

Advance Care Planning for Mechanical Ventilation:
Health Care Providers' Perspectives on Cross-Cultural Care

Ayah Nayfeh

Interdisciplinary School of Health Sciences
Faculty of Health Sciences
University of Ottawa, Ottawa, Ontario

Co-supervisors: Professor Isabelle Marcoux, Professor Jeff Jutai

Submitted to the Faculty of Graduate and Postdoctoral Studies in
partial fulfillment of the requirements of the degree of
Master of Science degree in Interdisciplinary Health Sciences

Abstract/Résumé

Background: Advance care planning (ACP) is a method used for patients to express in advance their preferences, beliefs and values for life-sustaining treatments at the end-of-life. With growing ethnocultural diversity in Canada, health care providers are managing an increasing number of diverse beliefs/values that are commonly associated with preferences for mechanical ventilation (MV) at the end-of-life. The aim of this project is to explore methods used by health care providers to set care plans for MV with ethnocultural populations.

Methods: Qualitative analysis of semi-structured interviews with open-ended questions and two clinical vignette components was conducted with eight (8) health care providers who engage in ACP. Participants were recruited using a snowball-sampling approach from five acute-care hospitals within the Ottawa region.

Results: Three major themes emerged from collected dataset: 1) Goals of care across illness trajectories, 2) Respecting beliefs, values, and wishes for care, and 3) Cross-cultural support in ACP. Using a value-based approach in ACP was described as an effective method for managing and interpreting diverse beliefs/values that impact decisions for MV. However, organizational, systemic, and personnel barriers that exist continue to hinder the provision of cross-cultural ACP across health settings.

Contexte: La planification préalable des soins (PPS) est une méthode utilisée par les patients et les familles pour exprimer à l'avance leurs préférences liées aux traitements de prolongation de vie. En raison de la diversité ethnoculturelle croissante au Canada, les professionnels de la santé sont confrontés à des croyances et valeurs différentes, souvent associées à une préférence pour l'initiation et le maintien de la ventilation mécanique (VM) en fin de vie. L'objectif de ce projet consiste à explorer les stratégies utilisées par les professionnels de la santé lors des discussions associées à la VM auprès d'une clientèle multiculturelle.

Méthodes: Huit (8) participants (médecins et infirmières) impliqués dans la PPS ont accepté de participer à une entrevue semi-structurée avec des questions ouvertes et deux scénarios cliniques. Les participants ont été recrutés à l'aide de la méthode d'échantillonnage par réseau (« boule de neige ») de cinq hôpitaux de la région d'Ottawa.

Résultats: Trois grands thèmes ont émergé des entrevues: 1) les objectifs de soins à travers les trajectoires de la maladie, 2) le respect des croyances, valeurs et souhaits pour les soins, et 3) le soutien dans la PPS en contexte interculturel. Lors de la PPS, utiliser une approche basée sur les valeurs a été décrite comme une méthode efficace pour interpréter et prendre en compte les diverses croyances et valeurs qui ont une influence sur les décisions liées à la VM. Cependant, les barrières systémiques, organisationnelles et personnelles continuent d'entraver les services associés à la PPS en contexte interculturel dans les établissements de santé.

Acknowledgements

First and foremost, I would like to thank Professor Isabelle Marcoux; I am extremely grateful to have had you as my thesis supervisor and have benefited tremendously from your knowledge and constant motivation. Thank you for the last two years, it has been so wonderful teaming with you.

To my co-supervisor, Professor Jeff Jutai; you have provided me with great support throughout my Master's degree. Thank you for lending me your expertise, you have been valuable to my professional and research development.

A special thank you to my Thesis Advisory Committee: Professor Martine Lagacé, it has been an honour to have your expertise as a part of my committee. Dr. Paul Hébert, though our time was short, your insights had a significant influence on my project.

I would also like to thank Dr. Ian Graham for your willingness to welcome me to the Ottawa Hospital Research Institute.

A special thank you to my family and boyfriend, Chris, for your constant love and support. As well as my friends and colleagues, who have been on this journey with me since day one. To my father, thank you always for being my inspiration and motivating me to succeed in everything I do.

I gratefully acknowledge financial support from Bruyère Research Institute and TVN (Technology Evaluation in the Elderly Network), which is supported by the Government of Canada through the Networks of Centres of Excellence program.

Thank you to the following institutes for allowing me access to their research sites: Bruyère Research Institute, Ottawa Hospital Research Institute, and Institut de recherche de l'Hôpital Montfort.

Table of Contents

Abstract/Résumé	ii
Chapter 1 - Introduction	1
Chapter 2 - Background.....	3
End-of-Life Care in Canada	3
Purposes and Policies of Advance Care Planning	7
Ethnocultural Variations in Death and Dying	11
Cross-Cultural Considerations in ACP	15
Cross-Cultural Skills at the End-of-Life	18
Rationale	23
Chapter 3 - Methodology	25
Research Design.....	25
Recruitment and Data Collection	27
Data Analysis.....	29
Chapter 4 - Results	31
Goals of Care Across the Illness Continuum	32
Respecting Diverse Beliefs, Values, and Wishes for Care	39
Cross-Cultural Support in ACP.....	45
Clinical Vignettes	49
Chapter 5 - Discussion	52
Respecting and Accepting Ethnocultural Beliefs and Values.....	52
Education and Support for Ethnocultural Assessments in ACP	57
Barriers Across the illness Continuum in ACP	59
Implications of ACP in Long-Term Care	61
Recommendations	63
Reflection of the Researcher	65
Limitations.....	66
Conclusion	67
References	68
Appendices	88
Appendix A Health Care Spending in Canada	88
Appendix B Advance Care Planning Jurisdictions in Canada	89
Appendix C Interview Guide	90
Appendix D.1 REB Approval Bruyère Research Institute	93
Appendix D.2 REB Approval University of Ottawa.....	94
Appendix D.3 REB Approval l’Hôpital Montfort.....	95
Appendix D.4 REB Approval Ottawa Hospital Research Institute	96
Appendix E.1 Information Consent form Bruyère Research Institute	97
Appendix E.2 Information Consent form l’Hôpital Montfort	100
Appendix E.3 Information Consent form Ottawa Hospital Research Institute.....	103

Chapter 1 - Introduction

Advances in medical technologies are allowing patients with complex and terminal disease to live longer, but this does not necessarily mean that treatment will restore health or improve quality of life. Making medical decisions at the end-of-life has become more complex with increasing control of disease and illness. Patients today have the opportunity to consider, choose, or refuse life-sustaining treatments that he/she deems appropriate through the process of advance care planning (ACP). How one views the world and makes sense of thoughts, behaviours, and events that transpire throughout the life cycle, such as illness and death, is dependent on one's ethnocultural worldview (Cooley & Jennings-Dozier, 1998). With growing ethnocultural diversity in Canada, health care providers are managing an increasing number of diverse beliefs and values that have significant impacts on medical decision-making at the end-of-life (Statistics Canada, 2008).

Medical decisions that are informed by cultural or religious beliefs are commonly associated with preferences for mechanical ventilation (MV) and hospitalization at the end-of-life (Phelps et al., 2009; True et al., 2005). Health care providers should be able to recognize and be sensitive to ethnocultural influences when discussing prognoses and options for care. Cross-cultural communication and culturally-competent skills support the provision of individualized health care plans that address physical, psychosocial, and spiritual needs of patients and families at the end-of-life (Coolen, 2012; Kagawa-Singer & Backhall, 2001).

Unfortunately, cross-cultural considerations in ACP have rarely been considered in public policy and legislative frameworks in countries recognized for their linguistic and ethnocultural diversity, such as Canada, Australia, United Kingdom, and United States

(Johnstone & Kanistaki, 2009). How we manage ethnocultural beliefs and values at the end-of-life is a significant indicator for the quality of care and quality of death that patients and families experience. The purpose of this thesis project is to provide an in-depth look at cross-cultural methods used by health care providers in ACP, which is pertinent to the development of a sustainable long-term care approach in Canada.

Chapter 2 - Background

End-of-Life Care in Canada

Aging population in Canada. End-of-life care decisions have become increasingly important in Canada in the face of an aging population, escalating health care costs, and advances in medicine and technology that allow older adults with co-morbidities to live longer (Ontario Health Quality Council [OHQC], 2007). With increasing control of disease and illness through the use of antibiotics, symptom management, and resuscitative measures, older adults (65+) have become the fastest growing age group in Canada and it is estimated that this group will make up 23-25% of the total population by 2036 (Statistics Canada, 2010).

As of 2011, the leading causes of death among seriously ill older adults were due to frailty and chronic illnesses such as cancer, cardiovascular disease, and respiratory disease (Statistics Canada, 2014). As reported by the Manitoba Centre for Health Policy (2004), a significant proportion of health care costs are consumed at the end-of-life and these costs are strongly associated with age (Menec et al., 2004). In the final six months of life, end-of-life patients (1% of total population) consumed 21.3% of total health care costs and frail older adults (75+) incurred almost three-quarters (72%) of these costs (see **Appendix A**) (Menec et al., 2004). Considering that 1 in 10 Canadians will be over the age of 80+ years by 2056 (Statistics Canada, 2010), there is a particular need for frail older adults to discuss end-of-life care in advance to prevent unnecessary or unwanted use of considerable health resources (Murray, Kendall, Boyd, & Sheikh, 2005).

End-of-life care helps those with serious illness to live as well as possible as they approach death (End-of-Life Care Network, 2011); policies in Canada are currently targeted

to illnesses that have a predictable timeline, where patients will experience a short period of evident decline in functional status (Fassbender, Fainsinger, Carson, & Finegan, 2009).

Palliative care is different in that it addresses different aspects of end-of-life care by maximizing quality of life for the patient, family and loved ones, with focus on achieving comfort through the management of pain and symptoms (Health Canada, 2009). While there is more of a holistic approach to palliative care, this term can be used interchangeably with end-of-life care in some cases, as is done throughout this report. Cancer patients make up about 85% of those who seek palliative care services and this shift from curative to comfort care has been associated with higher satisfaction, improved symptom control, and cost-savings (Higginson et al., 2003; McPhereson, Higginson, & Hearn, 2001; Ontario Medical Association, 2014). Unfortunately, physicians have difficulty predicting timing of death and there is no real urgency to plan for end-of-life care in frail older adults or patients suffering from chronic illnesses with serious intermittent declines (Fassbender et al., 2009). This population is generally not a priority for palliative care and episodes of deterioration are commonly associated with hospital admissions and aggressive treatments (Murray et al., 2005). This approach, however, is not affordable in the long run (Fassbender et al., 2009).

