this course, I realized that you just have to say “yes” to the client, and just do an

honouring of that person through the universal prayer. That was a wonderful skill that the hospice didn't provide for us (VT7, p.2).

I've traveled extensively and it's been the best learning experience I've ever had. Canada is a very small country, but it exposes you to all sorts of things that are different about people. I've lived in different cities all over North America, in Chicago, New York, the East Coast, Ottawa, and it's interesting to see how people have different tolerances of expressions. With traveling, I've learned that there's not just one way of doing things. And from my experience, people will tell you what they want and who they are, if you just ask them, and if you've asked them in the appropriate manner. I believe that people want to tell their stories, and their histories, and I feel that I can ask questions to find out more information from the family when I'm with a client, if I need to (VT12, p.2).

Another volunteer with quite vast traveling experiences discussed the role and importance of seeing and experiencing different cultures around the world and the impact that had on being a hospice volunteer specifically, but also in being sensitive and culturally competent in general.

I'm very informed, because I've traveled extensively and lived in various places around the world. I also work with many different culture in my day-to-day job. I've lived in Kaput, lived in communal farms, lived in South East Asia, in the West Coast, the East Coast, in the Yukon. I've lived in Mexico and traveled to South America. I've lived in Europe and I've been in youth travel exchange programs all throughout school. I've lived in Japan as a kid and as a group leader I've lived in India. I'm a child and youth worker, so that's how I've been able to visit so many places. You know, everyone is so concerned about their RSP's these days, and in my time, it was all about the experience, the traveling, meeting new people, new cultures, new places. I was lucky, I was able to work on a contract basis for 6 months or so at a time, and that's how I was able to live in so many different places. I've seen so many different cultures and I've become more sensitive to people as a result of that (VT11, p.2-3).

One volunteer in particular was quite adamant about providing details of her traveling experience, because she felt that her travels in essence shaped her values and understandings of other cultures and ethnicities and allowed her to be a better volunteer.

I have traveled extensively and found that people who travel a lot, tend to care a lot and are interested in other cultures. I've spent 10 years living outside of Canada. I've traveled in Asia, and lived in Australia and Papua New Guinea for 4 years. I've also lived one month of the year in Mexico and I've also lived in France for 3 months. Traveling has taught me to be more aware about death practices, different ways of being, others' spirituality, others' religious practices (VT7, p.4-5).

When asked if she thought that people who had not traveled as much were perhaps hindered in their level of cultural awareness, she answered:

People like to travel to the cottage where it's pleasant and nurturing because the environment is the same. But, I'm not going to place a value judgement on it. Perhaps they're just not as curious as other cultures and people. It also depends on how you travel. If you only travel in 5 star resorts then you're probably going to learn less about the cultures and people there (VT7, p.5).

When asked if they would like further training on cultural competency 13 of the 14 volunteers expressed an interest in it. *"Oh yes, of course. Learning about different cultures is very important, especially for the work what we do. I'm lucky, because I knew about many different cultures, I was married to an Asian man for 10 years, so I got to know about the Asian culture and beliefs quite well"* (VT3, p.2). Others knew they wanted more training, but could not articulate what they needed from the hospice. *"I don't know what else the hospice could do, but yes, I would like more [training on cultural competency]"* (VT8, p.2). Others stated that *"more would always be useful"* (VT10, p.2), *"Yes, more is always better, I'm a life long learner"* (VT11, p.2).

That's a really good question. With the training, it's almost a –it's so intensive, it's almost a whirlwind of information, so probably in some respects yes, if you could focus on each section, but one you get out into the real world, if you do not have a lot of experience with people and also experience with people who are dying and their families, because that's a whole different dynamic–it can be a little frightening and well, scary, it can be scary (VT4, p.2).

When asked if they would like to be better informed about the different cultures and ethnicities of their clients, 13 of the 14 volunteer participants responded positively that they would like more information. The only participant who did not particularly support further training, stated *"At the moment, I don't see a need for it...I don't see them as different as everyone else see them"* (VT5, p. 3). This particular volunteer felt that people share more similarities than differences therefore,

more training on cultural competency was not necessary.

2c. Importance of cultural competency training

Almost all the volunteers (13 out of 14) were unanimous in their belief of the importance of cultural competency training. For instance, *“Yes, Toronto is very diverse, and the clients served by Hospice Toronto reflect this diversity more and more” (VT14, p.2). “Absolutely, especially at a time as important as the end-of-life. It’s very important to recognize the variety of belief systems that exist and do everything you can to support that, to support people’s beliefs, especially at this time in their lives” (VT13, p.2).* Some of the volunteers were very eloquent and their responses were rich with detail.

Absolutely, because, I mean, it’s just, it doesn’t necessarily have to be in Toronto. I mean it’s everywhere you go, in any country you go to, you can find so many different people from different cultures and languages and especially when you’re working with people who are dying, some of those cultural differences. I mean what might not be so relative when you’re going to the grocery store to buy milk and eggs,– I mean, it could be a whole different ball game if you’re interacting with these people in their home, when a family member is dying, because it just brings up cultural issues, that if you’re not from that culture, you may never have even considered, or know nothing about (VT1, p.1)

The volunteers seemed to acknowledge the great diversity of Toronto and their clients and realize the importance of being sensitive to and understanding these different cultures in general, but especially during the dying process where people are more vulnerable. *“Yes, for some people especially. Everyone of us has our own prejudices, no matter where we come from” (VT12, p.2).* *“Absolutely, especially living in such a multi-cultural society and city, we have to be sensitive, especially in that critical time in someone’s life where they are dying, it’s necessary to be sensitive” (VT11, p.2).* For instance, *“It’s so that you don’t offend people accidentally, so that you don’t hurt people’s feelings, or say tactless things”.*

Yes, in a household where someone is dying, absolutely. When dealing with clients and their families, you have to be sensitive. For example, I had a Japanese client that had immigrated to Canada as adults, and although they were Canadianized—they were still very much Japanese, and had Japanese cultural traits. So, being aware of the Asian culture, since I am Korean myself, I was aware of the cultural expectations and norms of household culture, such as talking off your shoes outside. I mean it's surface stressors really, but at least I knew something about the culture (VT10, p.2).

Others were more pragmatic in their assessment of different cultures, and simply tried to avoid any controversial topics so as to not inadvertently offend their clients.

You need to have some sensitivity and know that there are certain areas that you just don't go into. It's inappropriate to get into a heavy discussion on religion with your clients. I started in 1988 with spirituality and have always been interested in that aspect (VT7, p.2).

Another volunteers expressed the same sentiments by stating that:

You're there to relax them, to hang out with them. I refuse to engage in anything remotely controversial or in differences of opinion. I'm only there to help them, and I don't take their "stuff" home with me. When I'm there, I'm there. When I'm gone, then I don't think about it. I try to use the most non-invasive option in every sense of the word (VT5, p.3).

The same volunteer participant felt that cultural competency training was not necessary because people were more alike than they were different.

No, I don't see them as different as everyone else sees them. In essence, we are all the same, and we all want the same things. We want to create a life for ourselves, we want to look after our kids, and we want to do it in a loving and joyful way (VT5, p.3).

2d. Equating being culturally competent with being a better volunteer or citizen

When asked if they thought becoming culturally competent would make them better hospice volunteers, 11 of the 14 volunteers agreed, and some in fact, thought that being culturally competent went beyond the hospice and extended into their lives and made them better people and better citizens of Canada. *"Yes, being culturally competent will make you a better hospice volunteer, and a better citizen of Canada"* (VT14, p.3). *"Yes, it always makes it better [to be more*

informed]. More knowledge and information will make you more sensitive and aware of different cultures” (VT 9, p.2). Another volunteer agreed that cultural competency could technically make you a better volunteer, but cautioned that the most important skills when dealing with culturally diverse people in end-of-life care, are usually innate and can not be taught. “The most important part of what we do as volunteers has to do with having empathy, and either you have it or you don’t. Empathy is something that you’re born with, and if you don’t have empathy, you can be trained in it for your entire lifetime, and you’ll never really get it” (VT11, p.3). Another volunteer echoed the same response, stating that there were clear differences between being taught cultural competency and executing it in real life.

There’s a difference between text-book knowledge and real life. Text-book knowledge doesn’t translate into practical knowledge all the time. You need to engage people in what they need, you can’t get that from a book. It’s all about liberalism and fundamentalism in every religion and culture, –you’re always going to have it, but it’s important to respect what people believe in and they must also respect you. You have to understand that whatever others believe, it isn’t personal. It’s not about us, it’s about the client (VT12, p.3).

Finding #3 - Volunteer participants have valuable knowledge on how to improve cultural competency training

Learning the proper techniques for becoming culturally competent as a hospice volunteer requires the commitment of both the hospice organization and the volunteers to engage in the dialogue, attend educational sessions, and read up on information on their own. When asked if the volunteers had any suggestions that Hospice Toronto could implement for increasing cultural competency, all the volunteers had very specific ideas of training materials and initiatives.

For example,

I think some of the most helpful bits in the training was when other volunteers came in and spoke about their experiences, or when a family member came in

and talked about what an impact it made on their family, their situation, or even some of the written case studies that we looked at. The first-hand experience bits were the most helpful to me and I think could be really helpful for people coming up against cultural scenarios that they haven't encountered before (VT 1, p.4).

For education purposes, 11 of the 14 participants shared an enthusiasm for pamphlets, brochures or hand-outs, or even educational manuals that could list the most useful information on a particular cultural, such as important customs, dates of celebration, dates of remembrance, rituals surrounding death and dying and bereavement issues. *"I also think some type of booklet or handout would be useful for the hospice to give out to volunteers on the major cultures surrounding death and dying"* (VT8, p.3).

I think anything helps, any training helps out. I think pamphlets on different cultures that you might come across would be helpful. I remember when I was teaching ESL they had all these great pamphlets on different cultures, and one thing I remember was that you were never supposed to touch a Cambodian kid on the top of the head, because it had something to do with the spirits. I remember being startled when I read that, because I absolutely wouldn't have known about that before. So there are things that you just wouldn't know, and if we can be prepared and told any of that stuff beforehand—you know we're going there to help these people, we don't want to offend them or hurt their feelings, or accidentally make it more difficult for them (VT3, p.4).

Another volunteer thought having a calendar showcasing the most important dates for a specific culture would be helpful.

Some type of a calendar that showed the most important dates of both celebration and revolution, both sides of the spectrum. Obviously, they haven't have a sheet on every type of ethnic group there is, but you know, the main ones. Chinese, for instance, what are the languages they speak? How about the Eastern European's—even keeping it that broad. I hate watching the news, but I guess in some respects, depending on who your client is, and what is going on in the world, it may, —it can affect your service, depending on how the world news affects them. You know, they may have relatives and family in other places (VT4, p.6).

Many volunteer participants agreed that listening to community minority leaders would be quite helpful. One volunteer thought that the only way to learn is to experience first-hand and cultural competency training is a nice idea but not necessary. *"I don't know. I can only tell people my own*

experience and my successful experiences, and what I've done, but whether that will work for them is unknown" (VT5, p.2). "Bringing in community members from different cultural backgrounds to speak to anyone at the hospice who was interested in learning about different cultures, religions and ethnicities" (VT9, p.2).

I think guest speakers wouldn't be a bad idea, especially from different faiths, to come in and talk to the volunteers to discuss particular challenges, especially when someone is dying. Like those that have AIDS or because whose illnesses may be tied to their ethnicity or sexual orientation—that's difficult, so to have someone come in and talk to the volunteers to give sensitivity training on it would be good, —to put a human face on things (VT13, p.2).

Others wished to hear directly from other volunteers and listen to their experiences.

Bringing in family members to talk to volunteers about cultural differences would be helpful. Also, listening to volunteers who have worked in diverse cultural settings and have overcome obstacles, hearing about their solutions and experiences would be helpful. Any kind of experiential learning is helpful, not just telling us about it, not just hearing about it, but experiencing it (VT11, p.2).

Another volunteer mentioned information over-load, where volunteers could have too much text-book knowledge about cultures that may not even be applicable to the client, depending on their level of acculturation into Canadian society, and how much of their own cultural customs they still practice.

I don't think so, because it's just general information. I don't want to go into a situation with a client with too many general assumptions about their culture and who they are. I'm not going to go into someone's house and bow when I meet them just because they're Japanese, even though that's what the brochure says. But mean while, they haven't been practicing that tradition in years, and now it's an awkward situation. I don't know if there's something that the hospice can really do to better inform us about culture. There's too many diverse cultures out there. I don't know if they have the time or budget to do that (VT6, p.2).

What was most surprising was how detailed the responses were in terms of what volunteers wanted and expected the hospice to provide to increase cultural competency. Their ideas for

training were well thought out, specific and comprehensive in detail. Some preferred to have web-based training available, while others vehemently disagreed with web-based training, and wanted face-to-face interactions, where they could ask questions and listen to speakers themselves. *“I don’t want any web-based training. I want to ask questions and hear the responses in person. I want dialogue with others, I want a face-to-face interaction, nothing to read about, I want to hear it and understand it” (VT11, p.2).* Twelve volunteers thought brochures were a great idea, while one thought any printed material was a waste of money. Either way, volunteers were very particular in their preferences for training and their opinions were well thoughtful and almost itemized in a sense. *“I think that web-based training would be helpful, as would written materials. I probably wouldn’t come to an actual meeting for more specialized training, but I would read the material on-line” (VT12, p.2).*

Perhaps on a bi-monthly, or monthly basis, there could be some on-line training for people who can’t make the get together, or prefer web-based training. But I think that the first training on cultural competency should be a face-to-face interaction so people can ask questions and get issues clarified, and then after that there should be training available on-line (VT11, p.3).

One volunteer suggested raising the consciousness of people as a way of increasing cultural competency.

The most useful techniques would be raising the consciousness of people. Bringing up issues that could possibly come up and how to handle them. The general principle of cultural sensitivity is important to know, and specifically, to know what cues and signals you should be sensitive to. I think the hospice e-newsletter is a good forum. Maybe having a regular feature like “Keep in Mind”, which would point out the important points of cultural competency, and would help keep the message up front so people would remember. I think print brochures are a waste of money. I also think that the regular or irregular hospice get together for the volunteers is a good forum for raising issues. People could bring their experiences to share with other volunteers, of situations that occurred and how to handle them (VT10, p.2).

Thirteen of volunteer participants though, did have very detailed ideas of how they would like to

be supported through further training in cultural competency and their responses show how seriously they take their volunteering and how much thought and effort goes into working with people who are dying. Volunteers in this study showcased a great deal of sensitivity and emotion towards their clients and genuinely wished to improve their level of cultural competency. One volunteer had a great idea of increasing cultural competency that was not previously stated, “...perhaps a course on non-verbal communication skills” (VT 6, p.2).

Others wanted more detailed training.