Use of mechanical ventilation at the end-of-life. Mechanical ventilation (MV) is the most used form of life-sustaining treatment at the end-of-life and most frequently the treatment withheld or withdrawn in anticipation of death (Cook et al., 2004). This resuscitative measure is used to protect a patient from respiratory failure by reducing work involved with breathing and promoting optimal conditions for recovery (O'Higgins, 2003). Mechanical ventilation treatment is commonly delivered invasively through an endotracheal or tracheostomy tube (intubation), or non-invasively using a tight-fitting face or nasal

mask (O'Higgins, 2003). It is the responsibility of the physician to discuss with the patient and family the severity of illness, underlying health conditions, and appropriate options for care (O'Higgins, 2003; Stacy, 2012).

Unfortunately, these conversations occur infrequently (Heyland et al., 2006; Mirza, Kad, & Ellison, 2005; You et al., 2014) and patient preferences for MV are often unknown upon hospital admission (Cook et al., 2004). In such situations, the default directive is often to initiate intensive care; however, nearly half of physicians felt they had acted against their conscience while providing care to seriously ill patients and four times as many physicians felt they had provided over-treatment at the end-of-life (Cook et al., 2004; Council on Ethical and Judicial Affairs [CEJA], 1991). It is this intensive use of health services at the very end of life combined with the higher probability of death as we age that drives health care spending (Brown & Suresh, 2004).

Generally, physicians and nurses feel more comfortable withholding rather than withdrawing MV (Rubenfeld, 2004). While there are no distinctions from an ethical standpoint between withdrawing MV and other life-sustaining treatments like dialysis, hydration, or nutrition, the withdrawal of MV leads to discomfort and dyspnea (difficulty in breathing), extensive medication to manage pain and symptoms, and is most likely the event that precedes death (Rubenfeld, 2004). A study by Heyland et al. (2006) found troubling evidence that a majority of seriously ill hospitalized patients had very limited knowledge about resuscitative measures, including MV, and a significant number (37%) were unwilling to partake in the decision-making process regarding their treatment. Unwillingness to participate in decision-making may be a result of constraining patients to consider options for

care without adequate discussions regarding the burden and outcomes of treatment (Heyland et al., 2006).

A majority of older adults and families have misconceptions and misunderstandings about MV, and family members often believe they are causing the patient's death by withdrawing life-sustaining treatment (Heyland et al., 2006; Rubenfeld, 2004). In fact, a study by Marcoux, Mishara, & Durand (2007) shows that 66% and 38% of the Canadian population identify withdrawing and withholding treatment as an act of euthanasia, respectively. Euthanasia or physician-assisted suicide is the intentional act of ending a life to relieve pain and suffering and is illegal in most industrialized countries including Canada. The withdrawal or withholding of MV is different in that health care providers stop doing actions or do not act in manner necessary for keeping a patient alive (Canadian Medical Association, 2007). Health providers are encouraged to clarify for patients and families the moral equivalence between 'acts' and 'omissions' that result in death in order to avoid misperceptions or disagreements that ultimately leave the patient in pain or receiving unwanted treatments (Marcoux et al., 2007; Rubenfeld, 2004).

Patients who receive end-of-life care that is inconsistent with their wishes are more likely to be dissatisfied at the end-of-life, as found in a study measuring disparities between care received and patient/family preferences for care (Teno, Fisher, Hamel, Coppola, & Dawson, 2002). Additionally, the use of MV with little potential for health recovery continues to place a significant burden on health care spending in Canada (Alberta Heritage Foundation for Medical Research [AHFMR], 2005). Prognostic information provided early in the disease course may improve decision-making for MV and have a favourable impact on patient/family satisfaction with care (Leclaire, Oakes, & Weinart, 2005). Using a low-cost

strategy like advance care planning (ACP) may be a valuable tool for reducing the use of considerable health resources that do not provide a health benefit or restore quality of life for seriously ill patients.

Purposes and Policies of Advance Care Planning

Advance care planning was introduced into the Canadian health system as a method for patients to express in advance their preferences, beliefs, and values for end-of-life care. The purpose of ACP is to improve the provision of quality care by respecting patient autonomy and reducing uncertainty with making medical decisions that may precede death (Canadian Hospice Palliative Care Association [CHPCA], 2012). These discussions are most effective when they occur on an on-going basis with patients to ensure recent wishes are expressed and are dependent on the physician's training and experience with ACP, his/her comfort level with discussing death and dying, and availability of adequate time to have the discussion (CHPCA, 2012; Coolen, 2012).

Patients with the capacity to make meaningful decisions have the right to express their wishes for care and may do so through oral or written inquiries. Over the last 15-20 years, jurisdictions for advance directives have been enacted in almost all provinces and territories with variations across Canada (see **Appendix B**). Goals for care may be documented through two formal mechanisms of advance directives: 1) *Instructional Directive* outlines patient desires for life-sustaining treatments in a given level of health, and 2) *Proxy Directive* designates the person or surrogate responsible for making medical decisions when the patient becomes incapable of doing so for him/herself (Canadian Association of Critical Care Nursing Working Group [CACCN], 1999; Guo & Harstall, 2004).

The majority of advance directives are used to instruct health care providers to initiate, continue, withhold, or withdraw life-sustaining treatments such as MV, CPR, dialysis, blood transfusions, and artificial nutrition/hydration (CACCN, 1999). In provincial legislations that recognize instructional directives like Alberta, Saskatchewan, and Manitoba, it is important to understand that in the event of mental incapacity where an individual has left an advance directive, prior instructions or wishes for care do not always provide consent to or refusal of treatment (Educating Future Physicians in Palliative and End-of-Life Care [EFPPEC], 2008).

There is great difficulty with sufficiently detailing every possible reaction in a hypothesized situation; advance directives documented in a vague or ambiguous manner cannot be taken on their own to govern medical decisions (Health Law Institute [HLI], 2009). Additionally, seriously ill patients change their minds about medical treatments as their health status changes and there is instability in ACP when the topic is not frequently revisited (Carmel & Mutran, 1999). Health care providers who feel that an advance directive is not representative of the patient's most recent wishes may seek clarification from family members or surrogate-decision-makers (Fritsch, Petronio, Helft, & Torke, 2013).

On the other hand, jurisdictions in Ontario, British Columbia, Nova Scotia, and Quebec only provide proxy directives for the mandate of care; for example, Ontario has the '*Power of Attorney for Personal Care*' and Nova Scotia has '*Written Authorizations*' (Dunbrack, 2006; EFPPEC, 2008; CHPCA, 2012). In other words, consent is always required prior to initiating or changing treatments, whether it is from the patient him/herself, a family member, or a surrogate decision-maker (CHPCA, 2012). Bioethical standards for surrogate decision-making state that decisions must be made using a patient-centered

approach that takes into consideration the patient's previously stated wishes and best interests (Emanuel & Emanuel, 1992).

Family members rely heavily on advance directives and patient input when this information is available; the majority of older adult patients, however, do not have advance directives and surrogate decision-makers frequently make inaccurate predictions of the patient's wishes for care (Fritsch et al., 2013). A study by Fritsch et al. (2013) showed that surrogates include factors such as their own wishes, religious beliefs, and past hospital experiences to make decisions on behalf of their loved one, and that these decisions were more closely aligned with preferences for themselves than with the patient.

Especially in cases where patient preferences are unknown, making medical decisions on behalf of a loved one can cause emotional distress and family members may be emotionally-driven to give the patient every chance at recovery in an effort to avoid feelings of guilt (Fritsch et al., 2013). Looking back to the death of a loved one, family members express desires to have had more information on patient preferences and wishes for end-of-life care (Fritsch et al., 2013; Hanson, Danis, & Garrett, 1997). Unfortunately, physicians rarely suggest for patients to involve family members in discussions regarding resuscitative measures and MV (Heyland et al., 2006).

The use of advance directives among older adults is especially important considering the number of patients affected by Alzheimer's disease or dementia is expected to double to 1.1 million by 2038, or 3% of the population (Alzheimer's Society of Canada [ASC], 2010; Raymont et al., 2004). A study by Raymont et al. (2004) reported that 40% of hospitalized patients do not have the capacity to be making medical decisions due to cognitive impairment, and physicians most often work with family members to determine an

appropriate plan for care (Raymont et al., 2004). The involvement of family in ACP discussions presents an opportunity to prepare surrogates and mitigate distress associated with medical decision-making (Fritsch et al., 2013).

The increased use of advance directives and policies for do-not-resuscitate (DNR) orders have resulted in significant health system improvements; two decades ago; patients who died in intensive care units (ICU) were staying longer and using more resources (Cook et al., 2004). In a study by Molloy et al. (2000), Ontario nursing homes that implemented the ‘Let Me Decide Health and Personal Care Directive’ program had reduced health care costs and improved patient/family satisfaction with care received (Molloy et al., 2000). Older adult patients that had discussed ACP and advanced directives with their physicians felt they had more ability to influence their medical decisions (Smucker et al., 1993). Likewise, family members or surrogates of patients with advance directives had greater understanding and comfort compared to surrogates of patients without any form of ACP (Tierney et al., 2001).

Unfortunately, advance directives continue to be underused in clinical contexts with only a 10% completion rate in Canada (CHPCA, 2012). Findings from several studies suggest reasons for not completing advance directives, including lack of knowledge and access to ACP forms, little understanding about life-sustaining treatments and clinical outcomes, and mistrust of advance directives as a means to exert control over end-of-life care (Guo & Harstall, 2004; Heyland et al., 2006; Perkins, 2000; Siegert, Clipp, Mulhausen, & Kochersberger, 1996).

Interestingly, several studies show that the completion of ACP is less common among ethnic minorities compared to the majority population (Baker, 2002; Johnstone & Kanitsaki, 2009; Kwak & Haley, 2005; Maciejewski et al., 2012). In fact, international

research suggests that end-of-life decision-making and uptake of ACP is more dependent on culture and ethnicity than variables such as age, socioeconomic status, and education (Baker, 2002; Crawley, 2005; Fowler & Hammer, 2013; Heyland et al. 2006; Kwak & Haley, 2005). In a country as multicultural as Canada, understanding the impact of ethnocultural beliefs and values on the process of ACP is a good starting point for improving clinical outcomes at the end-of-life.

Ethnocultural Variations in Death and Dying

Culture is one of the 12 key determinants of health and individuals living in Canada have a cultural right to maintain their ethnic, linguistic, and religious identities (Health Canada, 2003). Canada is home to over 200 ethnic groups, with more than half (54.2%) of visible minorities living in Ontario and the largest groups being South Asian, West Asian, Black Canadian, Filipino, and Chinese (Statistics Canada, 2008). An **ethnocultural group** is characterized by ethnic or cultural origins that share common values and perceptions that differ from another group, and are influenced by factors such as religion, language, and nationality (Ngo, 2008; Statistics Canada, 2008). Roman Catholic and Protestant religions remain the two largest denominations in Canada, though Islam, Hinduism, Sikhism, and Buddhism have grown substantially over time (Ngo, 2008). With a growth rate five times faster than the total population, it is estimated that one-fifth of the Canadian population will be a visible minority by 2017 (Statistics Canada, 2008).

Cultural, religious, and spiritual beliefs have been identified as the most important factor for coping with terminal illness, and there appears to be a positive correlation between illness severity and value of religion and use of prayer as a coping mechanism (Balboni et al., 2010; Pargament, Koenig, & Perez, 2000; Sulmasy, 2006; True et al., 2005). Positive religious coping is often used to have a sense of control or to give meaning to end-of-life,

and is defined as reliance on faith to promote healthy adaptation and psychological adjustment to serious illness (Pargament et al., 2000; Phelps et al., 2009). The use of cultural or religious methods for coping, however, is commonly associated with preferences for hospitalization, resuscitation, and MV (Phelps et al., 2009; True et al., 2005). Several studies have identified cultural and religious coping as a significant contributing factor to the use of health care resources at the end-of-life (Maciejewski et al., 2012).

Diverse ethnocultural perceptions challenge health care providers to engage in ACP when there is a clash in values, norms, and beliefs (Bowman, 2004; Coolen, 2012). Canadian studies that explore cross-cultural differences at the end-of-life are limited in scope (Bowman, 2004; Bowman & Singer, 2001; Clarfield, Gordon, Markwell, & Shabbir, 2003; Con, 2007; Ellerby, McKenzie, McKay, Garipey, & Kaufert, 2000; Rose, 2007), though international research from the United States, United Kingdom, and Australia have shown consistent findings that can be applied to Canada's ethnoculturally diverse population (Ali, Khalil, & Yousif, 1993; Bito et al., 2007, Blackhall, Murphy, Frank, & Azen, 1995; Candib, 2002; Goldstein, Thewes, & Butow, 2002; Johnstone & Kanitsaki, 2009; Koenig & Gates-Williams, 1995; Kwak & Haley, 2005; Maciejewski et al., 2012; Meleis & Jonsen, 1983; Sulmasy, 2006; Trill & Holland, 1993). Fundamental values for patient autonomy, truth-telling, quality of life, and control over dying may be deemed foreign or anti-ethical by ethnocultural groups who do not share the same beliefs.

Patient autonomy and truth-telling in ACP. Health care providers have an ethical and professional duty to uphold major bioethical principles central to decision-making: patient autonomy, nonmaleficence (do no harm), beneficence (do good), and justice (Beauchamp & Childress, 2009). The Canadian health system uses these principles to guide

ACP activities, where patient autonomy is regarded as the guiding principle in health care (Bowman, 2004; CHPCA, 2012). This is the belief that the best person to be making medical decisions is the person experiencing the illness. Health care providers are encouraged to empower patients to be assertive in medical decision-making by engaging in an open, truthful, and direct manner (CHPCA, 2012).

This individualistic stance, however, is not considered appropriate in some ethnocultural groups and may in fact cause more harm than good for patients and families (Bito et al., 2007; Johnstone & Kanitsaki, 2009). International research shows that individuals from ethnic groups like Greek, Italian, and Ethiopian cultures feel that patients are too sick to understand their medical information to be making meaningful decisions (Blackhall et al., 1995; Johnstone & Kanitsaki, 2009). As well, truth-telling and discussing a poor prognosis with a patient in ACP can be viewed as disrespectful and dangerous to a patient's health in Aboriginal communities (Ellerby et al., 2000) and Chinese populations from Taiwan, Hong Kong, and mainland China who are often fearful and reluctant to discuss end-of-life in fear that it will hasten the dying process and cause suffering for the patient (Bowman & Singer, 2001).

Collective or family decision-making is the norm in some ethnocultural groups, and patients and families will prefer that medical information be disclosed to family members who will then decide the direction of care or ensure that information is disclosed to their loved one in a sensible manner (Blackhall et al., 1995; Candib, 2002; Karim, 2003; Searight & Gafford, 2005). The process of ACP is deemed foreign and unnecessary within the context of familial autonomy, and disruptive to the idea of emotional harmony and positive energy (Bowman & Singer, 2001). Emphasizing patient autonomy and forcing negative information on patients can be considered paternalistic, disrespectful, and even racist (Candib, 2002).

Many have suggested that the persistent approach to patient autonomy in health care may be a significant factor for failing to improve aspects and outcomes of ACP (Heyland et al., 2006; Koenig & Gates-William, 1995). Preferences for decisional roles vary across ethnocultural groups and Canadian hospitals need to reconsider how consent should be obtained from patients; it is an autonomous expression and a self-determining choice for a patient to defer his/her decisional role and disengage from the decision-making process (Candib, 2002; EFPPEC, 2008; Heyland et al., 2006; Rose, 2007).

Sanctity of life and locus of control in death and dying. In Canada, health is the natural state and illness is caused by an unhealthy lifestyle or external factors that are not in the patient's control. Medical treatments are used to control disease and illness to support patients' health (Rose, 2007). Conversely, in certain ethnocultural groups only God has the power to heal terminal illness and the locus of control in death and dying is in the hands of God (Phelps et al., 2009; True et al., 2005). Control over dying by withholding or withdrawing MV treatment is considered inappropriate for human decision-making in Filipino, African American, and South Asian cultures (Bowman, 2004). It is deemed unacceptable to engage in ACP and take control over a decision that belongs to God. Advance directives are believed to deny God the opportunity to provide patients with health recovery (Nishimoto & Foley, 2001).

Some individuals believe that there is a religious purpose to suffering to overcome illness and this can be perceived as a 'test of faith' for seriously ill patients (Bullock, 2006; Crawley et al., 2000). To opt for palliative care or to express desires to withdraw or withhold MV treatment equates to giving up on God (Bullock, 2006; Candib, 2002; Maciejewski et al., 2012; Phelps et al., 2009; Sullivan, Muskin, Feldman, & Haase, 2004; Sulmasy, 2006).

Patients and families who have strong beliefs that God could heal terminal illness despite medical futility will often opt for intensive, life-prolonging treatments (Bullock, 2006; Crawley et al., 2000; Jacobs, Burns, & Bennett Jacobs, 2008; Maciejewski et al., 2012; Phelps et al., 2009; Sullivan et al., 2004).

As well, some patients and families who have strong values for the sanctity of life will push to preserve life at all costs (Clarfield et al., 2003; Jericho, 2011). Individuals from Jewish, Muslim, and Catholic religions believe that life is sacred and an invaluable gift from God; the longevity of life is often regarded with more value than the quality of life (Clarfield et al., 2003). While there is no obligation for individuals of these faiths to prolong dying with futile treatments, actions that hasten the process such as MV withdrawal are prohibited (Jericho, 2011). Suicide is condemned in these three monotheistic religions and the act of withdrawal can be interpreted as such; the inclusion of religious representatives from these communities can be important for providing religious inquiries to patients and families in ACP when the doctrine is flexible or misunderstood, or to convince the physician of the validity of beliefs (Clarfield et al., 2003; Jericho, 2011; Orr & Genesen, 1997). Health care providers who offer religious or spiritual support to patients and families may produce a five-fold reduction in preferences for MV at the end-of-life (Balboni et al., 2010).

Cross-Cultural Considerations in ACP

The Canadian national framework for ACP encourages health care providers to use a patient-centered approach that focuses on tailored care to meet diverse needs at the end-of-life (CHPCA, 2012). Health care providers are required to adjust to different ethnocultural contexts to achieve patient-centered care, with awareness of their own attitudes and behaviours that can have significant impacts on the process (Lewis, 2009). The goal is to

enhance a patient's capacity to self-manage and participate in their health care planning (Lewis, 2009). Evaluative research on the impact of patient-centered care found an increase in patient and health care provider satisfaction, facilitated teamwork, and reduced hospital costs (Charmel & Frampton, 2008; Sidani, 2008).

The Canadian Medical Association (2008) developed a policy document, *Achieving Patient-Centered Collaborative Care*, that states: "Medical care delivered by physicians and health care delivered by others should be aligned around the values and needs of patients. Collaborative care teams should foster and support patients, and their families, as active participants in their health care decision-making". This concept is different from patient autonomy that encourages individuals to direct their own medical care; with a patient-centered approach, patients are able to defer their autonomy in decision-making to family members in accordance with his or her values. While individuals have a cultural right to maintain their ethnic, religious, and linguistic identities, this does not mean that health care providers should blindly accept all cultural or religious beliefs (Fakuda-Parr, 2004). Ethnocultural beliefs and values are modifiable characteristics in that they can be recreated as people adapt to changing realities and redefine their values with exchanges of ideas (Fakuda-Parr, 2004; Maciejewski et al., 2012). Health care providers should do their best to expand the "capability of people to live and be what they choose with adequate opportunity to consider other options" (Fukuda-Parr, 2004, p. 4).

In 2000, Canada established the *Quality End-of-Life Care: The Right of Every Canadian* report in an attempt to move away from generating advance directives and putting emphasis on effective communication in ACP (CHPCA, 2012). While advance directives are important tools for documenting treatment preferences in ACP, their use is highly criticized

for providing vague information that fails to ensure beliefs and values are respected (Cantor & Pearlman, 2004). A Canadian study by Bravo, Dubois, and Wagneur (2008) revealed the best way to promote encourage people to express preferences for future health care is through oral information given over multiple sessions. Understanding the purpose and utility of advance directives is a sensitive matter that cannot be achieved through written materials alone; some researchers suggest that engaging in ACP with knowledgeable informants will allow informed decisions for end-of-life care to develop over time (Bravo et al., 2008; Perkins, 2000).

In fact, one of the largest studies exploring end-of-life decision-making in the United States (SUPPORT) found that advance directives have little impact on medical decision making for resuscitation among seriously ill hospitalized patients (Teno et al., 1994). While this data is relevant, its application to the Canadian context is limited; with increasing focus on patient-centered care in Canada, recent studies assessing the effectiveness of advance directives remain underexplored in Canada (Guo & Harstall, 2004; Molloy et al., 2000).

Health care providers are encouraged to elicit a values history from patients in addition to advance directives to facilitate the interpretation of treatment preferences in medical scenarios that cannot always be predicted (CHPCA, 2012). While physicians have a primary role in ACP, nurses also play an influential part and have a primary responsibility in advocating and eliciting important beliefs/values from patients and families (Canadian Nurses Association [CNA], 2008). Nurses have a unique role in providing daily care to patients and are in a position to promote the exploration of values, educate choices, and provide clarity through partial interpretation of medical information (CNA, 2008). Narrative inquires provided by patients allow nurses to play an instrumental role in ensuring

beliefs/values are effectively communicated to the health care team, and advocating for the patient if wishes are not being fulfilled (CNA, 2008; Werner, Carmel, & Zeidenberg, 2004).