I find the little hospice meetings where you get to ask questions quite helpful. Perhaps they could bring in some religious heads of different religions to come in and discuss the religious practices, cultural differences. Maybe other volunteers could discuss these things also, to discuss basic principles like numerology, what numbers are lucky or unlucky with certain cultures. Also colors, for instance, the color white in Chinese is the color of death, so being aware or conscious of your dress is important when visiting with clients. Maybe people could be brought in to just discuss some cultural differences or different food choices. It goes without saying that you can't generalize cultures, everyone is unique and different. I think the most important thing is to be present and really listen, those are the most important skills. You have to take their concerns seriously, and don't be dismissive of what they want to say. I think the hospice can certainly pay for more training or courses to take. I think putting resources on the Web is a great idea, that way people can look up the most important cultural differences before they visit with their client. I also think a handbook or a one-page summary on cultures and things that are related to death and dying, or cultural practices would be quite helpful. For instance, issues on religious beliefs, death practices and bereavement. I also wouldn't mind receiving little reminders about different cultures through the web from the hospice, because sometimes we don't even use the resources we know about, so reminders are good. Certain books that deal with different cultures, or articles should be assigned reading for volunteers, and make them available either through the web, or on loan through the hospice library (VT7, p.3).

One volunteer thought that cultural information should be given about the client being matched up with the volunteer, and that information should be disseminated before the first visit with the client. For instance,

I think the hospice needs to give more information about the clients' culture, ethnicity, religion and customs, when they're giving us the initial information about the client. I think that any cultural, religious or ethnic information related

to death and dying would be very helpful to know BEFORE (emphasis by volunteer), visiting with the client. For instance, I have a new client, and I'm going to be reading a lot with this client, and it would be really helpful to know before hand if this client was very religious, or if there were any specific cultural or ethnic things I should be aware about before I start reading to them. For instance, is there anything inappropriate that I shouldn't be reading to them? I think that would be very useful information to know what inappropriate customs to avoid regarding death and dying with your clients. I feel that the hospice just doesn't give enough information about the client other than the basic medical issues, before going into your first visit with a client. I mean, you know their level of mobility, their age, their gender, their name, but that's about it. Everything else, you're left to find out for yourself on your first visit. I would like to know their religion and cultural or ethnic customs to be aware or to avoid (VT8, p.2).

Volunteer participants in this study were keenly aware of the complexities involved not only in death and dying but also with dealing with such a diverse population as the Greater Toronto Area, and their responses expressed a deeper understanding of the intricate layers of disease, illness, family dynamics, culture, diversity, death, dying and vulnerability.

People who volunteer for the dying are a different sort of people already. I think they're probably more open to different experiences. They're a diverse group of people themselves anyhow. I think it's hard to think that the hospice training was lacking in anything, but I think that openness and awareness are key, and it's not based on any one theory or belief. I think hearing about stories from other volunteers would be helpful, what they've experienced in terms of cultural competency. I also think handouts would be useful. I think that web-based training would be helpful, as would written materials. I probably wouldn't come to an actual meeting for more specialized training, but I would read the material on-line. (VT12, p.2).

Finding # 4 - Volunteer participants believe Hospice Toronto is unsupportive of some of their needs

There were quite a three hospice participants who felt Hospice Toronto was unsupportive of their needs, or felt that there were definite changes that needed to be made within the hospice. Volunteers discussed such issues as the hospice not utilizing their time efficiently, not having enough clients to be matched up with the volunteers, not having their questions or concerns answered. This was a surprising finding that warranted its own category

within the analysis.

I think the hospice has been unsupportive of my questions, and instead of saying “I don’t know, but I’ll find out for you”, or “I don’t know, but I can put you in touch with someone who does”, –all I get is unreturned phone calls. But that’s not a judgment of the hospice, I’ve simply lowered my expectations of them, and sought out my own advice. I’ve realized that they are who they are, and I don’t try to make them fit into a mold of who I want them to be (VT5, p.3).

One volunteer asked how many others had participated and when I explained that I was actually having difficulties in recruiting volunteers to be interviewed, she was not surprised. She expressed her concerns as:

Maybe that has to do with the fact that people are really feeling distant from the hospice lately, because they’re not getting clients. If you’re not getting a lot of clients, you don’t really have much to say. I mean I had to go elsewhere to get some more clients, because I felt that the hospice wasn’t utilizing my time efficiently. I mean, I can give a certain amount of time weekly for volunteering and they weren’t using that time, so it was being wasted. Also, maybe people have had run-ins with different cultures and they don’t feel comfortable talking about it, or how they felt about it (VT7, p.4).

Another volunteer thought the hospice was not doing enough to help train volunteers on cultural competency. *“I think that some people are more aware than others of different cultures, but that is something that the hospice needs to be doing to help people with this aspect” (VT 8, p.1)*. Hearing that volunteers were upset with the hospice, or even worse, had lowered their expectations of the hospice is cause for concern. Hospice organizations can not risk alienating their vital volunteer base, without them, non-profit organizations would not exist. The risk involved with unhappy volunteers is lower retention rate, which then cycles into recruiting, hiring and training new volunteers which costs the hospice precious time and money. Volunteers are absolutely essential to the maintenance of community health care agencies, such as hospices. If volunteers are not satisfied, or feel that their time is being wasted, they will look elsewhere to volunteer. Hospices can not alienate their volunteers at a time when

the health care community is in such need and the supply of volunteers can not keep up with the demands for care.

Hospice volunteers are unique in that they willingly choose to work with people who are dying, in situations that are stressful and emotional, knowing that a cure is not an option and that their clients will in fact die. Hospice volunteers are rigorously and uniquely trained in the complexities of death and dying in terms of the medical, social, physical, and emotional support they provide to their clients through their initial thirty hours of hospice volunteer training. It is an absolute investment in humanity for the hospice to train each new volunteer for thirty hours and prepare them in a variety of areas to comfort the dying. Having unhappy volunteers can lead to lower retention rates, higher recruitment and training for the hospice, which necessarily cuts into their already diminished budgets. Communication is the key to retaining volunteers and making them feel like valued members of the community. Ensuring that communication is proficient, entails cultural competency training, so that volunteers enter into culturally diverse situations with the confidence, knowledge and skills necessary to handle any situation that arises.

Finding #5 - The hospice volunteer team is not ethnically, culturally and linguistically diverse

Of the 14 volunteers interviewed for this study 13 of them were White/Caucasian. Hospice Toronto stated in their administrator interview that approximately 80% of their volunteers are White/Caucasian, but admitted that it was a difficult aspect to assess, because they do not require their volunteers to self-identify, nor do they keep a track of the ethnicity or cultural backgrounds of their volunteers. The administrator also pointed out the methodological

issues with using the term “Caucasian”, as it is based on skin color rather than ethnic or cultural background, and someone can actually appear to be White/Caucasian, but in actuality they may self-identify with a completely different ethnicity. Hospice Toronto states that approximately 20% of their volunteers are ethnic and visible minorities, and their volunteers are able to provide linguistic support in 13 different languages (English, Portuguese, Spanish, Cantonese and Mandarin Chinese, Korean, Polish, Hindi, French, Urdu, German, Farsi, and Greek). To date, Hospice Toronto has not been able to provide data on the ethnic composition of their clientele base. One volunteer in the interview actually mentioned the lack of diversity of hospice volunteers as strange, “*It would be nice to recruit more volunteers of different ethnic and cultural backgrounds*” (VT4, p. 6). Finding volunteers to work in the health care sector, for a four hour shift per week, for a minimum of one year is quite difficult in and of itself, but to find volunteers willing to work with people who are dying, and to find volunteers who are ethnically, culturally and linguistically diverse who speak more than one language is a huge feat for the hospice to overcome. This is a challenge that must be taken on by the hospice, and their recruitment techniques should target a more diverse and multi-lingual population, so that they are truly representative of their community.

Finding #6 - Most of the hospice volunteers are not religious

Almost all the previous research on hospice volunteers has found that the majority tends to be religious, but this particular study did not support that finding (Caldwell and Pearson-Scott, 1994; Caldwell and Pearson-Scott, 1996; Roessler, Carter, Campbell, and MacLeod, 1999; Claxton-Oldfield et al., 2005; Claxton-Oldfield and Claxton-Oldfield, 2007). When

asked if they considered themselves to be religious, 11 of the 14 volunteers stated that they were not religious at all. Their answers ranged from: *“No, I’m not religious, I’m a spiritual atheist”* (VT1. Q:2), *“No, I went 40 years without attending Church”* (VT3. Q: 2), *“No, I’m not religious at all”* (VT6. Q: 2) and *“No, I had a very strong religious upbringing and education, but I’m not a believer now”* (VT2. Q:2) The three volunteers that considered themselves religious stated *“Yes, I’m religious, although I am not attached to any one particular Church or denomination, I do participate in Church services on a fairly regular basis”* (VT4. Q:3), and *“Yes, I am a practicing Christian”* (VT10. Q: 2), and finally, *“Yes, I’m religious. I’m spiritual. I believe in God and a higher power, and principles like the Golden Rule”* (VT14. Q:2) Many of the volunteers wanted to make a distinction between being religious and being spiritual. Being religious for many in the study, represented a lack of spirituality, so their answers reflected this: *“No, I’m not religious, but I am spiritual. I believe in the existence of God, but not in organized religion”* (VT11. Q: 3), *“I’m spiritual, not religious. I don’t believe in organized religion and its hierarchy, I’ve been there and done that. I go to Unity Church or the Center for Conscious Living”* (VT5. Q:2), *“No, I’m not religious, but I believe in spiritual practices that are Buddhist based”* (VT12. Q:2), *“I’m not religious, but I’m a person of faith”* (VT9. Q: 2), *“No, I’m not religious, but spirituality is my life”* (VT7. Q:2). The three volunteers who described themselves as religious also attended a place of worship, *“Yes, I attend Church weekly”* (VT10. Q: 2), *“Yes, I attend a place of worship, but not on a regular basis”* (VT14. Q:2), and *“Usually I get to Church once or twice a month”* (VT4, Q:2).

Although most of the previous hospice palliative care research was done in the United States and their levels of religiosity are higher, the Canadian data (Claxton-Oldfield, 2005; Claxton-Oldfield et al., 2007) also confirmed that hospice volunteers tend to be religious but my

study in fact, did not support these findings. The majority of volunteer participants were adamant about stating their non-religious nature, even if they considered themselves to be spiritual.

4.6 Theoretical Sociological Contribution

This research contributes to the field of sociology by examining the role between culture, race and health care status. Culturally competent care is one of the ways to reduce social exclusion towards minorities. By exploring the dynamics of the experiences of being excluded, or not fully participating in the health care system, this study has shown that cultural competency is vital for health care agencies and providers, and must be a core value for each institution.

Minorities suffer cultural and linguistic barriers when trying to access competent end-of-life care. These barriers include health care staff and volunteers who are inadequately trained in cultural competency, who lack the linguistic abilities to communicate in languages other than English and French, and whose breadth of knowledge regarding different cultural beliefs and attitudes towards death and dying are weak, if not completely lacking. Future research in this area of social exclusion and minority health will benefit from a conceptual framework that addresses race, culture, health and end-of-life issues. People's cultural values and beliefs differ greatly in terms of their desires for pain relief, power of attorney, denial or acceptance of their disease, how they perceive their illness, the role of family members and last rites and organ donations. Ignoring cultural worldviews at the most tender and vulnerable period of one's life is unnecessary and only serves to heighten the stress and anxiety of the clients, their family and the health care providers.

Providing culturally competent care for minorities during the end-of-life is one of the ways to reduce social exclusion and can boost the confidence and knowledge of health care

providers, giving them the necessary skills and education to competently handle any situation, regardless of language, culture, or ethnicity.

Chapter 5: Conclusion

5.1 Recommendations

It is possible to adequately train both hospice volunteers and staff, along with health care providers, such as hospitals and hospices, to become culturally competent. To do so, requires a commitment from individuals and agencies to assess their internal values, to be open to learning, and be willing to make the time to create positive changes. To foster an environment conducive to learning, and to prepare people to be culturally competent, individuals and agencies must begin to bear the responsibilities for this change to occur. Policies need to be implemented and monitored, and people need to have the resources and tools to enable them to achieve cultural competency. To achieve this level of awareness and knowledge certain recommendations are given below. I have divided them into two groups: individual recommendations and agency recommendations.

Volunteer Recommendations

Individual volunteers working for health care providers such as hospitals or hospices need to access their own internal values, belief systems, attitudes, judgments and worldviews (Lyke & Colon, 2004, p. 132-133). Volunteers need to accept personal responsibility for learning about different cultures and ethnicities since they have volunteered to work with such a diverse public, as those found in the GTA. Through the assistance of the hospice, volunteers should be able to access on-line resources, attend lectures by cultural specialists, or borrow literature from the hospice.

Volunteers in this study, and in previous research (Pearson, Scott & Caldwell, 1996, p.24;

Colon & Lyke, 2003, p.189), have expressed their preferences for increased training on cultural competency and refresher courses or training modules to be given on a regular basis on a variety of topics pertaining to hospice care. Volunteers would also benefit from building stronger relationships with their colleagues by having on-line chat rooms, or discussion boards to talk about difficult situations or clients, to ask questions and give or receive advice in a friendly environment. Having on-line resources that are available to download, such as, literature and research on cultural competency in particular and topics surrounding death and dying in general, would be a simple and convenient opportunity to enhance volunteer confidence and effectiveness. Having an interactive forum where volunteers can log on to the hospice website to watch ‘hospice episodes’ of lectures, other volunteers speaking, specialists discussing pertinent hospice issues, or hospice staff discussing policy and procedures would also be helpful and cost-effective. Having an interactive website that allows volunteers to email, phone or ‘skype’ (free software that allows users to make phone calls over the internet) in to discuss issues creates the beginning of effective communication, allowing volunteers to access the training at a time and place convenient for them.

Volunteers from previous research (Pearson, Scott and Caldwell, 1996, p.24) and also this study, have mentioned the value of listening to first hand accounts from other volunteers about difficult situations or clients, so that they may personally hear how someone handled a situation and are able to ask questions. Volunteers would also appreciate hearing from minority volunteers, staff and community leaders about topics specific to death and dying or end-of-life care related to different cultures.

Agency Recommendations

For health care providers to represent the diverse community they serve, by increasing

cultural competency, recommendations are made based on four aspects of hospice **training**:

1) Volunteer support; 2) internal changes; 3) training; and 4) community outreach.