However, nurses have lower decisional latitudes than physicians and often experience higher levels of moral distress in end-of-life scenarios (Elpern, Covert, & Kleinpell, 2005; Dodek, Norena, Ayas, & Wong, 2013). The Canadian Nurses Association's (2002) defines **ethical or moral distress** as "situations in which nurses cannot fulfill their ethical obligations and commitments, or they fail to pursue what they believe to be the right course of action, or fail to live up to their own expectation of ethical practice" (CNA, 2002, p. 6). Nurses who experience moral distress report adverse effects on job satisfaction, retention, and physical and psychological well-being (Elpern et al., 2005).

With growing cultural diversification in health care, nurses are encountering cross-cultural barriers that impede their ability to provide quality end-of-life care (Mitchell, Gale, Matzo, McDonald, & Gadmer 2002). Ethnocultural populations can successfully adapt to ACP models, though health care providers must be equipped with the cross-cultural skills to adjust to ethnocultural contexts for patient-centered care (CHPCA, 2012; Health Canada, 2008). Health care providers who have the knowledge and skills to inquire and understand that which is sacred to a patient and family's life may be the key to overcoming cultural, religious, and linguistic boundaries.

Cross-Cultural Skills at the End-of-Life

Simply because a patient identifies to a specific ethnocultural group does not mean that he/she maintains the same beliefs as that group; there is extensive heterogeneity between and within ethnocultural groups and failing to recognize diversity within cultures can significantly impact a patient's well-being by unknowingly providing fragmented care,

inadequate symptom management, miscommunication, and a poor quality of death (Coolen, 2012; Eues, 2007; Giger, Davidhizar, & Fordham, 2006; Moore & Spiegel, 2004). Culturally competent skills and cross-cultural communication support the provision of individualized health services that assist physicians and nurses in actively engaging in cultural assessments that address physical, psychosocial, and spiritual needs of patients and families in ACP (Coolen, 2012; Kagawa-Singer & Backhall, 2001).

Cultural competency. Culture provides a map of meaning through which people understand and interpret the world around them, and health care providers who carry different “cultural maps” may have hindered communication in ACP if they do not have adequate skills to adjust to different ethnocultural contexts (Bowman & Singer, 2001). Cultural competency is defined as the adaptation and adjustment of care in a culturally sensitive manner that is consistent with the norms and traditions of diverse populations being served (Purnell, 2002), and is defined as “the application of knowledge, skills, attitudes, and personal attributes required to provide appropriate care and services in relation to cultural characteristics of their clients” (CNA, 2004, p. 1). Providing culturally competent care can have positive health impacts on many ethnocultural groups in Canada, including Aboriginal peoples who make up 5.4% of the Canadian population and have higher rates of infant mortality and chronic illnesses than the rest of the population (Health Canada, 2003; Statistics Canada, 2008).

Being equipped with culturally competent skills that bring attention to ethnic or religious needs ensures patients and families have the opportunity to make meaningful decisions in ACP. The Purnell Model of Cultural Competency is a well-known framework that is used by health care providers across the globe including Canada, for practice, research,

and administration (Purnell, 2002). This model encompasses 12 domains that take into consideration primary and secondary characteristics of culture that can impact health: heritage, communication, family roles/organization, workforce issues, biocultural ecology, high-risk behaviours, nutrition, pregnancy/childbearing, death rituals, spirituality, health care practice, and health practitioners (Purnell, 2002).

The key elements to achieve cultural competency include: 1) **cultural desire**: the motivation to actively engage and commit to becoming culturally competent, 2) **cultural awareness**: the process of becoming more sensitive, respectful and attentive to a patient's cultural beliefs, 3) **cultural knowledge**: the process of understanding similarities and differences in values, beliefs, and practices between and within cultural groups, 4) **cultural skill**: the ability to engage in cultural assessments to understand patient beliefs, values, and practices, 5) **cultural collaboration**: a partnership approach to reach mutual goals between health care providers, patients, and families, and 6) **cultural encounter**: openness to learning and understanding meaningful cultural experiences (Camphina-Bacote, 2011; Kachingwe & Huff, 2007). Health care providers who are culturally competent engage in self-reflection or self-awareness of their own personal values, beliefs, and experiences to meaningfully communicate and address patient needs without letting these factors impact patient care (CHPCA, 2012).

Cross-cultural communication. Cross-cultural communication is a skill critical for completing cultural assessments that address physical, psychosocial, and spiritual needs of patients and families (Coolen, 2012). The goal of cross-communication is to arrive at a shared understanding of health and disease, and for health care providers to establish trust with patients and families in order for information to flow freely (Coolen, 2012). While

building trust and rapport can be time consuming, it is essential for having effective communication that allows physicians to observe, gather and document information regarding the patient's beliefs/values in ACP (Coolen, 2012; Schyve, 2007).

Unfortunately, studies devoted to understanding cultural influences at the end-of-life found that verbal and nonverbal communication between physicians and patients/families continues to be the greatest barrier throughout the decision-making process (Coolen, 2012). Physicians' use of technical medical language and jargon makes it difficult for patients to understand valuable information regarding care and treatment; consequently, patients with limited English proficiency suffer from more serious adverse events with misinterpretation or miscommunication in comparison to English-speaking patients (Schyve, 2007; Workshop Scientific Community [WSC], 2004). The inability to communicate effectively across cultures can also lead to stress for health care providers, causing anxiety and job dissatisfaction (Gibson & Zhong, 2005).

A study by Trill & Holland (1993) suggests that ACP discussions that are not in the patient's primary language may burden the patient and cause him/her to emotionally withdraw from the conversation (Trill & Holland, 1993). A language translator can be used to facilitate communication in ACP and improve patient comprehension and satisfaction, as well as provide physicians with an understanding of diverse ethnocultural worldviews (Chambers et al., 2000; Con, 2007). Even then, however, research shows that patients conversing with physicians in their primary language experience better outcomes than patients working with translators (Con, 2007; Gregg & Saha, 2007). The use of language translators can also be costly and time-consuming (WSC, 2004).

While a relative or friend may fulfill this role as a trusted and preferred messenger for the patient (Goldstein et al., 2002; Papadaoplous & Lees, 2004), this is often not encouraged in situations where the translator is emotionally involved. Discussing a poor prognosis with a patient is seen as impolite and ‘bad luck’ in some ethnocultural groups; a relative/friend may not provide their loved one with all of the information needed to make an informed decision and there is a risk that information will be filtered or inaccurately conveyed (Chambers, 2000). More so, it remains difficult to provide translations for words like ‘palliative’ or ‘cancer’ that do not have equal terms in other languages or instill negative feelings in other cultures (Con, 2007; Meleis & Jonsen, 1983; Payne, Chapman, Holloway, Seymour, & Chau, 2005; Rose, 2007; WSC, 2004).

The disclosure of information also occurs in non-verbal contexts that use body language to communicate by means of gestures, eye contact, and bodily contact. What may be acceptable in one culture, however, may be considered inappropriate in another. For example, Chinese and Japanese cultures believe in indirect communication - knowing what another person wants without being told. It is considered socially unacceptable to express emotion, complain, or ask for help outside of family (Ali et al., 1993). Health care providers who are unaware of non-verbal cues may unknowingly provide inadequate pain and symptom management (Chambers, 2000; Rose, 2007).

Although health providers have access to ethnocultural assessments and models for cross-cultural care, some critics suggest that these models presume that care improves simply through basic knowledge of different cultures (Higginbottom et al., 2011). While it is not possible for health care providers to be knowledgeable of all ethnocultural subtleties, researchers have suggested that efforts to improve communication between health care

providers, patients, and families is likely to have the greatest impact for achieving quality care at the end-of-life (Eues, 2007; Heyland, Rocker, O'Callaghan, Dodek, & Cook, 2003; Rose, 2007).

Rationale

Advance care planning is a fairly new concept in Canada and the cross-cultural application of this process remains under-explored, with only one major study conducted with the Canadian population (Con, 2007). While other studies have explored methods and approaches used by physicians to engage in end-of-life discussions (Hudelson, Perron & Perneger, 2011; Jackson et al., 2008; Mallery, Hubbard, Moorhouse, Koller, & Eeles, 2011; Quinlan & O'Neill, 2009; Reid et al., 2013), there is little research that explores this process from a cross-cultural perspective. Having basic knowledge and access to culturally-competent models for care does not grant predictability of health care providers' behaviours (Chambers, 2000; Higginbottom et al., 2011), and physicians' experiences with current methods of practice is not well understood. A deeper understanding of the facilitators and barriers that impact the ACP process can highlight gaps that hinder the provision of patient-centered care across cultures.

The aim of this thesis project is to explore practices/strategies used by health care providers to engage in ACP for MV with patients and families from different ethnocultural backgrounds. The objectives for this project are: 1) understand methods used to manage ethnocultural beliefs/values in ACP, 2) highlight barriers in ACP that may hinder health care providers' ability to provide cross-cultural care, and 3) explore methods used to overcome perceived cross-cultural barriers and challenges. Research outcomes from this study can have

short-term and long-term implications that are important for meeting diverse ethnocultural needs at the end-of-life.

Chapter 3 - Methodology

Research Design

A qualitative approach is often used to explore the topic of end-of-life and address meaning-centered questions that are not easily quantifiable (Gysels, Shipman, & Higginson, 2008; Marshall & Rossman 1999; Merriam, 2014). To best meet our research objectives, using the approach of phenomenology was appropriate for describing what all participants have in common as they engage in ACP cross-culturally and to reduce individual experiences to a description of experience (Creswell, 2006). Other qualitative methods, such as grounded theory, were not used since the aim of this project is not to move beyond a description of experience to develop theory. As well, using the approach of ethnography, narrative studies or case studies would not capture a collective essence of experience (Creswell, 2006). Designing a phenomenological study strengthens our understanding of health care providers' experiences in ACP and perceived facilitators/barriers that impact cross-cultural aspects of this process.

The most common method used to collect data in qualitative health care research is through the use of semi-structured interviews that consist of a few key questions that define areas to be explored, with flexibility for the interviewer to pursue a response for more detail (Gill, Stewart, Treasure, & Chadwick, 2008; Legard, Keegan, & Ward, 2003). Several qualitative studies that explore end-of-life discussions use a semi-structured approach with open-ended questions and clinical vignettes to probe for a deeper understanding (Hudelson, Perron & Perneger, 2011; Jackson et al., 2008; Mallery et al., 2011; Quinlan & O'Neill, 2009; Reid et al., 2013). Clinical vignettes have been shown to be a feasible method for exploring physicians' knowledge on ethnocultural factors that impact health care (Hudelson, Perron, & Perneger, 2011). With these considerations, the interview guide developed for this

study includes open-ended questions and two clinical vignettes that define three themes to be explored with participants along the knowledge-attitude-behaviour continuum.

Open-ended questions were designed to address gaps highlighted in the literature review and to achieve a greater understanding of the cross-cultural experience and application of ACP. Clinical vignettes were developed based on cross-cultural scenarios at the end-of-life that are frequently encountered by health care providers, as described through the literature and reinforced in our pilot study. Follow-up questions were developed to assess consistency with the participant's previous responses or to elicit new themes. All interviews were conducted in English by the principal investigator, Ayah Nayfeh, and took place in a private and quiet location (e.g. hospital, office).

The interview guide was pilot tested with 10 health care providers to ensure applicability of questions across different health disciplines, including: two physicians, four nurses, three respiratory therapists, and one social worker. Participants were initially recruited with the assistance of Clinical Managers and a snowball sampling approach was used thereafter. The results of the pilot study show that non-physicians' roles and responsibilities in ACP vary across different health settings. For example, a respiratory therapist at one hospital may have responsibility covering major aspects in ACP discussions, whereas a respiratory therapist at another hospital may have minimal involvement. Several questions in the interview guide could not be answered by some of the respiratory therapists and the social worker in the pilot study. As well, some nurses also had varying degrees of involvement in ACP, though nursing roles and responsibilities had significant contributions to the generation and implementation of advance care plans.

Based on these results, the inclusion criteria for this study was limited to English-speaking physicians and nurses who engage in ACP discussions with patients/families in

acute-care settings (medical residents were permitted to participate in the study if the inclusion criteria was met). The questions included in the interview guide were slightly revised and adjusted according to pilot study feedback. A copy of the interview guide is included in **Appendix C**.

Recruitment and Data Collection

In accordance with qualitative research guidelines that suggest phenomenological studies sample at least six or five to 25 participants (Creswell, 1998; Morse, 1994), this study aimed to recruit a sample of eight participants (four physicians and four nurses) or until data reaches saturation and no new themes emerge. In comparison to our pilot study that included four different types of health care providers, a sample of eight participants collected from two types of health professionals is appropriate for meeting study objectives. Ethics approval was received from Bruyère Research Institute (Spring 2013), University of Ottawa (Spring 2013), Ottawa Hospital Research Institute (Winter 2014), and Institut de recherche de l'Hôpital Montfort (Winter 2014) (see **Appendix D**). Participants were recruited by the principle investigator, Ayah Nayfeh, between March 2014 – July 2014 from the following research sites: l'Hôpital Montfort, Ottawa General Hospital, Saint-Vincent's Hospital, Civic Hospital, and Queensway Hospital.

A purposeful sampling approach was used to recruit physician and nurse participants with maximal phenomenal variation in dimensions of interest, including (1) demographic factors such as gender, age, and ethnocultural diversity, and (2) environmental factors such as hospital organizations, acute-care settings, and years of medical/nursing experience (Sandelowski, 1995). Clinical Managers, Medical Directors, and Research Directors were helpful in identifying physician and nurse staff that met the inclusion criteria for the study. With permission to be contacted, potential participants received an e-mail letter of invitation

for voluntary participation. Two weeks after initial contact with no response, a follow-up e-mail letter was sent as a kind reminder for the pending invitation. Participants were recruited using a snowball sampling approach thereafter (Social Research Methods, 2006).

Information consent forms (available in French and English) were verbally detailed and signed prior to the interview, which was conducted in-person for approximately 30-40 minutes at a time and place most convenient for the participant (see **Appendix E**).

One of the advantages of using a semi-structured interview is that it allows researchers to elaborate on information that may not have been previously considered or known to be important (Gill et al., 2008). At 50% data collection, our interview was slightly revised to ensure that areas of information that emerged in the previous interviews were also collected from subsequent participants (McNamara, 2009). Tracked changes in the interview guide show the removal of one question that was difficult to answer and the addition of three questions that probe for more detail in responses describing cross-cultural methods.

Interviews were audio-recorded and transcribed by the principle investigator, Ayah Nayfeh, to facilitate data analysis. Data collected from research participants throughout the study remained confidential and secured in an encrypted file in Professor Jeff Jutai's research lab at Saint-Vincent's Hospital. Personal identifiers were removed and participants were assigned a code prior to the interview using a letter-number system to ensure on-going confidentiality (e.g. P1, P2, N1, N2). The code-list linking the participant's name to their research file was kept in a locked cabinet separate from the encrypted file in Professor Jeff Jutai's research lab at Saint-Vincent's Hospital. Only the principal investigator and co-investigators in the study have access to these research files.

Data Analysis

Narrative data from the transcribed interviews were analyzed and interpreted using content data analysis, which was done separately for physicians and nurses in order to highlight potential differences in approaches used under different scopes of care (Taylor-Powell & Renner, 2003). Due to a small data set and modest analysis needs, data analysis was completed traditionally by hand using Microsoft Word and Microsoft Excel. Themes that emerged from the transcribed interview dataset, as well as any observational and interactional data obtained during the interview, were inductively coded and categorized using emergent codes and context coding units, such as words, sentences, or paragraphs (Krippendorff, 1980; Mayring, 2000). Emergent themes were confirmed early in the analysis process by validating consistency of the coding scheme on a sample of data. Little is known about health care providers' experiences with cross-cultural ACP, therefore deduction or a priori coding was not appropriate for addressing our research question.

By establishing frequency counts of emergent themes in Microsoft Excel, we were able to establish meaningful variation of major approaches used by physicians and nurses under different scopes of care. Inferences were made from emergent themes to meet the research objectives of the study. As well, field notes that reflect the interviewer's thoughts, ideas, and feelings throughout the interview were noted to bring awareness to any preconceptions or biases to enhance credibility during analysis (Krefting, 1991).

The term reliability relative to quantitative research does not fit objectives of qualitative approaches whose major purpose is to generate hypotheses for further investigation rather than to test them (Sandelowski, 1986). However, the term validity in a qualitative sense can be used to gain credibility, knowledge and understanding of the nature

of the phenomenon under study (Leininger, 1985). To gain credibility and trustworthiness of study findings, the use of open-ended questions and clinical vignettes in the interview guide were strategically designed to help verify meanings of experiences by assessing truth value of responses (Krefting, 1991; Lincoln & Guba, 1985). Another method often used to establish validity in qualitative research is triangulation, “where researchers search for convergence among multiple and different sources of information to form themes or categories in a study” (Creswell & Miller, 2000). This project incorporates environmental triangulation by using a multi-institutional approach to recruit participants from different acute-care settings to establish validity with the results (Guion, Diehl, & McDonald, 2002). As well, co-investigator examination of emergent categories helped to enhance credibility with the evolving design of the study (Krefting, 1991).

Chapter 4 - Results

As a reminder, the objectives for this thesis project are: 1) understand methods used by health care providers to manage ethnocultural beliefs/values in ACP, 2) highlight barriers in ACP that may hinder health care providers' ability to provide cross-cultural care, and 3) explore methods used by health care providers to overcome perceived cross-cultural barriers and challenges. Recruited participants work at one or a combination of the following acute-care hospitals within the Ottawa region: l'Hôpital Montfort (N=4), Ottawa General Hospital (N=4), Civic Hospital (N=1), Queensway Hospital (N=1), and Saint-Vincent's Hospital (N=1). Two of the physicians interviewed work in ICU, one physician works in palliative care, and one physician works in both ICU and palliative care. Some physicians also do rotations in the ambulatory clinic, long-term ventilation, emergency room, operating room, and also practice as hospitalists and internists within the hospital. Of the nurses interviewed for the study, three work in ICU and one nurse works in palliative care with consults in psychiatry, ICU, emergency room, operating room, and family medicine (see **Table 1**).

All study participants completed their medical or nursing training and education in Canada, with the exception of one nurse who studied in Paris, France. Participants recall providing care to many ethnocultural groups, including African (Somalian, Haitian), Eastern European (Italian, Polish), Asian (Chinese), South American, First Nations, and Caribbean populations from various religious backgrounds (Muslim, Jewish, Jehovah's Witness, Greek Orthodox, Christianity). Support for ACP is found through hospital policies/frameworks, Speak Up campaign materials/resources, and journal articles (e.g. ACCEPT, Family Meetings).

The coded dataset of transcribed interviews revealed three major themes: 1) Goals of care across the illness continuum, 2) Respecting beliefs, values, and wishes for care, and 3)

Cross-cultural support in ACP. Methods of practice used within these themes, as well as factors that act as facilitators or barriers, are described in more detail below.

Table 1 – *Characteristics of Physician and Nurse Participants*

Number of participants invited	12
Number of participants recruited	8
Physicians	4
Nurses	4
Number of participants who are male	4
Mean number of years in practice	11
Medical	10.5
Nursing	11.5
Participation in cultural competency training/workshops	2
Physicians	0
Nurses	2

Goals of Care Across the Illness Continuum

Physicians and nurses describe goals of care as an important process for setting care plans with patients and families. Understanding beliefs and values for end-of-life care facilitates the interpretation of goals that encompass decisions for MV. A value-based approach is deemed an effective way for health care providers to ensure a respectful and dignified death. Physicians and nurses use several methods to explore goals for care with ethnocultural populations (See **Table 2**).

Exploring beliefs and values systems of patients and families. All participants believed that ethnicity, culture, or religion had a significant influence on patient/family decision-making and expectations for care. All physicians and nurses described using a ‘one size fits all’ approach with different ethnocultural populations in ACP, asking general questions to elicit cultural/religious values, meanings, and perceptions on death, dying, and

quality of life. Eliciting beliefs and values that encompass goals for care for care was seen as an effective method for interpreting treatment preferences in medical scenarios that could not always be predicted.

If I were lucky enough to meet people early in their disease course, what I would be telling them is: 'what brings meaning to your life, what are your values, what's important you, what would be acceptable for you', as opposed to 'I never want a [nasogastric] tube'. You don't know the circumstances of your future illness, it's very difficult to pinpoint particular interventions and MV would fall into that. (N1)

You 'feel' your way differently, so just the way you interact with [patients and families], there is a different expectation, it's a different approach, it's more of a blank slate. They're not the same people, they don't hear the same things, they don't recognize the same issues, so it's different. (P1)

You can't predict every possible scenario at the end-of-life, so when something is based on values, then the physicians can interpret 'Well, what was important to this person was to live independently, was to have their full mind, etc. This treatment is unlikely to give that person what was important to them, therefore we will not do it'. (P2)

While there are common ethnocultural perceptions or trends seen in medical or nursing practice, three nurses and one physician discuss the importance of not generalizing or stereotyping beliefs/values to certain ethnic or religious groups based on these past experiences. All participants recognize that variations exist between and within ethnocultural groups and believed their role was important for understanding unique patient/family perceptions.