1) Volunteer Support

The research is consistent in describing the importance of valuing and satisfying and even meeting the expectations of volunteers. If volunteers are satisfied with their work and feel valued and appreciated, they are less likely to leave. Decreasing volunteer turn-over saves money, time and resources for the hospices (Chevrier, Steuer, and MacKenzie, 1994, p.35). Volunteers need to feel as if they are making a difference, that they are appreciated, valuable and unique individuals. Ensuring that volunteers are consistently reminded of their value and contribution to patients, the community and the hospice, will secure their longevity as happy hospice volunteers, and save health care providers money and time in both recruitment and training (Chevrier, Steuer and MacKenzie, 1994, p.4-5). Volunteers need to be engaged with their colleagues and feel connected. They would benefit by creating stronger bonds or alliances with their fellow volunteers. Whether that is through volunteer specific forums, such as discussion boards or chat rooms, or mentoring programs, volunteers truly need that human touch, to keep them engaged.

One of the findings from my study revealed that some volunteers felt unsupported by the hospice. They felt that either their questions or concerns were being ignored, or that their time was being wasted as there were not enough patients for the volunteers to be matched up with. Alienating the valuable volunteer base of a hospice can have disastrous consequences for lowering morale and decreasing loyalty, which can very easily lead to apathy and a high desertion rate. Hospices must make it a priority to keep their volunteers engaged, involved and must strive to answer all questions and concerns within a timely manner. Hospices must make sure their volunteers feel appreciated and supported or else they will risk losing them.

2) Internal Changes

Hospices need to make a commitment from the front lines by ensuring that their staff and volunteers are culturally and ethnically diverse themselves and can accurately reflect the community they serve. Communication and services must be provided in a variety of different languages (Field, Maher and Webb, 2002, p.541-542). Looking within, hospices must evaluate and assess their belief systems in general, but specifically the beliefs of their staff and volunteers (Lyke and Colon, 2003, p.189). Hospice administrators must assess the level of awareness, sensitivity to and competency of different cultures from their own staff and provide regular progress reports, and develop training initiatives to ensure recommendations are being followed.

There should be increased funding made available to create a new board or committee on cultural competency (Field, Maher and Webb, 2002, p.189). This committee should be responsible for handling all cultural competency issues, such as; training of staff and volunteers, analyzing the training techniques and modules; developing a mission statement; establishing goals and “a plan of progress on how to tackle cultural competency” (Ibid). This new mission statement should reflect the core values of the hospice and all training material and brochures should feature this statement.

The status quo in hospices regarding funding, research, training and support should no longer be deemed acceptable. Hospice staff, administrators and volunteers should push the boundaries and demand more of themselves and their work. Hospices and all those who work for them, do a great service to the community by giving of their time to help those in need, but going about “to just get the job done” as Giblin remarks (2002), can have lasting repercussions for the “spirit of the hospice” (p.239). The bar must be raised so that we are all continually growing, learning and supporting the community we work and live in. With the incorporation of

increased research, training, education, funding and a commitment to better ourselves, the learning curve will never cease.

3) Training

To improve the cultural competency of their staff and volunteers, hospices must engage people with innovative training techniques and incorporate training modules on a consistent basis. Beginning from the initial volunteer training program, cultural competency must be introduced in an in-depth manner. Volunteers should have the opportunity to learn about cultural competence and the importance of respecting and valuing diversity through modern training exercises, including visuals, media, lectures, written material, webcasts, on-line training, discussion boards, regular meetings, role-playing, and short skits and listening to first-hand experience from fellow volunteers, minority leaders and cultural competency specialists. Volunteers must be given the necessary tools to continually learn, assess and re-assess their skills and knowledge about the importance of servicing diverse clients in the GTA in a culturally competent manner. It is evident from the findings that the majority of volunteers could not remember if they were trained on cultural competency, or what the training entailed. Not being able to remember if they were trained on cultural competency means the training was not adequate and needs to be given on a regular basis.

4) Community outreach

Advertisements about hospice services such as brochures should be accessible in major community centers in different languages to continuously attract new clients while affirming continuity and trust in the community. Brochures and pamphlets should be made available in Churches, community centers, walk-in-clinics, libraries and hospitals. It is important for hospices

to increase the recognition of their services in the community by creating stronger relationships with minority community leaders and centres. Alliances should be formed so that community members feel safe, comforted and respected by the competent community health care services provided by the hospices (Field, Maher and Webb, 2002, p.541-542; Lyke and Colon, 2004, p.132-133).

5.2 Future Trends

There is a paucity of research on the implementation of culturally competent healthcare policies. The future of cultural competency in health care research must deal with additional research on a multifaceted level of issues. There needs to be further supplementary quantitative and qualitative research. This research must look at various levels of interactions between health care providers and recipients of care. Research is needed from not only a nursing perspective (which dominates the field), but from the viewpoint of doctors, volunteers, staff and administration members, -- but most importantly, research needs to focus on the patient's vantage point. We need to hear from the people who will benefit most directly and immediately from culturally competent initiative and policies. Having said that,--there needs to be comparative research detailing the consequences of implementing culturally competent measures within a health care agency or institution, and the success or failures of these measures.

The current research on cultural competency focuses on four main areas:

1. Definitions of cultural competency and its importance for health care systems (Cross 1989; Isaacs 1998; NCCC; OMHRC);
2. Theoretical frameworks (Camphina-Bacote, 2002; Cross, 1989; Isaacs, 1998; Giger and Davidhizar, 2002; Leininger, 1978; Purnell, 2000);

3. Culturally competent barriers and/or techniques: usually nine are cited – interpreter services; recruitment and retention; training; coordinating with traditional healers; use of community health workers; culturally competent health promotion; including family and/or community members; immersion into another culture; and administrative and organization accommodations- (Brach & Fraser, 2000, p.183-187; Fong and Gibbs, 1995; Anderson et al., 2003); and
4. Racial and ethnic health disparities (Chin et al 2007; Mayberry, Mili, and Ofili 2000; Tseng and Streltzer 2008; Weinick et al., 2000; Yang and Kagawa-Singer 2007).

What is missing from this field of data is the aftermath of implementing culturally competent health care measures. When culturally competent techniques are enforced, does that necessarily lead to better health outcomes for patients or clients? If so, how are culturally competent policies and progress measured within agencies or institutions? I believe future trends on cultural competency must focus on the follow seven key issues:

1. Definitions- each health care agency and/or discipline defines cultural competency somewhat differently. There needs to be a unifying definition when dealing with health care. Instead, we have mental health perspectives, nursing perspectives, psychological perspectives, and child welfare perspectives. If it is impossible to use a consistent and agreed upon definition, then a separate definition of cultural competency for hospice palliative care must be used.
2. Measurement Issues- how is it measured? Who measures it? Is it valid? Is it reliable? Is it biased? How is progress measured within an agency? How do you enforce implementation? Is it possible to enforce policies, mission statements and/or procedures on cultural competency? (Geron 2002/03, p.42). If an agency has culturally competent policies, it does not necessarily mean that they are being implemented or that cultural competency has

become a reality within that particular agency. Also, if an agency does not have culturally competent mission statements, it does not mean they are not practicing it. It is important to know which of the culturally competent techniques (interpreter services, training of staff) actually improve “cultural competency, health outcomes, and increase efficacy and efficiency, etc.?” (Geron 2002/03, p.43). Are the measures reliable? How do you measure progress or improvement of culturally competent techniques? Once culturally competent policies are put into place, what happens if they are not enforced? Are there penalties or consequences for lack of implementation? If so, who enforces it?

3. Payment – who pays for training of the staff members and volunteers? Who pay for the printing of new materials, DVDs, CDs, brochures, training and workshops, booklets, books, and magazines or journals? Who pays for translator services? Is it the fiscal responsibility of the individual agencies and institutions, or provincial and/or national responsibilities?
4. Responsibility –where does it rest? Is there any personal responsibility for the patient to try to have their own translator on hand and medical documents up to date? Does the patient bare any responsibility to let staff know ahead of time of their cultural preferences? Is the responsibility with the hospital or with minority community leadership, Churches, or organizations to assist in implementing culturally competent health care practices?
5. Assessment Tools/Conceptual Frameworks – again this requires a unifying measure. Assessment tools, checklists, and appraisals should be standardized. Cultural competency is a complex subject and needs multi-level constructs, but each agency has different checklists, which makes for confusion when attempting to assess skill levels or competencies in cultural awareness for health care providers.

6. Patient perspectives: this is the most important category. What do the patients think? Can they tell if an agency is culturally competent? What do they seek from their health care providers? Do patients have any suggestions for improving the system to make it more culturally competent? To date, there have been no studies researching the viewpoint of hospice patients regarding cultural competency.
7. Training: where does it start? It is too late to train health-care providers, specialists and professionals once they have already achieved their degrees and diplomas. The training should begin in undergraduate and graduate schools, in medical schools, in undergraduate textbooks for nurses, social workers, and other specialists. Training on cultural competence should be taught in all health-related volunteer agencies and minority communities. Training should not be a one-time thing—training needs to be continuous and taught on a regular basis. Consideration should be given to who is handling the cultural competency training. It should always be given by cultural competency specialists. There should always be training materials on hand in any given health care agency. People who need answers on cultural competency should know where to go within their own agency to find it. There should be books, articles, DVDs and CDs on reserve, so that anyone can read them, borrow them, and/or photocopy them. As can be shown from the above list, cultural competency within health care has many shortcomings and future trends must focus on filling in the gap so that definitions are standardized, assessments tools and checklists are uniform, policies are easily implemented, and progress is monitored in a timely and efficient manner.

5.3 Limitations of the Study

The main limitations of this study are the small sample size with only 14 individual volunteers and 1 administrator participating. The original desire to have a focus group never materialized because the response rate was low and out of a possible 168 volunteers only 14 participated. Although having a focus group would have enriched the data and allowed for a comprehensive discussion on cultural competency issues with hospice patients, -it is something that will need to be addressed in future research. With people living such over-scheduled and hectic lives, it is quite difficult to get a small group of people together on the same day, time and location for a focus group discussion. Perhaps using monetary incentives in the form of gift cards for the future recruitment of participants should be employed. To reduce costs, no incentives were given for this study. As such, the small sample size of hospice volunteers in the Greater Toronto Area can not be representative of the general public, hospice volunteers across Canada or minority patients using hospice services. Also, the case study nature of this research is perhaps not generalizable to other hospices either in Ontario or across Canada. Future research would benefit from a comparative look at numerous hospices in rural and suburban areas, palliative care wards in hospitals and long-term care facilities, free-standing hospices and home-based hospice care.

Because of time constraints I did not interview patients, but they could be a valuable resource hospice research. In fact, the ethical dilemmas of incorporating hospice and palliative care patients into research always center on issues of free will, informed consent and unnecessary burden during the dying process. Challenges such as obtaining informed consent, involving family members, location of interviews, and unmerited suffering, usually prohibit the use of palliative care patients as a sample group in research (Jubb, 2002, p.343). Future studies would

greatly benefit from the participation of palliative care patients, through the assistance of gentle and humane researchers (Ibid).

It is hoped that by funding this type of ground work future investigations will be encouraged to expand the knowledge of hospice and palliative care research. There are a plethora of possible avenues to research, including a larger sample size of hospice volunteers, comparative studies between home-based hospices and those in hospitals, and longitudinal studies analyzing cultural competency training over time are all deserving of further attention.

5.4 Conclusion

The demographics of the greater Toronto area are dramatically changing as the city has the highest number of visible minorities in all the metropolitan areas in Canada (Statistics Canada, 2006, p.29). Almost 43% of the Toronto population are visible minorities and the health care sector must be able to competently and respectfully handle their health care needs. To do so requires health care agencies and individuals to begin the journey of becoming culturally competent. This necessitates that they have the proper skill sets, tools and knowledge to train, educate and self-reflect on the processes of working with such a multi-cultural, multi-lingual, multi-ethnic and multi-religious population.

Culture is all-encompassing, pervading every aspect of someone's life, and influencing their health care decisions, so it is incumbent upon the health care community to be able to handle the various cultural and linguistic demands made on them from their diverse clientele base. The health care agencies must be representative of the populations they serve by practicing what they preach, and making sure that their own staff is culturally diverse, multi-lingual, and capable of dealing with a vast array of cultures and their individual health care needs.

Culture and health care intersect at the most vulnerable and stressful times during end-of-life care. Cultures vary in how they perceive illness, how they choose to prevent or handle their illness, how they view death and dying and all the rituals involved in that process. Cultures also vary in how they access community health care services and how they perceive those services to be. The health care community must be able to provide visible minorities with equal access to end-of-life care services enriched with staff and volunteers who are culturally competent and respectful.

The main objective of this research was to analyze the current status of culturally competent care in a hospice in Toronto. This study showed the strengths and limitations of current hospice care and reviewed the challenges in providing culturally competent care providers. Policy recommendations are aimed to increase the awareness of cultural competency within hospices and the general health care community.

Hospice palliative care research in cultural competency is important because of the current dearth of research in this field, especially a lack of Canadian data regarding hospice volunteers and cultural competency. Second, this research is significant because of the changing demographics of Canada in general, and Toronto specifically Third, ethnic minorities under-utilize hospice palliative care services, and it is crucial that services become equally available and accessible to all cultures and ethnicities within the city of Toronto. Canada has a duty as laid out in the Canadian Multiculturalism Act to “preserve culture, reduce discrimination, enhance cultural awareness and understanding, and promote culturally sensitive institutional change” (Canadian Heritage, 2002-03).

By integrating a social determinants of health theory with social exclusion, it has been shown that cultural competency is one of the ways to reduce social exclusion of minorities.

Social exclusion is a process of inequality that prevents visible minorities from accessing and acquiring the same types of health care services as non-minorities. These inequalities manifest themselves as cultural and linguistic barriers, stereotyping, biases and racism that disproportionately affect visible minorities (Galabuzi, 2002, pp.1-3).

The relationships between race, culture and exclusion have not been adequately addressed in the literature and it is the reason for conducting this case study of cultural competency within hospice care. This research is the first step in bridging that knowledge gap and creating sustainable future policy recommendations that will decrease the inequalities minorities encounter when attempting to access hospice palliative care.

APPENDIX A: RECRUITMENT POSTER

Department of Sociology
University of Waterloo

PARTICIPANTS NEEDED FOR RESEARCH IN CULTURAL COMPETENCY IN PALLIATIVE CARE

We are looking for volunteers to take part in a study of the current status of cultural competency (ability to work effectively with individuals from different cultural, ethnic, religious and linguistic backgrounds) within a hospice setting.

We are looking for 10 volunteers to participate in a self-administered questionnaire, followed by an in-depth interview, and 5 volunteers to participate in a focus group, involving a self-administered questionnaire and in-depth interview.

Your participation would involve one session, which is approximately 60 minutes, consisting of a 15 minute self-administered questionnaire, and a 45 minute in-depth interview.

The self-administered questionnaire will ask very general demographic questions and the in-depth interview will focus on your experiences working with multi-cultural, multi-faith, multi-lingual and multi-ethnic clients within the hospice setting.

All interviews will be tape-recorded for accuracy purposes, only with the permission of the participants.

For more information about this study, or to volunteer for this study, please contact:

Maja Jovanovic
Department of sociology
at 519-888-4567 Ext. 37768 or cell 416-399-2667
Email: m2jovano@uwaterloo.ca

This study has been reviewed by, and received ethics clearance through, the Office of Research Ethics, University of Waterloo.

APPENDIX B: LETTER OF INFORMATION

University of Waterloo

Date: Wednesday, January 23rd, 2008

Dear Hospice Toronto volunteers and/or administrator

Thank-you fro your interest in participating in a study I am conducting as part of my Master's degree in the Department of Sociology at the University of Waterloo under the supervision of Professor Dong. I would like to provide you with more information about this project and what your involvement would entail if you decide to take part.

As the population demographics change in the greater Toronto area, our health care and health care services must compliment these rapid changes and be flexible and accessible enough to allow for further growth. Educating health care practitioners on increasing their awareness of cultural competency can promote tolerance, acceptance and respect for people of different cultures, religions and ethnicities. Cultural competency is defined as the "ability to work effectively with individuals from different cultural and ethnic backgrounds, or in setting where several cultures coexist. It includes the ability to understand the language, culture and behaviours of other individuals and groups and to make appropriate recommendations" (Chin, 2000). Data has shown that ethnic minorities underutilize health care services such as hospices, and since the dying process is a stressful period when feelings of isolation, vulnerability and anxiousness can be amplified when cultural competency is weak, in is incumbent upon the health care community to effectively deal with this pressing issue.

There is a need for the health care system to catch up to the changing demographics and promote cultural competency as a core paradigm within all medical training facilities, undergraduate and graduate programs, social work degrees and volunteer training sessions. Incorporating cultural competency as a core paradigm means a full-time commitment to become familiar with other cultures, languages, beliefs, customs, religions and spirituality, and to effectively deliver health care for all segments of the population, not just the most dominant ones. The purpose of this study, therefore, is to discover what the current status of culturally competent care is in a hospice setting.

This study will focus on the measures employed in recruiting, training and retaining volunteers within the hospice, and also the challenges to providing culturally competent care in a hospice in the GTA, and what policy recommendations or strategies can be developed for increasing cultural competency within a hospice. Therefore, I would like your input as a valuable member of either the volunteer or administrative team with Hospice Toronto to be involved in my study. I believe that because you are actively involved in either the volunteering or administrative duties of Hospice Toronto that you are best suited to speak to the various issues, such as wither or not volunteers receive training on cultural competency, or whether you believe it is an important aspect of providing health care services to the public.

Participation in this study is voluntary. It will involved an interview of approximately 60 minutes in length to take place in a mutually agreed upon location. You may decline to answer any of the items on the self-administered questionnaire or any of the interview questions if you so wish. A total of 10 volunteers are needed to take part in a 15-minute self-administered questionnaire followed by a 45 minute in-depth interview. An additional 5 volunteers are needed to participate in a 15 minute self-administered questionnaire and a 45 minute focus group in-depth interview. Lastly, 2 administrative volunteers from the board or staff at Hospice Toronto are needed to participate in a 15 minute self-administered questionnaire, followed by a 45 minute in-depth interview. The self-administered questionnaires focus on general demographic questions while the in-depth interviews will focus on your experiences in working with multi-cultural, multi-faith, multi-lingual and multi-ethnic clients within your work and experience with Hospice Toronto.

You may decide to withdraw from this study at any time without any negative consequences by advising your researcher. With your permission, the interviews will be audio-recorded to facilitate collection of information, and later transcribed for analysis. Shortly after the interview has been completed, I will send you a copy of the transcript

to give you an opportunity to confirm the accuracy of our conversation and to add or clarify any points that you wish. All information you provide is considered completely confidential. Your name will not appear in any thesis or report resulting from this study, however, with your permission anonymous quotations may be used. Once an interview is complete it will be transcribed and deleted within 48 hours. Also note that no identifying information will appear on the transcripts. Data collected during this study will be retained electronically for five years in a locked filing cabinet in my supervisor's office. Only researchers associated with this project will have access. There are no known or anticipated risks to you as a participant in this study. It should be noted that a decision to not volunteer or to volunteer and subsequently withdraw from the study will have no negative consequences on the person's relationship with Hospice Toronto.

Since the sample size of administrators involved in this study is only 2, confidentiality can not be ensured.

I will provide a copy of the executive summary with participants and the Board of Directors at Hospice Toronto, once the data has been collected, transcribed, and analyzed. I will also provide either participants or the Board of Directors with the final written report, if they so choose. This will be provided at the completion of my M.A. thesis, this summer, August 2008.

If you have any questions regarding this study, or would like additional information about the research please contact me on my cell: 416-399-2667 or by email at m2jovano@uwaterloo.ca. You can also contact my supervisor, Professor Dong at 519-888-4567 ext. 37768 or email weizhen@uwaterloo.ca

I would like to assure you that this study has been reviewed and received ethics clearance through the Office of Research Ethics at the University of Waterloo. However, the final decision about participation is yours. If you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes of this office at 519-888-4567 ext. 36005.

I hope that the results of my study will be of benefit to those organizations directly involved in the study, other voluntary recreation organizations not directly involved in this study, as well as to the broader research community.

I very much look forward to speaking with you and thank-you in advance for your assistance in this project.

Yours Sincerely,

Maja Jovanovic

APPENDIX C: CONSENT FORM

CONSENT FORM

I have read the information presented in the information letter about a study being conducted by Maja Jovanovic under the supervision of Professor Weizhen Dong of the Department of Sociology at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions, and any additional details I wanted.

I am aware that I have the option of allowing my interview to be audio recorded to ensure an accurate recording of my responses.

I am also aware that excerpts from the interview may be included in the thesis and/or publications to come from this research, with the understanding that the quotations will be anonymous.

I was informed that I may withdraw my consent at any time without penalty by advising the researcher.

This project has been reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. I was informed that if I have any comments or concerns resulting from my participation in this study, I may contact the Director, Office of Research Ethics at 519-888-4567 ext. 36005.

With full knowledge of all foregoing, I agree, of my own free will, to participate in this study.
 YES NO

I agree to have my interview audio recorded.
 YES NO

I agree to the use of anonymous quotations in any thesis or publication that comes of this research.
 YES NO

Participant Name: _____ (Please print)

Participant Signature: _____

Witness Name: _____ (Please print)

Witness Signature: _____

Date: _____

APPENDIX D: PARTICIPANT FEEDBACK LETTER

University of Waterloo

Cultural Competency in Hospice Care: A Case Study of Hospice Toronto

Supervisor: Dr. Weizhen Dong.

Date: Wednesday, January 23rd, 2008

Dear Hospice Toronto volunteer and/or administrator

I would like to thank you for your participation in this study. As a reminder, the purpose of this study is to identify the current status of culturally competent care in a hospice setting; and to find out what measures are employed in recruiting, training and retaining volunteers in the hospice; and to provide any recommendations or strategies for increasing competency within a hospice setting.

Please remember that any data pertaining to you as an individual participant will be kept confidential. Once all the data are collected and analyzed for this project, I plan on sharing this information with the research community through seminars, conferences, presentations, and journal articles. If you are interested in receiving more information regarding the results of this study, or if you have any questions or concerns, please contact me at either the phone number or email address listed at the bottom of the page. If you would like a summary of the results, you can indicate this now or at a later date by providing me with your email address. When the study is completed, I will send it to you. The study is expected to be completed by May 30th, 2008.

As with all University of Waterloo projects involving human participants, this project was reviewed by, and received ethics clearance through, the Office of Research Ethics at the University of Waterloo. Should you have any comments or concerns resulting from your participation in this study, please contact Dr. Susan Sykes in the Office of Research Ethics at 519-888-4567, Ext. 36005.

Maja Jovanovic

University of Waterloo
Department of Sociology

Cell 416-399-2667

m2jovano@uwaterloo.ca

Table 4. Permanent Residents by Top Source Countries and Regions

Source countries	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
& regions	Number									
China, People's Republic of	18,526	19,790	29,148	36,750	40,365	33,307	36,256	36,429	42,292	33,080
India	19,615	15,375	17,457	26,123	27,904	28,838	24,593	25,575	33,148	30,753
Philippines	10,872	8,184	9,205	10,119	12,928	11,011	11,989	13,303	17,525	17,717
Pakistan	11,239	8,089	9,303	14,201	15,354	14,173	12,351	12,795	13,575	12,332
United States	5,030	4,776	5,533	5,828	5,911	5,294	6,013	7,507	9,262	10,943
Iran	7,486	6,775	5,909	5,617	5,746	7,889	5,651	6,063	5,502	7,073
United Kingdom	4,657	3,899	4,478	4,649	5,360	4,725	5,199	6,062	5,865	6,542
Korea, Republic of	4,001	4,917	7,217	7,639	9,608	7,334	7,089	5,337	5,819	6,178
Colombia	571	922	1,296	2,228	2,967	3,226	4,273	4,438	6,031	5,813
France	2,858	3,867	3,923	4,345	4,428	3,963	4,127	5,028	5,430	4,915
Sri Lanka	5,071	3,329	4,728	5,849	5,520	4,968	4,448	4,135	4,690	4,490
Romania	3,916	2,976	3,468	4,431	5,589	5,689	5,466	5,658	4,964	4,393
Russia	3,735	4,304	3,782	3,523	4,073	3,677	3,520	3,685	3,607	2,851
Taiwan	13,324	7,193	5,483	3,535	3,114	2,910	2,126	1,992	3,092	2,823
Hong Kong	22,250	8,087	3,672	2,865	1,965	1,541	1,472	1,547	1,783	1,489
Yugoslavia (former)	1,384	1,172	1,492	4,745	2,803	1,623	941	708	272	126
Top 10 source countries	118,070	87,490	98,461	121,520	134,285	123,228	119,055	123,757	144,449	135,346
Other countries	97,968	86,705	91,496	105,939	116,356	105,823	102,296	112,067	117,790	116,303
Total	216,038	174,195	189,957	227,459	250,641	229,051	221,351	235,824	262,239	251,649

Source: www.cic.gc.ca/english/resources/statistics/facts2006/overview/01.asp

Table 5. Permanent Residents by Top Source Countries and Regions in Percentages

Source countries	1997	1998	1999	2000	2001	2002	2003	2004	2005	2006
& regions	Percentage distribution									
China, People's Republic of	8.6	11.4	15.3	16.2	16.1	14.5	16.4	15.5	16.1	13.2
India	9.1	8.8	9.2	11.5	11.1	12.6	11.1	10.8	12.6	12.2
Philippines	5.0	4.7	4.9	4.5	5.2	4.8	5.4	5.6	6.7	7.0
Pakistan	5.2	4.6	4.9	6.2	6.1	6.2	5.6	5.4	5.2	4.9
United States	2.3	2.7	2.9	2.6	2.4	2.3	2.7	3.2	3.5	4.4
Iran	3.5	3.9	3.1	2.5	2.3	3.4	2.6	2.6	2.1	2.8
United Kingdom	2.2	2.2	2.4	2.0	2.1	2.1	2.4	2.6	2.2	2.6
Korea, Republic of	1.9	2.8	3.8	3.4	3.8	3.2	3.2	2.3	2.2	2.5
Colombia	0.3	0.5	0.7	1.0	1.2	1.4	1.9	1.9	2.3	2.3
France	1.3	2.2	2.1	1.9	1.8	1.7	1.9	2.1	2.1	2.0
Sri Lanka	2.4	1.9	2.5	2.6	2.2	2.2	2.0	1.8	1.8	1.8
Romania	1.8	1.7	1.8	2.0	2.2	2.5	2.5	2.4	1.9	1.8
Russia	1.7	2.5	2.0	1.6	1.6	1.6	1.6	1.6	1.4	1.1
Taiwan	6.2	4.1	2.9	1.6	1.2	1.3	1.0	0.8	1.2	1.1
Hong Kong	10.3	4.6	1.9	1.3	0.8	0.7	0.7	0.7	0.7	0.6
Yugoslavia (former)	0.6	0.7	0.8	2.1	1.1	0.7	0.4	0.3	0.1	0.1
Top 10 source countries	54.7	50.2	51.8	53.4	53.6	53.8	53.8	52.5	55.1	53.8
Other countries	45.4	49.8	48.2	46.6	46.4	46.2	46.2	47.5	44.9	46.2
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0

Source: www.cic.gc.ca/english/resources/statistics/facts2006/overview/01.asp

Appendix E: Participants Demographic Information

Volunteer and Gender	Age	Marital Status	Race	Languages Spoken	Religious Affiliation	Education	Income	Previous Hospice Volunteer Experience	Reason for Becoming Hospice Volunteer	Distance Traveled for Shifts
VT1- Female	33	Married	White	English	None	University	\$51,000 +	None	Loss	10 min.
VT2- Female	67	Divorced	White	English & French	None	M.A.	\$51,000 +	None	Loss	45 min.
VT3- Female	75	Married	White	English & French	None	University & L.L.B.	\$21,000 +	None	Education	5-30 min.
VT4- Female	50	Divorced	White	English	Yes - United or Spiritualist	University	Not Stated	None	Loss	45-60 minutes.
VT5- Male	72	Divorced	White	English	None	Grade 8	\$70,000 +	None	Education & reflection	30-45 minutes.
VT6- Male	31	Married	White	English	None	3 rd year of B.A.	\$21,000 +	Yes	Education & reflection	5-20 minutes.
VT7- Female	63	Widow	White	English	None	M.A.	\$51,000 +	None	Loss & reflection	45-90 minutes.
VT8- Female	32	Single	White	English	None	M.A.	\$31,000 +	None	Loss, reflection & giving back	20 minutes.
VT9- Female	54	Divorced	White	English	None	High School	\$21,000 +	None	Loss	20-30 minutes.
VT10- Female	46	Single	Korean	English & Korean	Yes-Christian	University	\$61,000 +	None	Education & reflection	30-60 minutes.
VT11- Male	57	Married	White	English	None	University	\$70,000 +	None	Reflection & giving back	1 ½ -2 hours.
VT12- Female	42	Single	White	English & French	None	M.A.	\$41,000 +	None	Loss, education & reflection	1-2 hours.

VT13- Female	42	Married	White	English, French & Spanish	None	M.A.	\$70,000 +	None	Loss, education & reflection	1-2 hours.
VT14- Female	65	Married	White	English & Estonian	Yes - Lutheran	PhD.	Not Stated	Yes	Education	30 minutes to 2 hours.