I try to not generalize, so my approach shouldn't really be all that different, right? I've had French Canadians who are the same cultural background as myself with completely different views on end-of-life care and truth-telling. I think it's more of an individual family culture thing than one specific cultural worldview. (P2)

You can't generalize certain principles from a previous experience that you may have had with a similar family. There are so many variables within the same cultures that your role is really to learn about what their perception is and what is bringing that sort of meaning and value in how they interpret it. (N1)

Due to extensive heterogeneity between and within ethnocultural groups, two physicians and two nurses find it difficult to ensure that all important cultural or religious subtleties are addressed. Even though these two nurses in particular were the only participants in the sample to have participated in some form of culturally-competency training, both believed that patients and families had a responsibility to be verbal with beliefs/values, otherwise important aspects may be missed. The two physicians and one other nurse expressed a desire for more knowledge on ethnocultural perceptions to enhance their skills for exploring goals for care. There exists among all participants a dependency on interdisciplinary health care team members, like social workers, spiritual care, and physician/nurse colleagues, to lend insights on cross-cultural scenarios based on their experiences.

There are for sure some cultural trends, for instance truth-telling in a Chinese culture can typically be more of a difficult topic but it's not across the board. I mean it's pretty common to have that view but again I think there are some exceptions. I'd say I'm comfortable but I probably lack in some knowledge in all these subtleties in cultures, but I just try to ask. (P2)

With the number of different cultures, you never really know. There's a bit of an onus on the family to let me know because I'm not familiar with their own views or what they want. (N3)

It is not like I have a handbook, you know 'what does a Buddhist believe', I don't have any of that. It's mostly on experience and dealing with colleagues and spiritual care workers and social workers. But I'm not really aware of that, so that would be really helpful. (P4)

Finding common ground for setting care plans for MV. Participants mentioned the value in finding common ground and achieving mutual understanding in ACP with patients and families prior to making decisions for MV. All physicians described their role in exploring patient/family understanding of the medical situation, belief systems and reasoning behind medical decisions, and exploring views on what a patient/family considers to be a

reasonable or acceptable quality of life. This process allows an opportunity for physicians to address for patients and families the reality of the medical situation using data and evidence, and reinforcing their professional obligations in providing end-of-life care.

At the end of the day, it's getting people to understand what is and what is not a quality of life, because all of these different cultures that have a sanctity for life no matter the cost, they can all imagine a scenario whereby life at any cost is not reasonable. There's a quality that doesn't involve endless, intractable, untreatable pain. So okay, now at least we have a point of agreement that we can start from, let's move forward from there. (P1)

Some people feel that if you're DNR you'll get suboptimal care, you know 'If you are DNR, it's equivalent to euthanasia'. So I try to explore what is behind the belief system, sometimes to say 'You're not actively participating in their death if we're not intubating, it's the natural progression of the disease, you're permitting a natural death'. Either way the person is going to die, it's about how it's going to happen. (P2)

We start talking about what their perspective is of what's going on, I need to try as much as possible to see how much of an understanding they have about the gravity of the situation. The other thing I explore, I somehow very delicately get at what their needs are. So let's say we've reached a point where we can't cure this, we can't make this better, but we're going to try and ensure a dignified passing: what are the family's needs, and what would the patient's needs be from a cultural perspective, spiritual perspective, and social supports? (P4)

The key thing is to gain an understanding of who you're dealing with and why they think the way they do. Usually if you could have that understanding, you could establish some common ground somewhere. (P3)

One physician describes practical challenges in having all health care team members deliver the same message, especially in situations where there is a real risk of mortality that cannot be undermined.

The largest, single most important thing is ensuring that my team speaks with a single voice and a single message. That is incredibly hard to manage on a practical basis because all it takes is one nurse to say 'Oh yeah, there's a good chance that this could work' and the whole thing is undermined. (P1)

Nurses describe finding common ground by educating or addressing misconceptions regarding the dying process, MV, euthanasia, and palliative care that often occur and could

significantly impact the decision-making process. Although there are resources aimed at supporting patients and families through the dying process, one physician and one nurse see organizational barriers with providing generic materials that may not meet cultural, religious or linguistic needs.

There's a lot of misinformation out there about what end-of-life illness is and what it's not, and I think everybody needs to be better educated as to what that entails. I think if people had a better idea of what it entailed before they ended up in that situation, then that may translate into how they view their spiritual, religious or cultural beliefs. (N4)

I think often patient/families don't understand what MV is and if it is explained, they have a lot of misconceptions coming into it. I think it's important for patient/families to actually understand what that is, but I think it's also incredibly difficult because they hear about life support and they see it on in media sources and now that reality is in front of them. I think you can think about things like that in abstract terms, but my experience has been that it's extremely hard for them to translate those abstract terms into a concrete reality. All of those discussions often go out the window because when they see the reality of what's happening, they will change their minds. (N3)

I came to the realization that the reason that I exist in the hospital is to teach about dying: 'How do you die, what's normal when you die, recognizing dying, how do you talk about dying'. Almost everything I think about when I'm with people is based on my role to teach them. It doesn't matter if it's a day or if it's five-month relationship, it's almost always based on that and honestly that has served me well. (N1)

Our resources are only in English and in French, there are so many people that don't speak those languages or they would like support in other languages; I think that is a barrier. (N3)

Interpreting goals of care into care plans for MV. The content and questions of ACP move across the illness continuum from general goals of care towards the translation of those goals into treatment preferences as patients' transition between curative and comfort care. Physicians and nurses describe several methods used to help patients and families interpret their beliefs/values into goals for MV and other life-sustaining treatments. One nurse suggests avoiding yes/no questions for treatments and instead focusing on how goals for care fit into different medical scenarios. It can be difficult to interpret in different medical

contexts the true meaning of advance directives that simply pinpoint treatment preferences.

Using this approach is said to facilitate interpretation of end-of-life wishes and is seen as effective for avoiding family guilt or burden associated with feeling actively involved in a loved one's death.

What I've learned is you need to bring [patients and families] beyond these yes/no questions, because first of all they're kind of false, that is not the questions that we are asking. The question or the statement usually is 'Your loved one is dying. They are unable to sustain their life without advanced technology. How do you see that dying phase unfold?' So we're not actually asking you about the tube. People feel an incredible weight and feel like they're actively participating in people's dying. (N1)

We try to make contact with our families just to discuss who the patients is and what their goals are, not necessarily end-of-life goals, but just goals period right at the beginning. Then as times goes on, again it really depends on the patient's trajectory and the family's perception as to when and how we entertain discussions about 'We think this patient is now acutely dying and now we're going to talk about end-of-life and how to keep them comfortable'. (P4)

If I am being 100% honest, I think it is important to get a sense of where patients are and really it depends on what the cause is, right? Sometimes I think it's more important to get a sense of what the values are, get a sense of 'Is quality of life more important to you?' To answer your question directly, MV is important but what is more important to me is your goals, objectives, and values. (P3)

Two nurses specifically described the involvement of non-denominational chaplains or religious persons to assist patients/families with interpreting important religious principles that can be misinterpreted or misunderstood.

We have some non-denominational chaplains who know and have taken courses in different religions and cultural backgrounds and stuff, so they know better than we do. Sometimes we will talk with the non-denominational chaplain or the social worker about how best to proceed. (N4)

Table 2 - *Goals of Care Across the Illness Continuum*

Methods	Facilitators (F) or Barriers (B)	Illustrative Quotes
Exploring beliefs and values systems of patient and families	(F) Do not generalize (F) Interdisciplinary support (B) Lack ethnocultural knowledge (B) ICU tech-heavy environment (B) Onus on patient/family for guidance	<p>“If they’re open to talking about, then the best way is to just talk about it. Every now and then if they’re not open to talking about it, I can go on the internet and read about stuff but the internet isn’t the greatest resource.” (N4)</p> <p>“These discussions are extremely important, I think that they’re undervalued because in ICU it’s great when we’re doing our tasks, but we sort of see emotional support for the families and things secondary because we’re a very tech-heavy, machine-heavy, task-heavy environment.” (N3)</p>
Finding common ground with negotiating care plans for MV	(F) Data and evidence (B) Team Consensus (B) Resources in other languages	<p>“You have to keep bringing the object of reality back to them; an object of reality is data and evidence and in certain stages of illness, there’s certain prognostic scales you can use. If you come into ICU and have these set criteria, you may have a 50% chance of dying. So you need to talk about that realistically, openly, and honestly. That is a very real conversation that I don’t think we have with enough import, it’s often glossed over.” (P1)</p> <p>“Our hand-outs that we give to patients are pretty generic. Does it meet the needs of different cultural backgrounds? I have no idea, I don’t think it’s ever been looked at. Maybe they look at it and that’s not at all what they need.” (P2)</p>
Interpreting goals of care into care plans for MV	(F) Avoid yes/no questions (B) Difficult to pinpoint treatments	<p>“I had a call once of a woman who came in with an acute stroke and they wanted to put in a [nasogastric] tube in order to give her medication to reduce her pressure...but the daughter was frantic because her mother’s advance will had said ‘no NG tubes’. In that context, I think it could have been interpreted differently. We get involved in cases like that to help them interpret what the advance directives really mean and that is why we find it more useful when we do rely on values and meaning of life.” (N1)</p>

Respecting Diverse Beliefs, Values, and Wishes for Care

A health care providers' role in ACP is to provide patients and families with the information and skills to make informed decisions for care. Physicians have an obligation to uphold preferences for MV even if these wishes are inconsistent with what they believe to be appropriate care for the patient. Physicians and nurses use several methods to work with the patient/family to set care plans for MV in a culturally sensitive manner (see **Table 3**).

Accepting ethnocultural beliefs/values.

No objectives to convince care plans in ACP. Two physicians and one nurse recognize from experience that ethnocultural beliefs/values never fade. Patients and families will prefer to die in different ways and there will always be demand for aggressive care. The most helpful approach for avoiding frustrations described by these three participants is to accept the existence of diverse beliefs/values for care, and to avoid going into ACP discussions with objectives to convince other care plans. Doing so will only cause roadblocks and feelings of failure when patients/families do not adopt different views for care.