APPENDIX F: EXAMPLES OF CULTURAL COMPETENCY IN HEALTH CARE

Dominant Cultural Traits for 19 Different Cultures

The following nineteen tables represent the most dominant cultural traits for Anglo-Americans, Mexican-Americans, African-Americans, North American (Indian), Chinese-Americans, Arab-American Muslims, German-Americans, Polish-Americans, Southeast Indian Americans, Vietnamese-Americans, Japanese-Americans, Italian-Americans, Greek-Americans, Jewish-Americans, Danish-Americans, Swedish-Americans, Lithuanian-Americans, Finnish-Americans, and Philippine-Americans. They are listed with the ‘culture care’ actions and modes that would be most appropriate for the particular cultures. All findings are gathered from Leininger’s transcultural nursing studies of the past forty years. *Culture Care* meanings and action modes are “...assistive, supportive, and facilitative caring acts towards self and others focused on evident or anticipated needs for the client’s health or well-being or to face disabilities, death, or other human conditions” (Leininger 2006, p.83).

Table 1.1 Anglo-American Culture (Mainly US Middle and Upper Class)

Dominant Cultural Values	Culture Care Meaning/Action Modes
1. Individualism—focus on a self-reliant person	1. Stress alleviation by: -physical means -emotional means
2. Independence and freedom	2. Personalized acts -doing special things
3. Competition and achievement	-giving individual attention
4. Materialism (things and money)	3. Self-reliance (individualism) by -reliance on self -self-care
5. Technology dependent	-independent
6. Instant time and actions	-reliance on technologies
7. Youth and beauty	4. Health instruction -teach us “how to” self-care
8. Equal sex rights	
9. Leisure time highly valued	
10. Reliance on scientific facts and numbers	
11. Less respect for authority and the elderly	
12. Generosity in time of crisis	

* Emic data from several transcultural nursing studies 1970-1995.
(Leininger 2002b, p.109; Leininger 2006, p.289).

Table 1.2 Mexican American Culture

Dominant Cultural Values	Culture Care Meaning/Action Modes
1. Extended family valued	1. Succorance (direct family aid)
2. Interdependence with kin & social activities	2. Involvement with extended family (“other care”)
3. Patriarchal (machismo)	3. Filial love/loving
4. Exact time less valued	4. Respect for authority
5. High respect for authority and the elderly	5. Mother as care decision maker
6. Religion valued (many Roman Catholics)	6. Protective (external) male care
7. Native foods for well-being	7. Acceptance of God’s will
8. Traditional folk-care healers for folk illnesses	8. Use of folk-care practices
9. Belief in hot-cold theory	9. Healing with foods 10. Touching

Findings from Leininger’s transcultural nurse studies (1970, 1984, 1990). Emic Data.
(Leininger 2002b, p.109; Leininger 2006, p.289).

Table 1.3 African-American Culture

Dominant Values

1. Extended family networks
2. Religion valued (many are Baptists)
3. Interdependence with “Blacks”
4. Daily survival
5. Technology valued, e.g., radio, car, etc.
6. Folk (soul) food
7. Folk healing modes
8. Music and physical activities

Culture Care Meaning/Action Modes

1. Concern for my “brothers/sisters”
2. Being involved with
3. Giving presence (physical)
4. Family support and “get togethers”
5. Touching appropriately
6. Reliance on folk home remedies
7. Rely on “Jesus save us” with prayers and songs

*These findings were from Leininger’s study of two southern USA villages 91980-1981) and from a study of one large northern urban city (1982-1991) along with other studies by transcultural nurses. (Leininger 2002a, p.111; Leininger 2006, p.290).

Table 1.4 North American Indian Culture (U.S. and Canada)

Dominant Values

1. Harmony between land, people, and environment
2. Reciprocity with “Mother Earth”
3. Spiritual inspiration (spirit guidance)
4. Folk healers (Shamans)
5. Practice culture rituals and taboos
6. Rhythmicity of life with nature
7. Authority of tribal elders
8. Pride in cultural heritage and ‘Nations’

Culture Care Meaning/Action Modes

1. Establishing harmony between people and environment with reciprocity
2. Actively listening
3. Using periods of silence (‘Great Spirit’ guidance)
4. Rhythmic timing (nature, land, and people) in harmony
5. Respect for native folk healers, Careers, and curers (use of Circles)
6. Maintaining reciprocity (replenish what is taken from Mother Earth)
7. Preserving cultural rituals and taboos
8. Respect for elders and children

*These findings were collected by Leininger and other contributors in the United States and Canada during the past three decades. Cultural variations among all nations exist, and so the data are some general commonalities about values, care meanings, and actions. (Leininger 2002b, p.111; Leininger 2006, p.291).

Table 1.5 Chinese-American Culture

Dominant Culture Care Meanings and Action Modes

1. Serving others (not self care)
2. Compliance with authority and elders
3. Obedience to authority, elders, and government officials (discipline children)
4. Surveillance: watching near and at distances
5. Dependence on generic folk herbs, treatment modes (acupuncture, etc.)
6. Group communal assistance to others
7. Work hard and give to the society

* These findings are from Chinese living in the United States over five years. The data were collected by Leininger and other transcultural nurse researchers (1983-1991). Leininger also documented similar findings in the People's Republic of China (1983). (Leininger 2006, p.295).

Table 1.6 Arab-American Muslim Culture

Dominant Culture Care Meanings and Action Modes

1. Providing family care and support –a responsibility
2. Offering respect and privacy time for religious beliefs and prayers (five times each day)
3. Respecting and protecting gender cultural role differences
4. Knowing cultural taboos and norms (i.e. no pork, alcohol, smoking, etc.)
5. Recognize honor with obligation
6. Helping to 'save face' and preserve cultural values
7. Obligation and responsibility to visit the sick
8. Following the teaching of the Koran
9. Helping, especially children and elderly, when ill

* These care findings reflect several Arab-Muslims in Detroit (the largest Arab group outside of the Middle East) and need to be viewed as common patterned expressions. While cultural variations existed among all Arab-Muslim groups, these were dominant themes supported by L. Luna's research (1989) and Leininger's work with Arabs for over a decade (1982-1997). Many of these findings were also observed in Saudi Arabia by Leininger and L. Luna (1987). (Leininger 2006, p.295).

Table 1.7 German-American Culture

Dominant Culture

1. Industriousness and being hard workers
2. Maintain order and organization
3. Maintain religious beliefs
4. Stoicism
5. Keep environment and self clean
6. Cautiousness
7. Knowledge is power
8. Controlling self and others
9. Maintain rules and norms
10. Scientism with logic valued

Culture Care Meanings/Action Modes

1. Being orderly (orderliness)
-things in “proper places”
-right performance
-being well organized
2. Being clean and neat
3. Direct helping to others
-give explicit assistance
-get into action
4. Watch details
-follow rules
-be punctual
5. Protecting others against harm and outsiders
6. Controlling self and others
7. Eating proper foods and getting rest/fresh air
8. Do not complain, “grin and bear it”

*Findings from urban and rural United States over the past four (4) decades by transcultural nurses. Similar values and care patterns also were observed and confirmed in Western Germany in past decades (1970-1990). Emic data. (Leininger 2002b, p.110; Leininger 2006, p.297).

Table 1.8 Polish-American Culture

Dominant Values

1. Upholding Christian religious beliefs and practices (‘pray’)
2. Family and cultural solidarity (other care)
3. Frugality as way of life
4. Political activity for justice
5. Hard work: “Don’t complain”
6. Persistence: “Don’t give up”
7. Maintain religious and special days
8. Value folk practices

Culture Care Meanings/Action Modes

1. Giving to others in need
2. Self-sacrificing for others and God
3. Being actively concerned about
4. Working hard whatever one does
5. Christian love of others
6. Family concern for others
7. Eating Polish foods and folk care to stay well or recover from illness (including home remedies)

*These findings are from transcultural nursing studies with Midwest Polish Americans (primarily in Detroit and Chicago—two of the largest Polish settlements in the United States) by several transcultural nurses over the past decade. Emic data. (Leininger 2002b, p.111; Leininger 2006, p.297).

Table 1.9 Southeast Indian American Culture

Dominant Culture Care Meanings and Action Modes

1. Respect extended family members
2. Involve family as responsible caregivers
3. Use of folk treatment modes
4. Avoid cultural taboos with foods and culture lifeways
5. Use spiritual caring modes
6. Males responsible for public care decisions; females for domestic (home) care
7. Respect general role differences in care and curing
8. Use limit setting with children to discipline
9. Request religious beliefs and practices

*These findings were obtained from Southeast Indian men and women living in the United States the past two decades and collected by transcultural nurses. (Leininger 2006, p.294).

Table 1.10 Vietnamese-American Culture

Dominant Culture

1. Harmony and balance in universe
2. Extended kinship family ties (centrality of extended family)
3. Religious and spiritual values (Buddhism and Catholicism)
4. Respect for elderly and authority
5. Folk-care practices
6. Food and environment
7. Spirit healing

Culture Care Meanings and Action Modes

1. Harmony and balanced caring ways
2. Respect for elderly, family ties, cultural taboos
3. Using natural folk-care practices and food (hot-cold theory)
4. Spirituality in caring
5. Enabling others to do daily functions (other care)
6. Family-centered carings
7. Touching to heal

*These findings are mainly from Vietnamese refugees living in the United States and studied by Leininger and other transcultural nurses (1974-1990). (Leininger 2006, p.294).

Table 1.11 Japanese-American Culture

Dominant Values

1. Duty and obligation to kind and work groups
2. Honor and national pride
3. Patriarchal obligations and respect
4. Systematic group work goals
5. Ambitiousness with achievements
6. Honor and pride toward elders
7. Politeness and ritual acts
8. Group compliance
9. Maintain high educational standards
10. Futurists with worldwide plans

Culture Care Meanings and Action Modes

1. Respect for family, authority, and corporate groups; family included in caring
2. Obligations to kin and work groups
3. Concern for group with protection emphasis
4. Prolonged nurturance “care for others overtime”
5. Control emotions and actions to “save face and prevent shame”
6. Look to others for affection (*Armaeru*) “save face and prevent shame”
7. Indulgence from caregivers (young and old)
8. Endurance to support pain and stress
9. Respect for and attention to physical complaints
10. Personal cleanliness
11. Use of folk therapies (Kanpo medicine)
12. Quietness and passivity for healing

*These findings were from Japanese living and working in the United States the past two decades (1971-1991). Similar patterned findings were documented by informants in Japan, but with some recent intergenerational changes. (Leininger 2006, p.293).

Table 1.12 Italian-American Culture

Dominant Values

1. Extended and close family ties
2. Patriarchialism
3. Strong religious practices (Roman Catholics)
4. Being socially and politically active with extended family and wider community
5. Generosity and charitableness
6. Expressive in music, art, and Community service
7. Responsible for Italians
8. Openly express feelings (actions, Music, art)

Culture Care Meanings and Action Modes

1. Well-being of our families
-“best for the family good”
-keeping family active and well
2. Promoting family integrity
-sharing among family (other care)
-protecting family name and status
3. Involvement with family and other Italians (being active and dealing with family affairs)
4. Closeness with presence or connectedness
-being there; “touching a lot and hugs”
5. Expressing oneself freely
6. Eating fresh Italian market foods and use of wine with meals
7. family support (stay close to home)

*These findings were confirmed and substantiated by key and general informants living in a large, Italian, urban mid-central community in the United States by Leininger, and several transcultural nursing researchers. Leininger worked in community project for ten years (1982-1992). While variability among Italians from the homeland was evident, the above commonalities prevailed. (Leininger 2006, p.298).

Table 1.13 Greek-American Culture

Dominant Values

1. Maintain Greek family ties
2. Preserve religious beliefs and practices
3. Be responsible for Greek families
4. Strong respect for cultural heritage
5. Sacrificing for good of others/kin
6. Generosity to Greek kin, and other community groups
7. Work with youth to help them become good adult Greeks
8. Be with other Greeks when ill (presence)

Culture Care Meanings and Actions Modes

1. Being responsible for other Greeks as religious and social obligation
2. Assisting others as soon as possible to prevent illnesses
3. Actively involved with Greek families
4. Preventing illnesses with proper exercise; using the arts family folk practices; avoiding hospitals; and eating ‘good, healthy’ Greek foods
5. Hospitality (Greeks and strangers)
6. Keeping active with family and church
7. Reflecting on goodness of others
8. Keeping clean and properly dressed
9. Exercise daily
10. Family stories of serious kin illness

*These care findings are from Greek families in urban United States by Leininger’s research team (1984-1999). Similar findings with other nurse-researchers (e.g. Muriel Larson), and with Greeks in Australia and Greece (1978-1990) (Leininger 2006, p.299).

Table 1.14 Jewish-American Culture

Dominant Value

1. Maintain respect for religious beliefs and practices (Judaism)
2. Keep centrality of family with patriarchal rule and mothercare
3. Support education and intellectual achievements
4. Maintain continuity of Jewish heritage
5. Be generous and charitable to arts music, and community service
6. Achieve success (financial and education)
7. Be persistent and persuasive
8. Enjoyment of art, music, and religious rituals

Culture Care Meanings and Action Modes

1. Express feelings openly
2. Get more direct and best help
3. Accept shared sufferings
4. Maternal nurturance, e.g. generous feeding, permissiveness, protectiveness
5. Giving and helping others as social justice (*tsdokeh*)
6. Performing lifecycle (birth, marriage, and death)
7. Attentiveness to others
8. Caring for own people
9. Teaching Jewish values

*These findings are from Jewish groups living in several urban communities in the United States (1975-1991). Pattern variations were evident with orthodox, conservative, and reformed Jewish-Americans and with intergenerational differences. Several transcultural nurses contributed to findings. (Leininger 2006; p.300).

Table 1.15 Danish-American Culture

Dominant Culture

1. Egalitarianism: “All alike”; “One as good as another”
2. Society more important than family
3. Social obligations and responsibilities
4. Non-gregariousness
5. Consensus building
6. Cultural pride in heritage

Culture Care Meanings and Action Modes

1. Treating people alike
2. Being quiet (leave alone at times)
3. Giving or sharing to others
4. Accommodating other (ideas and needs)
5. Avoiding conflicts
6. Maintaining societal care responsibilities
7. Eating proper foods
8. Daily exercise

*These findings were from key and general informants in Denmark and the United States with limited variability (Leininger 2006, p.302).

Table 1.16 Swedish-American Culture

Dominant Culture Care Meanings and Action Modes

1. Attention to detail
2. Self-responsibility
3. Maintaining privacy
4. Being hospitable
5. Showing orderly responsibility
6. Cleanliness: self and environment

*These findings were from Swedish informants in the urban Midwest collected by Leininger and research team (1984-1991). Many of these findings were also substantiated by key and general native informants in Sweden in the 1980s. (Leininger 2006, p.301).