When the patient and family have a different opinion than the team, generally speaking, it's rare that you're going to change that opinion or change those goals. If you go in there with an agenda of convincing them that their way is wrong and your way is right, it's not going to work. (P2)

I think it's important to be open-minded because sometimes you have your own values, your own culture, and sometimes it could hurt your own values. So you have to deal with this and accept the differences but still be a nurse. (N2)

I've come to believe that we don't approach [patients/families] with these objectives to get them somewhere they're not ever going to get to. We all die very differently and there are some people who are going to die with aggressive interventions and resuscitation and they're never going to be a DNR, but that's not my job. (N1)

Depending on how restrictive or aggressive they want to be, say if it's the example of 'do everything no matter what', I have learned over the years there's not much purpose of fighting and bringing it up nine times. (P3)

There's still frustrations, there's still a feeling that we failed to bring them to that spot where we want all the families to be at the end-of-life, which is accepting of comfort care. There's still that feeling of not having been completely successful, but what I have always said is that it's okay some people don't want that. It's about having made the effort and having had those discussions and if you've done your very best to explain your perspective and to inform them so they can make an informed decision, that's all you can do really. (P2)

Of all eight health care providers, two physicians and three nurses described having experienced ethical/moral distress in situations where cultural or religious beliefs/values were inconsistent with what they believed to be appropriate for care. One physician and two nurses describe this experience to be more emotionally difficult for nurses because of their intimate role in the daily care of patients. The two physicians who did not experience distress were both male and instead described feeling 'uncomfortable' and 'physically and emotionally drained' in these situations. Of all participants, only one nurse described having no negative feelings and does not experience ethical/moral distress in such situations.

You just feel like 'this is not who I am as a person, this is not who I feel as a nurse, and this situation is wrong'. I can emotionally tell you it's wrong, I can cognitively tell you it's wrong, I physically feel sick being in this room, like this is just not right. And so it's very distressing, you don't want to come into work, you don't want to do that work. (N3)

I think that as much as possible we want to honor peoples' ethnic and cultural background and their beliefs. You want to respect people for their beliefs and sometimes they're in conflict with our beliefs. And yeah it's tough, that's very, very tough. Or the whole quality of life decision, with some ethnic or cultural beliefs, any life is life, right? I could think of this one family member where he was explaining to me that it doesn't matter that his mom can't move or can't communicate, the fact that she can just open her eye, that's life. And all the resource stuff comes into it too, not that you want to think about resources in that context, but it's really challenging. (P4)

I used to think it was my job to make [patients and families] change their mind, like that's the perception when you're younger, especially when you're the palliative care team. We actually have more success now that we don't feel that pressure. (N1)

In this setting in the ICU, it's harder on the nurses to take care of a patient that you feel you're just prolonging their suffering. They're with the patient for 12 hours a day, they know the patient intimately. I'm with the patient for 10 minutes. I think it

impacts them even more than it impacts [physicians], so that's a pretty difficult challenge to manage at times. (P3)

Support from interdisciplinary health care teams. All participants describe informal support from interdisciplinary health care teams as a helpful method for dealing with ethical/moral distress or clashes in values for care. In addition to physician and nurse colleagues, social workers and spiritual care teams offer support and input based on past cross-cultural experiences, and validate that the situation is being perceived or managed accordingly. One nurse described involvement in ethics debrief meetings as a helpful method for relieving stress and frustration, and discussing new ways to manage similar situations. Involvement of the ethics team and ethics case conferences were said to be rarely used in clinical practice by one physician and one nurse both from ICU, with no mention of this service from the remaining five participants. Only one physician described using ethics case conferences to determine whether treatments like MV should be offered in medically futile cases.

In my hospital, every first Tuesday of every month we have a staff meeting where we talk about all of the ethical situations we had during the month. We sometimes invite family representative members, the ethical nurse, ethical team, priests - it is a multidisciplinary meeting. And we talk about all the situations: 'How do you we think we could manage this? Could we manage this in other ways?' I think it helps us to deal with these kinds of situations and I try to attend every meeting because it helps me to listen to other experiences and how they deal with it. I think it is a kind of support for the team and for the nurses because you can talk about all of your frustrations. Sometimes you don't have a lot of say, you just follow the [care plan] and that could be frustrating." (N2)

I lean on my colleagues that have more experience than me: 'I'm at a loss here, help me out or help me understand this, or help me come to terms with what this is, am I seeing things properly or am I being biased' or sort of double check yourself on stuff, because it's tough...it's tough stuff. (P4)

If the goals are the same like if everyone is on the same page, I feel like there's lots of support. But when there isn't, the support usually lies in each other within the group, so other [physicians], other nurses, allied health professionals within our

organization. I don't know technically what's out there but I feel supported within our own circle. (P3)

Revisit the conversation. When inconsistent wishes for MV must be respected, all physicians and one nurse describe upholding wishes for care with the expectation to revisit the conversation with new information as the health status changes. One physician suggests setting a timeline in advance to proceed to next steps if health conditions deteriorate or do not improve. Allowing time for the medical situation to progress is said to instill trust with patients and families, and helps with grief when major steps like MV withdrawal must be made.

What I tend to do is do everything with the expectation to reconvene and rediscuss goals when it's clear things haven't been working, or things are going in the wrong direction, or if they're actively dying. I find that approach can be more useful because you're still able to maintain trust because you're doing everything. So when you eventually come and say 'despite everything the patient is dying', there tends to be less resistance and at the time the more appropriate treatment, so palliative care or comfort care, is provided. (P3)

We will continue doing whatever we're doing and then inevitably get them out of ICU or they will get worse and we can revisit the family with new information. But in the mean time we just wait, which is not a nice. The care plan for no patient should ever be wait. (N3)

In situations where a patient experiences a sudden or acute deterioration in their illness, there is uncertainty in the health outcome or benefits of MV treatment. Three of the physicians express difficulty with initiating a hard-topic like end-of-life when there is a potential that the decline can be reversed or that MV can actually provide a health benefit. Three nurses and one physician describe difficulty with discussing goals for care with patients/families when there is pressure for timely action or they are in a state of shock at the sudden risk of mortality. In these circumstances, all physicians said they would initiate MV to allow time for the situation to progress, and for the family to be calm and ready to discuss next steps.

If [the patient] comes to us and they haven't been intubated yet, how do I put it, it's a touchy subject because usually the family is under such stress that you can tell them what it means, but they don't necessarily understand because there's too much information coming all at once and they're really stressed out about what's happening to their loved one. (N4)

There's uncertainty in an acute situation, is the person going to pull through? Whereas it's more certain when you're seeing a progressive decline. When there's uncertainty with the outcome, you kind of tend to say 'do I really need to discuss this?' Because it's obviously not a topic anybody wants to discuss, including myself, like it's a hard topic. If you can avoid it, you will, right? (P2)

The problem is usually by the time they come to the ICU they're ventilated, or if they're in the [emergency room] and they're in extremis and a decision has to be made - that is the most non-optimal time to be having a discussion with the family about ventilating or not ventilating someone. So to be honest, I don't have many of those discussions. The discussions we'll have are 'the patient is ready to have the tube out, we think we've got them as good as we can get them. If they're not able to sustain themselves when having the tube, what's the next process?' (P4)

However, one nurse finds it more challenging to discuss MV withdrawal once treatment has already been initiated.

Sometimes the patient is already on a ventilator because we have to treat in emergency situations so after that, we say 'What were the patient's wishes or what was the family's wish?' There are patients who come to emergency and they are DNR, no CPR, no ventilation, etc. but at the end they finish with ventilation, CPR, etc. because we don't their wishes. For me it's very important to have a discussion before the worst happens but sometimes it's too late and it is harder to say 'Okay, now he's on ventilation - do we stop the ventilator or what?' (N2)

Table 3 - *Respecting Diverse Beliefs, Values and Wishes for Care*

Methods	Facilitators (F) or Barriers (B)	Illustrative Quotes
Accepting beliefs and values	(F) Ethics debrief meetings (F) Interdisciplinary support (B) Clash with training/experience (B) Ethical/moral distress (B) Caregiver attitudes	<p>“Sometimes you just accept that they’re going to die in the ICU with very aggressive management and that’s what their story was going to be. Try to not to let that get in the way of end-of-life care, although it’s very difficult.” (P2)</p> <p>“Especially working with First Nations, I’ve seen some colleagues have some really negative attitudes for a variety of reasons...Especially if they sort of approach with a mindset of suspicion or distrust or a lack of respect. That sets a tone for the entire health care team and then for all the interactions with that family.” (N3)</p> <p>You want to try to prevent harm, suffering, and discomfort in your patients. If the patient or family themselves want it, [physicians] have very little weight in saying ‘no, we’re not doing it’. That’s really hard because you know more what the outcome is going to be and then it’s trying to communicate that. (P2)</p>
Revisiting ACP	(F) Instills trust/rapport (F) Address family concerns (B) Costs of time (B) No previous ACP discussions (B) State of shock (B) Difficult to discuss MV withdrawal	<p>“In palliative care, our patients are kind of our easy part, we’re very comfortable with how to manage end-of-life and symptoms. We appreciate it could be much harder to be the person journeying and we’re very attentive to [the family’s] needs because we know it makes an impact on their future grief and future experience. So we’re sort of all over their perception and how we can help them.” (N1)</p> <p>Time has a very real cost in terms of cost to the team, cost to yourself, an actual financial cost to the system, there’s all of these things. (P1)</p> <p>“In someone who was previously well and acutely unwell and may die, it is very likely, especially in our society, that they’ve never thought about end-of-life. So you’re bringing up a topic that is completely new to them and unlikely that they want to discuss.” (P2)</p>

Cross-Cultural Support in ACP

Physicians and nurses use several methods to provide patients/families with the support and skills to be making meaningful decisions within ethnocultural contexts in ACP. Providing recommendations in the decision-making process and using the support of language translators can reduce burden associated with decisions for MV (see **Table 4**).

Participation in the decision-making process. Three participants described using the approach of shared decision-making as a method to provide patients/families with varying degrees of input, options, and recommendations for care. Although decisions ultimately rest with the patient/family, this approach is seen to be helpful for reducing burden and providing patients/families with evidence and support to consider different options for care. One physician finds it helpful to offer an alternative plan or an action, as opposed to presenting a plan that simply refuses MV.