Table 1.17 Lithuanian-American Culture

Dominant Culture

1. Extended family closeness
2. Religious beliefs and prayers (Roman Catholic)
3. Education important
4. Hard work and industriousness
5. Thriftiness and good use of material resources
6. Endurance, persistence, and suffering with economic hardships
7. Charity to others

Culture Care Meanings and Action Modes

1. Presence (being there)
2. Helping in times of need
3. Hospitality to others
4. Sharing with others (other-care)
5. Flexibility to adapt
6. Cooperation with others
7. Praying with others (spiritual healing)
8. Using subtle humor

*These findings were from a large urban community in the United States. Dr. Rauda Galazis at Wayne State University, shared her findings from two studies in the United States and from a field study in Lithuania, her parents' homeland (1986-1991). (Leininger 2006, p.300).

Table 1.18 Finnish-American Culture

Dominant Culture

1. Enduring hardships
2. Being frugal and watchful
3. Being productive
4. Maintaining neutrality
5. Being non-punitive
6. Keeping beliefs (mainly religious)
7. Maintaining national pride and Traditionalism
8. Quiet action
9. Maintaining proper rituals and healing decorum
10. Belief in folk and modern healing modes

Culture Care Meanings and Action Modes

1. Being responsible for others (*Hetios*); charity and love (*Caritas*)
2. Folk healing (saunas)
3. Listening attentively to others
4. Being quiet and contemplative
5. Being able to suffer and obtain meaning with contemplation
6. Being nonassertive
7. Loving others
8. Protecting the vulnerable
9. Getting sick people well
10. Taking care of self and others in their environment
11. Communion with others

*These findings were from the United States, but with support from key and general informants from Northern and Southern Finland with help from Anita von Smitten, Dr. Pirkko Merilainen, Dr. Katie Eriksson, and other Finnish authors' research associates (1989-1991). (Leininger 2006, p.301).

Table 1.19 Philippine-American Culture

Dominant Culture	Culture Care Meanings and Action Modes
1. Family unity and closeness	1. Maintain smooth relationships (<i>Pakikisama</i>)
2. Respect for elder/authority	2. Save face and self-esteem (<i>Amor propio</i>); (<i>Hiya</i> —avoid shame)
3. ‘Leave one-self to God’ (<i>Bahala na</i>)	3. Respect for and deference to authority
4. Obligations to sociocultural ties	4. Being quiet; privacy
5. Hot-cold beliefs	5. Mutual reciprocity (<i>Utang Na Loob</i>) “the give and take” in relationships
6. Use of folk foods and practices	6. Giving comfort to others
7. Religion valued (mainly Roman Catholic)	7. Tenderness acts when ill
	8. Being as pleasant as possible

* These findings were from Philippines living in the United States for at least two decades and collected by the Leininger, Z.Spangler and other transcultural nurse researchers. (Leininger 2006, p.292).

The readings of the above cultural differences found in the nineteen examples serves as a foundation for health care providers on all levels to begin the necessary steps to become aware of, understand and respect the plethora of cultures that interact with the health care industries and professionals on a daily basis. These culture care values, meanings and action modes are not representative of every aspect of the cultures mentioned, but they act as a guiding framework to assist health care providers to become familiar with and competent in cultural diversity.

Remembering that the premise of the Culture Care theory is to “...discover, document, know, and explain the interdependence of care and culture phenomena with differences and similarities between and among cultures”, these tables will assist in furthering that discovery (Leininger 2006, p.4). For a much more detailed explanation of all the various cultural differences in health, illness, nutrition or dietary limitations, pregnancy and childbirth, death and dying processes/rituals, spirituality and folk practices, and much more, Purnell and Paulanka *Transcultural Health Care* (2003) is a tremendous resource.

Appendix G. National Standards on Culturally & Linguistically Appropriate Services

Conceptual Frameworks, Assessment Tools and Checklists

The Office of Minority Health (OMH) of the US Department of Health and Human Services (DHHS) developed 14 national standards on culturally and linguistically appropriate services (CLAS). The CLAS standards are primarily directed at health care organizations; however, individual providers are also encouraged to use the standards to make their practices more culturally and linguistically accessible. The principles and activities of culturally and linguistically appropriate services should be integrated throughout an organization and undertaken in partnership with the communities being served.

These 14 standards, released in December 2000, are organized by three themes; Culturally Competent Care (Standards 1-3), Language Access Services (Standards 4-7), and Organizational Supports for Cultural Competence (Standards 8-14). Within this framework, there are three types of standards of varying stringency: Mandates, guidelines, and recommendations as follows:

CLAS mandates are current Federal requirements for all recipients of Federal funds (Standards 4, 5, 6, and 7).

CLAS guidelines are activities recommended by OMH for adoption as mandates by Federal, State, and national accrediting agencies (Standards 1, 2, 3, 8, 9, 10, 11, 12, and 13).

CLAS recommendations are suggested by OMH for voluntary adoption by health care organizations (Standard 14).

Culturally Competent Care (Standards 1-3)

Standard 1

Health care organizations should ensure that patients/consumers receive from all staff member's effective, understandable, and respectful care that is provided in a manner compatible with their cultural health beliefs and practices and preferred language.

Standard 2

Health care organizations should implement strategies to recruit, retain, and promote at all levels of the organization a diverse staff and leadership that are representative of the demographic characteristics of the service area.

Standard 3

Health care organizations should ensure that staff at all levels and across all disciplines receive ongoing education and training in culturally and linguistically appropriate service delivery.

Language Access Services (Standards 4-7)

Standard 4

Health care organizations must offer and provide language assistance services, including bilingual staff and interpreter services, at no cost to each patient/consumer with limited English proficiency at all points of contact, in a timely manner during all hours of operation.

Standard 5

Health care organizations must provide to patients/consumers in their preferred language both verbal offers and written notices informing them of their right to receive language assistance services.

Standard 6

Health care organizations must assure the competence of language assistance provided to limited English proficient patients/consumers by interpreters and bilingual staff. Family and friends should not be used to provide interpretation services (except on request by the patient/consumer).

Standard 7

Health care organizations must make available easily understood patient-related materials and post signage in the languages of the commonly encountered groups and/or groups represented in the service area.

Organizational Supports for Cultural Competence (Standards 8-14)

Standard 8

Health care organizations should develop, implement, and promote a written strategic plan that outlines clear goals, policies, operational plans, and management accountability/oversight mechanisms to provide culturally and linguistically appropriate services.

Standard 9

Health care organizations should conduct initial and ongoing organizational self-assessments of CLAS-related activities and are encouraged to integrate cultural and linguistic competence-related measures into their internal audits, performance improvement programs, patient satisfactions assessments, and outcomes-based evaluations.

Standard 10

Health care organizations should ensure that data on the individual patient's/consumer's race, ethnicity, and spoken and written language are collected in health records, integrated into the organization's management information systems, and periodically updated.

Standard 11

Health care organizations should maintain a current demographic, cultural, and epidemiological profile of the community as well as a needs assessment to accurately plan for and implement services that respond to the cultural and linguistic characteristics of the service area.

Standard 12

Health care organizations should develop participatory, collaborative partnerships with communities and utilize a variety of formal and informal mechanisms to facilitate community and patient/consumer involvement in designing and implementing CLAS-related activities.

Standard 13

Health care organizations should ensure that conflict and grievance resolution processes are culturally and linguistically sensitive and capable of identifying, preventing, and resolving cross-cultural conflicts or complaints by patients/consumers.

Standard 14

Health care organizations are encouraged to regularly make available to the public information about their progress and successful innovations in implementing the CLAS standards and to provide public notice in their communities about the availability of this information.

(OMH-DDHS, 2000)

Table 6. Purnell's List of Primary and Secondary Characteristics of Diversity

<p>Primary Characteristics</p> <p>Nationality</p> <p>Race</p> <p>Color</p> <p>Gender</p> <p>Age</p> <p>Religious Affiliation</p>
<p>Secondary Characteristics</p> <p>Educational Status</p> <p>Socioeconomic Status</p> <p>Occupation</p> <p>Military Experience</p> <p>Political Beliefs</p> <p>Urban versus Rural Residence</p> <p>Enclave Identity</p> <p>Marital Status</p> <p>Parental Status</p> <p>Physical Characteristics</p> <p>Sexual Orientation</p> <p>Gender Issues</p> <p>Reason for Migration</p> <p> Sojourner</p> <p> Immigrant</p> <p> Undocumented Status</p>

Table 7. Metaparadigm Macro Aspects of the Purnell Model

Global Society	Seeing the world as one large community of multicultural people. Phenomena include world communication and politics; conflicts and warfare; natural disasters and famines; international exchanges in education, business, commerce, and information technology; advances in the health sciences; space exploration; and the expanded opportunities for people to travel around the world and interact with diverse societies. Global events are widely disseminated by television, radio, satellite transmission, newsprint, and information technology affect all societies, either directly or indirectly.
Community	Group of people having a common interest and living in a specified locality. Community includes the physical, social, and symbolic characteristics that cause people to connect.
Family	Two or more people who are emotionally involved with each other. They may, but not necessarily do, live in close proximity to each other and may be blood or non-blood related.
Person	A human being; one who is constantly adapting to his or her environment biologically, psychologically, and socially.
Health	A state of wellness as defined by an ethnic or cultural group and generally including physical, mental, and spiritual states as they interact with the family, community, and global society.

(Purnell 2000, p.41; 2005, p.12-13)

1.

Table 8. Purnell's Micro-Aspects of the Model- The 12 Domains of Culture

1. **Overview/heritage** – country of origin, current residence, effects of the topography of the country of origin and current residence, economics, politics, reasons for emigration, educational status, and occupations.
2. **Communication** – dominant language and dialects; contextual use of the language; paralanguage variations such as voice volume, tone, and intonations; and the willingness to share thoughts and feelings. Nonverbal communications such as the use of eye contact, facial expressions, touch, body language, spatial distancing practices, and acceptable greetings; temporality in terms of past, present, or future worldview orientation; clock versus social time; and the use of names are important concepts.
3. **Family roles and organization** – household and gender roles; family roles, priorities, and developmental tasks of children and adolescents; child-rearing; and roles of the aged and extended family members. Social status and views toward alternative lifestyles such as single parenting, sexual orientation, childless marriages, and divorce are also included.
4. **Workforce issues** – autonomy, acculturation, assimilation, gender roles, ethnic communication styles, individualism, and health care practices from the country of origin.
5. **Biocultural ecology** – variations in ethnic and racial origins such as skin coloration and physical differences in body stature; genetic, hereditary, endemic, and topographical diseases; and difference in how the body metabolizes drugs.
6. **High-risk behaviors** – use of tobacco, alcohol, and recreational drugs; lack of physical activity; nonuse of safety measures such as seatbelts and helmets; and high risk sexual practices.
7. **Nutrition** – having adequate food; the meaning of food; food choices, rituals, and taboos; and how food and food substances are used during illness and for health promotion and wellness.
8. **Pregnancy and childbearing practices** – fertility practices; methods for birth control; views toward pregnancy; and prescriptive, restrictive, and taboo practices related to pregnancy, birthing, and postpartum treatment.
9. **Death rituals** – how the individual and the culture view death, rituals and behaviors to prepare for death, and burial practices. Bereavement behaviors are also included.
10. **Spirituality** – religious practices and the use of prayer, behaviors that give meaning to life, and individual sources of strengths.
11. **Healthcare practice** – focus of health care such as acute or preventive; traditional, magicoreligious, and biomedical beliefs; individual responsibility for health; self-medicating practices; and views toward mental illness, chronicity, and organ donation and transplantation. Barriers to health care and one's response to pain and the sick role are included.
12. **Health care practitioner** – status, use and perceptions of traditional, magicoreligious, and allopathic biomedical health care providers. In addition, the gender of the health care provider may have significance.

Table 9- Explicit Assumptions upon which the Purnell Model is based

1. All healthcare professions need similar information about cultural diversity.
 2. All healthcare professionals share the metaparadigm concepts of global society, family, person and death.
 3. One culture is not better than another culture; they are just different.
 4. Core similarities are shared by all cultures.
 5. Differences exist within, between, and among cultures.
 6. Cultures change slowly over time.
 7. The primary and secondary characteristics of culture determine the degree to which one varies from the dominant culture.
 8. If clients are co-participants in their care and have a choice in health-related goals, plans, and interventions, their compliance and health outcomes will be improved.
 9. Culture has a powerful influence on one's interpretation of and responses to health care.
 10. Individuals and families belong to several cultural groups.
 11. Each individual has the right to be respected for his or her uniqueness and cultural heritage.
 12. Caregivers needs both cultural-general and cultural-specific information in order to provide culturally sensitive and culturally competent care.
 13. Caregivers who can assess, plan, intervene, and evaluate in a culturally competent manner will improve the care of clients for whom they care.
 14. Learning culture is an ongoing process that develops in a variety of ways, but primarily through encounters (Camphina-Bacote, 2004).
 15. Prejudices are biases can be minimized with cultural understanding.
 16. To be effective, health care must reflect the unique understanding of the values, beliefs, attitudes, lifeways, and worldview of diverse populations and individual acculturation patterns.
 17. Differences in race and culture often require adaptations to standard interventions.
 18. Cultural awareness improves the caregiver's self-awareness.
 19. When individual of dissimilar cultural orientations meet in a work or therapeutic environment, the likelihood for developing a mutually satisfying relationship is improved if both parties in the relationship attempt to learn about each other's culture.
 20. Culture is not border bound. People bring their culture with them when they migrate.
 21. Professions, organizations, and associations have their own culture, which can be analyzed using a grand theory of culture.
- Purnell, 2000. p.43; Purnell, 2002, pp.193-194; Purnell, 2005, p.12

Appendix H. Volunteer Participant's Self-Administered Questionnaire

A. Socio-Demographic Characteristics

1. What is your gender? Male Female
2. What is your age range? Please circle your answer. 20s 30s 40s 50s 60s 70s
3. What country were you born in? _____
4. Number of years lived in Canada, if you were not born in Canada? _____
5. What is your marital status?
 1. Married
 2. Common-Law
 3. Living with Partner
 4. Single (never married)
 5. Widowed
 6. Separated
 7. Divorced
6. How far do you travel for your volunteer shifts? (Please state approximate time, there and back, and type of transportation used?)
7. Would you consider yourself a religious person? Please explain.
8. Do you attend a place of worship? If so, do you attend worship on a regular basis?
9. If you do not consider yourself religious, are you agnostic?
10. If you do not consider yourself religious, are you're an atheist?
11. What is your religion, if you have/had one? _____
12. What ethnic group are you from? Please be specific if you fall into more than one group?

13. Are you currently employed?

Full-time

Part-time

Full-time & Part-time

Not in labour Force (unemployed, laid off, looking for employment, on disability, student, caring for family members, or ill)

Retired

Self-Employed

14. What is your job title? _____ Please explain.

15. What is the highest level of education you have completed? Please circle your answer.

1. Some primary school

2. Some secondary school

3. Some High school

4. Completed High School

5. Some college/trade school

6. Some university

7. College Graduate

8. University Graduate

9. Trade school Graduate

10. Some-post-graduate studies

11. Earned Master's degree

12. Earned Doctorate's degree

13. Other _____

16. Can you estimate in which of the following groups your annual personal income falls? Please circle your answer.

1. Less than \$5,000

2. \$6,000 - \$10,000

3. \$11,000 - \$20,000

4. \$21,000 - \$30,000

5. \$31,000 - \$40,000

6. \$41,000 - \$50,000

7. \$51,000 - \$60,000

8. \$61,000 - \$70,000

9. Over \$70,000

10. Do not feel comfortable answering.

B. Motivations of Hospice Volunteers

1. At what age did you first volunteer for Hospice Toronto? _____

2. How long have you been a volunteer with the hospice? _____

3. Is this your first palliative volunteer job? If not, where else have you volunteered?

4. Why did you initially choose to volunteer for Hospice Toronto and work with dying people?

Appendix I. Volunteer Participant's In-depth Interview

Cultural Competency definition: “The ability to work effectively with individuals from different cultural and ethnic backgrounds, or in setting where several cultures coexist. It includes the ability to understand the language, culture and behaviour of other individuals and groups, and to make appropriate recommendations” (Chin, 2000).

1. Have you ever received any training on cultural competency? If so, can you explain?

2. Do you think the training that you received was adequate, or would you like more?

3. If you received training, was it in the initial training volunteer program, or throughout the years?

4. Do you think it's important to be trained on cultural competency as a hospice volunteer? Please explain.

5. Have you ever dealt with a client who was not of your race, ethnicity, culture, religion, etc?

6. Did working with a client of a different race, ethnicity, culture, or religion make you feel different than working with clients of similar background to your? Please explain. Did it make you feel uncomfortable, anxious, unsure, hesitant, etc?

7. How often are your clients ethnically, culturally different than you?

8. Would you prefer, or find it easier or more comforting to volunteer with people of the same culture, religion or ethnicity as you?

9. Have you ever refused or asked to be taken off of a team because of cultural, religious or language reasons?

10. Has a client ever refused or asked that you NOT be their volunteer because of cultural, religious or language reasons?

11. Have you ever had a situation where you felt that culture, religion, language or ethnicity negatively impacted your ability to be an effective volunteer? Please explain.

12. Have you ever had a situation where you felt that your culture, religion, ethnicity or language helped you with a client? Please explain.

13. Can you describe a situation where there was a clash of cultures between you and a client?

14. What type of training or support do you think would be helpful to volunteers in this type of situation, where there is a clash of cultures or ethnicities?

15. What is your mother tongue? _____

16. How many different languages do you speak, and what are they?

17. In general, how informed do you think you are about different cultures, religions, ethnicities, when it comes to dealing with clients with Hospice Toronto?

1 = not well informed at all

2 = enough to get by

3 = undecided/don't know

4 = informed

5 = very well informed

18. Would you like to be more or better informed about different cultures, religions, and ethnicities?

19. How would you like to be more or better informed? Please be specific.

20. Do you think being better informed will make you a better volunteer with Hospice Toronto?

Appendix J. Administrator Interview

A. General questions regarding ethnic backgrounds of volunteers and staff

1. What percentage of your volunteers are Caucasians/non-visible minorities?
2. What percentage of your volunteers are ethnic and visible minorities?
3. What is the ethnic composition of your clients?
4. How many different languages are you able to support through your volunteers and staff?
5. How do you handle ESL issues from clients?
6. Is increasing the percentage of ethnically diverse volunteers important for the mandate of this hospice?
7. If so, do you have a plan for increasing the percentage of ethnically diverse volunteers?
8. How long has Hospice Toronto been servicing the GTA?
9. How are you funded?
10. How many volunteer do you currently have?
11. How many clients do you service in a year?

12. How many hours of care do the volunteers provide on a weekly and yearly basis?

13. How much money does one volunteer potentially save the family and/or government per shift? For example, nurses = approximately \$25.00/per hour and Social Support Worker = \$18.00/per hour.

B. Cultural Competency Questions

1. How do you know which segments of the GTA population most need hospice services?

2. How do you direct your services accordingly, to meet these needs?

3. How well does the Hospice meet the needs of a culturally diverse GTA population?

4. How do you try to reach minority groups in inform them of hospice services in their areas?

5. What type of collaboration or interaction do you have with community minority associations?

6. What policies/procedures do you have in place to deal with cultural diversity in your clientele base?

7. Do you train your volunteers and staff on cultural competency?

8. If so, how is that information disseminated?

9. Can you describe what the volunteers are trained in, during their first initial training?

10. Has there ever been an incident where lack of cultural competency was a problem for a client or a volunteer?

11. Are the volunteer recruitments based on the demographic needs of the community it serves?

12. Are there any barriers that you face in introducing, or increasing cultural competency among volunteers/staff?

13. What resources would help you improve cultural competency in the hospice?

14. What is the mandate of the hospice?

References

- Abercrombie, N., Hill, S., and Turner, B.S. (2000). *The Penguin Dictionary of Sociology*, 4th ed. London, England: Penguin Books.
- Administration on Aging, "Achieving Cultural Competence: A Guidebook for Providers of Services to Older Americans and their Families". U.S. Department of Health and Human Services: Washington, DC. Retrieved
URL: www.aoa.gov/Prof/addiv/cultural/cc-guidebook.pdf
- Ahmann, E. (2002). Developing Cultural Competence in Health Care Settings. *Pediatric Nursing*. 28(2):133-138.
- American Medical Association (AMA). (2003). *Delivering Culturally Effective Health Care to Adolescents*. Pp. 1-117.
URL: www.ama-assn.org/ama/pub/upload/mm/39/culturallyeffective.pdf
Downloaded: September 2007.
- Anand, Rohini. (2000). *Cultural Competence in Health Care: A Guide for Trainers*. Washington, DC; National Multicultural Institute Publications.
- Anderson, B., and Ohlen, J. (2005). Being a Hospice Volunteer. *Palliative Medicine*. 19: 602-609.
- Anderson, L.M., et al. (2003). Culturally Competent Healthcare Systems: A Systematic Review. *American Journal of Preventive Medicine*. 24(3S): 68-79.
- Andrews, M.M., and Boyle, J.S. (2003). *Transcultural Concepts in Nursing Care*, 4th ed. Philadelphia: Lippincott Williams & Wilkins.
- Andrulis, D.P., Delbanco, T.L., and Shaw-Taylor, Y. (1999). *Cross Cultural Competence in Health Care Survey*. Washington, D.C: National Public Health and Hospital Institute.
- Baily, M.L. (2005). "Cultural Competency and the Practice of Public Administration", in *Diversity and Public Administration: Theory, Issues, and Perspectives*, ed. Mitchell F. Rice. Armonk, N.Y: M.E. Sharpe. P.177.
- Benavides, A.D., and Hernandez, J.C.T. (2007). Serving Diverse Communities-Cultural Competency. *Public Management*. July:14-18.
- Bernanrd, W.T., and Moriah, J. (2007). Cultural Competency: An Individual or Institutional Responsibility? *Canadian Social Work Review*, 24(1): 81-93.

- Belvins, D., and Papadatou, D. (2006). "The Effects of Culture in End-of-Life Situation". In Dean Blevins and James L. Werth (Eds). *Psychosocial Issues near the end of life: a Resource for professional care providers*. Washington, D.D: American Psychological Association.
- Blackhall, L.J., Frank, G., Murphey, S.T. et al. (1999). Ethnicity and attitudes towards life Sustaining technology. *Social Science Medical*, 48: 1779-1789.
- Brannen, C. (2006). Women's Unpaid Caregiving and Stress. *Centres of Excellence for Women's Health Resource Bulletin*. 5(1):12-13.
- Braun, K.L., Pietsch, J.H., and Blanchette, P.L. (2000). Cultural Issues in End-of-Life Decision Making (Eds). LA: California: Sage Publications, Inc. pp1-10.
- Britannica On line Dictionary. URL: www.britannica.com
Downloaded, October, 2007.
- Bronheim, S. "It all Starts at the Front Desk". National Center for Cultural Competence-Georgetown University Center For Child and Human Development.
URL: www.gucchd.georgetown.edu/nccc
Downloaded May 2008.
- Brym, R. (2008). *New Society*. 5th ed. Toronto, ON: Nelson.
- Caldwell, J., and Pearson-Scott, J. (1994). Effective Hospice Volunteers: Demographic and Personality Characteristics. *The American Journal of Hospice & Palliative Care*. 40-45.
- Caldwell, J., and Pearson-cott, J. (1996). Needs and Program Strengths: Perceptions of Hospice Volunteers. *The Hospice Journal*. 11(1): 19-30.
- California Tomorrow (2006). *Cultural Competency: What is it and Why it matters*. Oakland, CA: California Tomorrow.
- Camphina-Bacote, J. (2002). The Process of Cultural Competence in the Delivery of Healthcare Services: A Model of Care. *Journal of Transcultural Nursing*. 13(3): 181-184.
- Canadian Heritage (2002-03). "The Canadian Multiculturalism Act – 15 years later".
URL: www.pch.gc.ca/progs/multi/reports/ann2002-2003/01_e.cfm?nav=2
Downloaded July, 2008.
- Canadian Hospice Palliative Care Association (CHPCA). "About Us".
URL: www.chpca.net/about_us/history.htm
Downloaded July 14th, 2008.

Canadian Hospice Palliative Care Association (CHPCA). 2002. "A Model to Guide Hospice Palliative Care" in *Hospice Palliative Care Definitions, Values, Principles and Foundational Concepts*. Pp.17-24.

URL: www.chpca.net/about_us/history.htm

Downloaded July 14th, 2008.

Canadian Mental Health Association (2002). *Creating a Culturally Inclusive Organization: A Resource Action Guide*.

Canadian Nursing Association (2008). *A Position Statement*. URL: www.cna-aiic.ca

Downloaded April 2008.

Chevrier, F., Steuer, R., and MacKenzie, J. (1994). Factors affecting satisfaction among Community-based Hospice Volunteer Visitors. *American Journal of Hospice and Palliative Care*. July/August:30-37.

Chin, J.L. (2000). Culturally Competent Health Care. *Public Health Reports*. 115(1/2):25-33.

Chin, M.H., Walters, A.E., Cook, S.C., and Huang, E.S. (2007). Interventions to Reduce Racial and Ethnic Disparities in Health Care. *Medical Care Research and Review*. 64(5): 7S-28S.

Citizenship and Immigration Canada. (2006).

URL: www.cic.gc.ca/english/resources/statistics/facts2006/permanent/28.asp

Downloaded: January, 2008.

CLAS- URL: www.omhrc.gov/CLAS. Downloaded December 2007

Claxton-Oldfield, S., Claxton-Oldfield, J., and Rishchynski, G. (2004a). Understanding of the Term Palliative care: A Canadian Survey. *American Journal of Hospice and Palliative Care*. 21(2): 105-110.

Claxton-Oldfield, S., Jerrfies, J., Fawcett, C., and Wasylkiw, L. (2004b). Palliative Care Volunteers, why do they do it? *Journal of Palliative Care*. 20(2): 78-84.

Claxton-Oldfield, S., Tomes, J., Brennan, M., Fawcett, C., and Claxton-Oldfield, J. (2005). Palliative care volunteerism among college students in Canada. *American Journal of Hospice and Palliative Medicine*. 22(2): 111-118.

Claxton-Oldfield, S., MacDonald, J., and Claxton-Oldfield, J. (2006). What Palliative Care Volunteers Would Like to Know About the Patients They Are Being Asked to Support. *American Journal of Hospice and Palliative Care*. 23(3): 192-196.

- Claxton-Oldfield, S., Crain, M., and Claxton-Oldfield, J. (2007a). Death Anxiety and Death Competency: The Impact of a Palliative Care Volunteer Training Program. *American Journal of Hospice and Palliative Medicine*. 23(6):464-468.
- Claxton-Oldfield, S., and Claxton-Oldfield, J. (2007b). The Impact of Volunteering in Hospice Palliative Care. *American Journal of Hospice and Palliative Medicine*. 24(4): 259-263.
- Colon, M., and Lyke, J. (2003). Comparison of hospice use and demographics among European Americans, African Americans, and Latinos. *American Journal of Hospice and Palliative Care*. 20(3), 182-190.
- Crawley, L.M., Marshall, P.A., Lo, B., and Koenig, B.A. (2002). *Annals of Internal Medicine*. 126(9): 673-679.
- Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approach*. California: Sage Publications.
- Crewe, C. (2007). Healthy Balance: Poor Health and Economic Insecurity are Realities for Female Unpaid Caregivers. *Canadian Women's Health Network*. 9(3/4):30-32.
- Cross, T., Bazron, B., Dennis, K., and Isaacs, M. (1989). Towards a Culturally Competent System of Care, Volume I. Washington, DC: CASSP Technical Assistance Center, Georgetown University Child Development Center.
- CSAP: Cultural Competence Series 7. (1998). U.S. Department of Health and Human Services Substance Abuse and Mental Health Services Administration Center for Substance Abuse Prevention.
- Denoba, D.L., Bragdon, J.L., et al. (1998). Reducing Health Disparities through Cultural Competence. *Journal of Health Education*. 29(5, suppl): S47-53.
- Denzin, N.K., and Lincoln, Y.S. (2005). "Introduction: The Discipline and Practice of Qualitative Research" in *The Sage Handbook of Qualitative Research*, 3rd ed. London: Sage Publications.
- Diversity Rx. Resources for Cross Cultural Health Care. Center for the Advancement of Health, Department of Health and Human Services. U.S. Office of Minority Health. *Cultural And Linguistic Standards and Research Agenda Project: Part 1-national standards Project overview*. [URL:www.diversityrx.org](http://www.diversityrx.org). Downloaded October, 2007.
- Doyle, D. (2002). "Volunteers in Hospice and Palliative Care: A Handbook for Volunteer Service Managers" in *The Training and Education of Volunteers*. New York, NY: Oxford University Press.

- Este, D., and Gwat, Y.L. (1999). *Professional Social Service Delivery in a Multicultural World*. (Eds.). Toronto: Canadian Scholar's Press.
- Este, D. (2007). Cultural Competency and Social Work Practice in Canada: A Retrospective Examination. *Canadian Social Work Review*. 24(1): 93-105.
- Fainsinger, R.L. (2002). Canada: Palliative Care and Cancer Pain. *Journal of Pain and Symptom Management*. 24(2): 173-176.
- Field, A., Maher, P., and Webb, D. (2002). "Cross Cultural Research in Palliative Care" in *Social Work Health and Mental Health*. London: The Haworth Press, Inc.
- Foster, E. (2002). Lessons We Learned: Stories of Volunteer-Patient Communication in Hospice. *Journal of Aging and Identity*. 7(4): 245-256.
- Galabuzi, G.E. (2002). *Social Exclusion*. A Paper and presentation given at the Social Determinants of Health Across the Life Span Conference. Toronto, November, 2002.
- Galabuzi, G.E. (2004). "Social Exclusion" in *Social Determinants of Health: Canadian Perspectives*. Toronto: Canadian Scholar's Press, Inc.
- Galambos, C.M. (2003). Moving Cultural Diversity toward Cultural Competence in Health Care. *Health and Social Work*. 28:3-7.
- Gallicchio, L., Siddiqi, N., Langenberg, P., and Baumgarten, M. (2002). Gender Differences in Burden and Depression among Informal Caregivers of Demented Elders in the Community. *International Journal of Geriatric Psychiatry*. 17:154-163.
- Geiger, H.J. (2001). Racial Stereotyping and Medicine: The Need for Cultural Competence. *Canadian Medical Association Journal*. 164(12): 1699-1700.
- Geron, S.M. (2002/03). Cultural Competency: How Is It Measured? Does It Make a Difference? *Generations: Journal of the American Society on Aging*. 26:39-45.
- Giblin, M.J. (2002). Beyond Principles: Virtue ethics in Hospice and Palliative Care. *American Journal of Hospice and Palliative Care*. 19(4): 235-239.
- Giger, J. and Davidhizar, R. (2002). The Giger and Davidhizar Transcultural Assessment Model. *Journal of Transcultural Nursing*. 13(3), 185-188.
- Hall, S.E. and Marshall, K. (1996). Enhancing Volunteer Effectiveness. *The American Journal of Hospice and Palliative Care*. May/June: 22-25.
- Hallenbeck, J., Goldstein, M.K., and Mebene, E. (1996). Cultural Considerations of Death And Dying in the United States. *Clinics in Geriatric Medicine*. 12: 393-406.

- Hallenbeck, J., and Goldstein, M. (1999). Decisions at the End-of-Life: Cultural Considerations Beyond Medical Ethics. *Generations*. 23(1): 24-29.
- Handy, F., and Srinivasan, N. (2004). Valuing Volunteers: An Economic Evaluation of the Net Benefits of Hospital Volunteers. *Nonprofit and Voluntary Sector Quarterly*. 33(1): 28-54.
- Handy, F., and Srinivasan, N. (2005). The Demand for Volunteer Labour: A Study of Hospital Volunteers. *Nonprofit and Voluntary Sector Quarterly*. 34(4): 491-509.
- Harrison, J.P., and Ford, D. (2007). A Comprehensive Community-Based Model for Hospice Care. *American Journal of Hospice and Palliative Medicine*. 24(2):119-125.
- Hawthorne, D.L. and Yurkovich, N.J. (2003). Human Relationships: The Forgotten Dynamic in Palliative Care. *Palliative and Supportive Care*. 1: 261-265.
- Hawthorne, D.L., and Yurkovich, N.J. (2004). Hope at the End of Life: Making a case for Hospice. *Hospice and Palliative Care*. 2: 415-417.
- Health Resources and Services Administration (HRSA). U.S. Department of Health and Human Services. "Mitigating Health Disparities Through Cultural Competence". URL: www.hab.hrsa.gov. Downloaded: November 13th, 2007.
- Hospice Association of Ontario (HAO). "Fact Sheet". URL: www.hospice.on.ca URL: www.hospice.on.ca/news/fact%20sheet/factsheet.html Downloaded July 14th, 2008.
- Isaacs, M. and Benjamin, M.P. (1991). Towards a Culturally Competent System of Care. Volume II. Washington, DC: CASSP Technical Assistance Centre, Georgetown University Child Development Centre.
- Isaacs, M. (1998). Towards a Culturally Competent System of Care. Volume III. Washington, DC: CASSP Technical Assistance Centre, Georgetown University Child Development Centre.
- Jubb, A.K. (2002). Palliative Care Research: Trading Ethics for an Evidence Base. *Journal of Medical Ethics*. 28: 342-346.
- Kaasa, S., and De Conno, F. (2001). Palliative Care Research. *European Journal of Cancer*. 27: S153-S159.

- Kao, H.F., and McHugh, M.L.(2004). The Role of Caregiver Gender and Caregiver Burden in Nursing Home Placements for Elderly Taiwanese Survivors of Stroke. *Research in Nursing & Health*. 21:121-134.
- Kehl, K.A. (2006). Moving Toward Peace: An Analysis of the Concept of a Good Death. *American Journal of Hospice and Palliative Medicine*. 23 (4): 277-286.
- Kemp, C. (2005). Cultural Issues in Palliative Care. *Seminars in Oncology Nursing*. 21(1): 44-52.
- Krakauer, E.L., Crenner, C., and Fox, K. (2002). Barriers to Optimum End-of-Life Care for Minority Patients. *Journal of Geriatric Studies*, 50(1): 182-190.
- Latimer, E., McDonald, J., and Krauser, J. "Towards the provision of effective palliative care in Ontario". Excerpts from OMA Colloquium on Care of the Dying Patient.
URL: www.
Downloaded August 10th, 2007.
- Leininger, M. (1978). *Transcultural Nursing: Theories, Research and Practice*. 2nd ed. New York: John Wiley.
- Leininger, M. (1996). Founder's Focus: Transcultural Nursing Administration: An Imperative Worldview. *Journal of Transcultural Nursing*. 8(1): 28-33.
- Leininger, M. (2002a). Culture Care Theory: A Major Contribution to Advance Transcultural Nursing Knowledge and Practices. *Journal of Transcultural Nursing*. 13(3): 189-192.
- Leininger, M., and McFarland, M. (2002b). Transcultural Nursing and Globalization of Health Care. In *Transcultural Nursing: Concepts, Theories, Research and Practice 3rd ed.* New York: McGraw-Hill.
- Leininger, M., and McFarland, M. (2006). Culture Care Diversity and Universality Theory and Evolution of the Ethnonursing Method. In M. Leininger and M. McFarland (Eds). *Culture Care Diversity and Universality: A Worldwide Nursing Theory 2nd Ed.* Sudbury, MA: Jones & Barlett.
- Littlewood, P., and Herkommer, S. (1999). "Identifying Social Exclusion: some problems of Meaning. In P. Littlewood (Ed). *Social Exclusion in Europe: Problems and paradigms.* Broofield, USA: Ashgate Publishing Ltd.
- Lorenz, K.A., Ettner, S.L., Tosenfeld, K.E., Carlisle, D., Diu, H., and Asch, S.M. (2004). Accommodating Ethnic Diversity: A Study of California Hospice Programs. *Medical Care*. 42(9): 871-874.

- Macionis, J.J., and Gerber, L.M. (2005). *Sociology, 5th Canadian Edition*. Toronto, ON: Pearson Prentice Hall.
- Mayberry, R.K., et al. (1999). Racial and Ethnic Differences in Access to Medical Care: A Synthesis of the Literature. Menlo Park, CA: The Henry J. Kaiser Family Foundation.
- Mellow, M. (2007). Hospital Volunteers and Carework. *The Canadian Review of Sociology And Anthropology*. 44(4): 451-467.
- Merriam Webster On line – URL: www.merriamwebster.com
Downloaded: October 2007.
- Ministry for Children and Families. “Cultural Competency Assessment Tool”. Government of British Columbia.
URL:
www.mcf.gov.bc.ca/publications/cultural_competency/assessment_tool/tool_introduction2.htm
Downloaded: December, 2007.
- Moss, E.L., and Dobson, K.S. (2006). Psychology, Spirituality, and End-of-Life Care: An Ethical Integration. *Canadian Psychology Integration*. 47(4): 284-299.
- Myers-Schim, S., and Doorenbos, A.L. (2004). Cultural Competence in Hospice. *American Journal of Hospice and Palliative Care*. 21(1):28-32.
- Myers-Schim, S., Doorenbos, A.L., and Borse, N.N. (2006). Enhancing Cultural Competence Among Hospice Staff. *American Journal of Hospice and Palliative Medicine*. 23(5): 404-411.
- National Center for Cultural Competence (NCCC)- Georgetown University Center for Child and Human Development.
URL: www.gucchd.georgetown.edu.
Downloaded: October, 2007.
- National Hospice Organization. (1993). *Standards of a Hospice Program of Care*. Arlington, VA: National Hospice Organization.
- National Standards for Culturally and Linguistically Appropriate Services in Health Care: Executive Summary. (2001). Washington, DC: U.S. Department of Health and Human Services, OPHS, Office of Minority Health.
URL: www.gucchd.georgetown.edu.
Downloaded: October, 2007.
- Nazroo, J. (1988). The racialisation of ethnic inequalities in health. In *Statistics in Society* (ed. D. Dorling and S. Simpson). Arnold: London.

- Owens, A., and Randhawa, G. (2004). It's Different from my culture, they're very different: Providing community-based culturally competent palliative care. *Health and Social Care in the Community*. 12(5): 414-421.
- Palys, T. (2003). *Research Decisions: Quantitative and Qualitative Perspectives*. Toronto: Nelson.
- Purnell, L. (2000). A Description of the Purnell Model for Cultural Competence. *Journal of Transcultural Nursing*. 11(1): 40-46.
- Purnell, L. (2002). The Purnell Model for Cultural Competence. *Journal of Transcultural Nursing*. 13(3): 193-196.
- Purnell, L., and Paulanka, B.J. (2003). *Transcultural Health Care: A Culturally Competent Approach*. 2nd Ed. Philadelphia, PA: FA Davis Company.
- Purnell, L. (2005). The Purnell Model for Cultural Competence. *The Journal of Multicultural Nursing Health*. 11(2): 7-15.
- Quality End-of-Life Care Coalition of Canada (2007). Recommendations for Federal Government Action Summerized. *A Pan-Canadian Partnership for Palliative and End-of-Life Care*. 1-4.
- Raphael, D. (2004). "Introduction to the Social Determinants of Health" in *Social Determinants Of Health: Canadian Perspectives*. Toronto: Canadian Scholar's Press, Inc.
- Roessler, A., Carter, H., Campbell, L., and MacLeod, R. (1999). Diversity among hospice Volunteers: A challenge for the development of a responsive volunteer program. *American Journal of Hospice & Palliative Medicine*. 16(5): 656-664.
- Rokach, A. (2005). Caring for those who care for the dying: Coping with the demands on Palliative care workers. *Palliative and Supportive Care*. 3: 325-332.
- Sepulveda, C., and Ullrich, A. (2002). Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*. 24(2): 91-96.
- Shaw, M., Dorling, D., and Smith, G.D. (2006). "Poverty, social exclusion, and minorities" in *Social Determinants of Health* (ed. M. Marmot and R.G. Wilkinson). New York: Oxford University Press. 196-223.
- Sheeha, D.C., and Foreman, W.B. (1996). Eds. in *Hospice and Palliative Care: Concepts and Practice*. Sudbury, MA: Jones & Barlett Publishers.

- Sheifer, S.E., Escarce, J.J., and schulmann, K.A. (2000). Race and Sex Differences in the Management of Coronary Artery Disease. *American Heart Journal*. 139 (5); 848-857.
- Silver, H. (1994). Social Exclusion and Social solidarity: three paradigms. *International Labor Review*. 133(5-6): 531-578.
- Siriwardena, A.An., and Clark, D.H. (2004). End-of-Life Care for Ethnic Minority Groups. *Clinical Cornerstone*. 6(1); 43-49.
- Suthers, K. (2006). Women Still Shouldering the Burden: Caregiving in the 21st Century. *The Women's Health Activist*. 31(4): 4-5.
- Stake, R.E. (2005). "Qualitative Case Studies" in N.K. Denzin and Y.S. Lincoln (Eds.), *The Sage Handbook of Qualitative Research*, 3rd Ed. London: Sage Publications.
- Statistics Canada (2004). The Daily, September, 28th, 2004.
URL: www.statscan.ca/Daily/English/040928/d040928b.htm
Downloaded: August, 6th, 2008.
- Statistics Canada (2005). Canadian Social Trends, Winter 2005. Catalogue no. 11-008.
- Statistics Canada (2006). Canada's Ethnocultural Mosaic. 2006 Census. Catalogue no. 97-562.
- Statistics Canada (2007). The Daily, Dec 4th, 2007
URL: www.statscan.ca/Daily/English/071204/d071204a.htm
Downloaded: October 10th 2008.
- Tesch, R. (1990). *Qualitative Research: Analysis types and software tools*. New York: Falmer.
- Trevalon, M., and Murray-Garcia, J. (1998). Cultural Humility versus Cultural Competence: A Critical Distinction in Defining Physician Training Outcomes in Multicultural Education. *Journal of Health Care for the Poor and Underserved*. 9(2): 117-125.
- Tsai, JHC., et al. (2004). Developing culturally competent health knowledge: Issues of data Analysis of cross-cultural, cross-language qualitative research. *International Journal Of Qualitative Methods*. 3(4): 1-14.
- Tseng, W.S., and Streltzer, J.M. (2008). "Healthcare for People of Different Ethnicities" in W.S. Tseng, and J.M. Streltzer (Eds.), *Cultural Competence in Health Care*. New York: Springer.

- U.S. Department of Health and Human Services, Office of Minority Health. National Standards On Culturally and Linguistically Appropriate Services (CLAS) in Health Care. (2000). URL: www.omhrc.gov/clas. Downloaded, October, 2007.
- Walker, L.J. (2007). Caregivers as Unsung Heroes. *Journal of Financial Planning*. 20 (6):32-33.
- Webster, J. (2002). "But isn't it depressing?"-The Vitality of Palliative Care. *Journal of Palliative Care*. 18(1); 15-24.
- Weinick, R.M., Zuvekas, S.H., Cohen, J.W. (2000). Racial and Ethnic Differences in Access to And Use of Health Care Services, 1977-1996. *Medical Care Research and Review*. 57(1): 36-54.
- Werth, J.L., Blevins, D., and Toussaint, K.L. and Durham, M.R. (2002). The Influences of Cultural Diversity on End-of-Life Care and Decisions. *American Behavioral Scientist*. 46(2): 204-219.
- Wilson, P.E. (2000). Hospice volunteer training: Making the experience more meaningful. *American Journal of Hospice & Palliative Care*. 17(2): 107-110.
- Wittenberg-Lyles, E.M. (2006). Narratives of Hospice Volunteers: Perspectives on Death and Dying. *Qualitative Research Reports in Communication*. 7(1): 51-56.
- World Health Organization (1990). *Cancer Pain Relief and Palliative Care*. Technical Report Series 804. Geneva: World Health Organization.
- World Health Organization. Palliative care: Issues and Challenges by Sue Lucas. URL: www.who.int. URL: www.int/entity/3by5/en/palliativecare_en.pdf Downloaded: July, 2008.
- Yang, J.S. and Kigawa-Singer, M. (2007). Increasing access to care for cultural and linguistic Minorities: ethnicity-specific health care organizations and infrastructure. *Journal of Health Care for the Poor and Underserved*. 18: 532-549.