Usually you get a sense of their values, who they are as a person, learn more about their illness, why are they here, what have they gone through with their illness, what stage of their illness they're at, what's their goals for treatment, are they hoping to be cured or are they hoping to just live at any costs, or hoping to maintain function? When I get a sense of that, then I usually make a recommendation and get feedback from them and whether they feel like that's an appropriate step or if they think I'm 'out to lunch'. (P3)

I have seen a lot of discussions where they're just asking a question, 'Do you want everything done? Do you want to go on a ventilator?' Well, what's the alternative? So I'll present the alternative, I'll say 'if things are going very badly, I don't think we should go to ICU, I don't think we should go on a breathing machine and it's not going to help in the long-run. I think at that point we should focus on your comfort'. I don't just say 'we're not doing this' but I also say 'this is what we're going to do', so there's something tangible and an action being made. (P2)

Share in the decision-making if you can ... They want that information and what they want is to know that this is reasonable, this is normal, this is respectful, this is loving. You don't want them to feel unsupported. There is a category of people that really just don't know and they're just not able to make decisions with the skills that they have, so you have to recognize that and support them. (N1)

One nurse believes that because nurses experience suffering with the patient at the bedside, they are therefore quicker to push for comfort care because they see situations where patients suffer and do not do well.

It can be hard for ICU nurses. I would say for myself that we so often see so much suffering and case after case where people don't do well. So if anything we're quick to say 'let's have comfort measures or let's move in a comfort direction' rather than give this three weeks, flog this poor person along, cause them all kinds of suffering, and then if we're going for comfort measures anyways, let's just go for it now. (N3)

In cultures with strong values for family decision-making, such as a patriarch/matriarch, one physician and one nurse find it challenging at times to participate in the decision-making process. Discord between decision-maker(s), other family members, and the health care team often defaults to aggressive life-sustaining care. To overcome this challenge, one physician describes using a 'family insider' to advance the physician's position on withdrawing MV within a group that is pushing for aggressive care.

I think one of our biggest challenges is when you look at old school patriarchal culture...if *the* patriarch or matriarch do not get it, it doesn't matter if everybody under them does, you're not making any headway. (P1)

You'll almost always find in a group somebody who will get it, if I can use that terminology, and then you tend to rely on them as an 'insider' in that group to advance your position within that group. (P1)

The other thing that can be hard in terms of culture is depending on how decisions are made and who the decision-makers are, you can get some strong opinions. You can have three sons and they all want to be involved. I find they can, not wanting to, but they can be in your face a little bit. (N3)

If you have discord within the family, I can't think of hardly any time where there's fighting among the family that we would quickly turn to palliate the patient or turn to comfort measures. If there's on-going fighting within the family, we're going to go full curative treatment for at least a period of time because they won't make any decisions about comfort vs. curative care if they're not all on the same page. (N3)

Language translators. Two physicians and three nurses identified language as a barrier for communicating with patients and families in ACP. Language translators were described as a great resource used to overcome language barriers and in some cases assist with understanding different ethnocultural worldviews. However, one nurse finds it difficult to provide emotional support through a translator. When translators were unavailable, two of the nurses mentioned the benefit of having a diverse, multidisciplinary team from which they are able to seek ethnocultural input. While family members can also serve as translators and trusted messengers for the patient, two physicians worry of the risk of having information filtered in a way that would impact patient understanding and decision-making.

Sometimes I worry about language barriers and sometimes we use patient's family to translate and so on. I'm not a big fan of that because you don't know what's being filtered and how it's being interpreted. I always think that if you're having these discussions and you're not 100% comfortable with speaking the language, then having an outside interpreter might have some value. (P3)

The thing that has been great is translating services or interpreter services. It's a service that before I was using barely enough and now even if the family can translate, I don't care I want an interpreter because I want the unbiased discussion with the patient without somebody filtering through. (P2)

There would be a comfort if there was someone I could reach out to. Sometimes we use translators for that but that's not their role. They're taught to translate words but they tend to come with more. I find that incredibly helpful because they can say 'in our culture, this is what we hear when you say that'. (N1)

What becomes difficult is when you're doing the day-to-day things. So we've had that big meeting, big discussion, but now I want to explain that I'm going to brush [the patient's] teeth. I want to tell the family that but I'm not necessarily going to get a translator for that, so I find what usually happens there is one family member, usually there's one child that was born in Canada and they speak English, and they'll act as the messenger and the translator for their family. That is good when they're there, I find that the rest of the time it can be really hard because you can't provide any emotional support and the language barrier can be really huge. (N3)

Table 4 - *Cross-Cultural Support in ACP*

Methods	Facilitators (F) or Barriers (B)	Illustrative Quotes
Participation in the decision-making process	<p>(F) Provide opinions for care</p> <p>(B) Nurses quick to push comfort care</p> <p>(B) Surrogate-centered decision-making</p>	<p>“[I] try and ask the questions to frame it in terms of goals of care, what they think the patient would want, not what they want, but what the patient would want...because the last thing we want is for our families to feel guilty, or to feel pressure, or to feel that they’re making the decision, because that’s an awful burden for family members.” (P4)</p> <p>The best approach is to find common ground and you work from there. We just need to figure out you think is best and is what we think is best, and what we can come to agree to is best. (P1)</p> <p>When I feel that it is not a reasonable treatment plan because the outcome will be very poor, I say it like that, ‘you’re very sick, there are things that could be done but I do not recommend you go to ICU, I do not recommend we put you on a breathing machine’. So I’m not at all reluctant to give my opinion, in fact I like to take that burden off. (P2)</p>
Language translators	<p>(F) Diverse interdisciplinary team</p> <p>(B) Communicating daily activities</p> <p>(B) Non-verbal communication</p> <p>(B) Difficult to provide emotional support</p>	<p>“Non-verbal communication can be a very big [barrier] too, a lot of people forget that but sometimes the way you interact with family members while you're providing care, you’re non-verbal communication can signal something that the family picks up on as not being congruent with care their loved one should be provided and that can cause issues.” (N4)</p> <p>“I had a translator once who made it very clear that all she would do was transfer words, and it was a very unpleasant experience. I have had other translators where they get tears in their eyes and they feel it and they help us with those things, ‘well, when you say that word it doesn’t translate well and it can mean a different thing’. It’s incredibly helpful. But you know, I don’t know if it’s Ottawa but our medical team or multidisciplinary teams are very diverse so that’s wonderful.” (N1)</p>

Clinical Vignettes**Box 1 – *Death as a taboo topic***

In some cultures, discussing death and dying with a seriously ill patient is considered offensive, taboo and inappropriate. In an attempt to develop an ACP for MV, the family pushes for familial autonomy and prefers to take responsibility for decision-making, despite the patient's capacity to make decisions.

All participants except one physician and one nurse specifically described having experienced a similar cross-cultural challenge with patients/families who have strong values for familial autonomy. No new themes emerged in response to this simulated scenario and proposed behaviours were consistent with previous methods described.

The principle of patient autonomy was regarded as the guiding principle in ACP with opportunities for the patient to defer decision-making. The main methods used to find a solution for care include (1) accepting beliefs/values, meaning patients who truly value familial autonomy can defer their role in the decision-making process, (2) adjusting to ethnocultural contexts that prefer a different approach to ACP, such as avoiding the use of negative terms like 'cancer', and (3) finding common ground and addressing family concerns, by having family members present during ACP discussions to ensure information is delivered in a sensible manner.

We always ask the [patient], we give them the option to defer or not. If it's truly cultural phenomenon, the [patient] will defer, they'll say 'nope, don't talk to me, talk to my family' and we respect that 100%. And when someone is competent and able to ask for their information, with principles of autonomy we can't - physicians will not hide it from them. Now we do respond to their cues, like some people want to know incredible details, other people are looking for very general. So there's no doubt there's that sort of adjustment. We try to make sure the families are there when we're having these discussions. (N1)

If they don't want you to say death and dying, work around it and say 'your lungs aren't able to breathe for you anymore, they have come to the end of what they can do'. Then it's no body's fault, no body has to make a hard decision. It is a statement of fact and then that provides a starting point. (N3)

The most important thing from a communication perspective is to say ‘your loved one who’s being ventilated and critically ill is able to have a conversation with us about this, so to be respectful of the human being, we need to communicate in a compassionate way what’s going on’ and have an open discussion about that. But I try to have the family there with me, I try not to have those discussions in isolation because that just sets up for mistrust. (P4)

If he/she didn’t want to know their prognosis or didn’t want to talk about, that’s their prerogative. I would try and explain to them the value in it, having a sense of control, and just having people not have to make difficult decisions for you, and just abiding by your wishes, even if it’s to do everything. But if he/she didn’t want to hear it, then I’ll respect that. (P3)

If the patient is capable and says ‘I want to be fully informed and I want to fully participate in decision-making’, then sometimes I will say ‘Well you know you’re family is concerned that this will be distressing to you and that this is in fact something we should not be doing’. I’ll be very honest and see what kind of response we’ll get. (P2)

Box 2 – Sanctity of Life

In some cultures, there is a strong value for the sanctity of life or the idea that human life is sacred and should be preserved at all costs. During an ACP discussion, a patient/family under your care express strong preferences for MV intubation, despite futility or minimal benefits of this treatment.

All participants described having experienced a similar scenario with patients and families who have strong values for the sanctity of life or preservation of life at all costs. One new method emerged in response to this simulated scenario; two physicians and one nurse made reference to a physician’s right to not offer futile treatments, like MV, in cases where it would not provide a health benefit.

Other methods used to find a solution for care include (1) respecting wishes for aggressive care, (2) initiating MV and revisiting the ACP discussion with emerging information regarding the illness, (3) receiving input and support from interdisciplinary health care team members throughout the decision-making process, (4) exploring belief systems and feelings of guilt with decision-making, (5) educating or addressing

misconceptions regarding MV, palliative care, and euthanasia, and (6) involving religious persons to assist with interpretation of beliefs/values.

Those are awful situations where you're feeling that you must intubate somebody that you don't want to intubate...To be honest, sometimes I will intubate them with the goal of continuing to have those discussions, and I'll bring other colleagues in and get support from other ways to try and help people come to terms with what the issues are. (P4)

If you're seeing that this is futile or really of no benefit, a way to go around that is to possibly put like a timeline, 'We will try it for 72 hours, if there is no improvement we are going to suggest an extubation and focusing on comfort'. So I think if that's done ahead of time rather than three days later, I think that can be helpful. (P2)

If they insist on wanting everything despite futility, I'll tell them that we could document this but reinforcing that no body is required to give you care that they deem futile. Futility is very difficult to determine, I find that in medicine there's few situations where you could say something is absolutely futile. (P3)

We have no ability without consent to remove therapy. We currently at this point today have the ability to not offer medically futile treatment. So in those cases where you can see that no body is going to listen because they have a preconceived position that they will not move off of, then we have to get the health care team involved, the hospital ethicist involved, and other people involved to make decisions as to what we feel is appropriate to offer and not offer. (P1)

In this situation, sometimes it's because [patients/families] don't know about palliative care. I think we don't talk a lot about palliative care, people sometimes think palliative care means we're going to give them medication to die...It's not like euthanasia. I think we have to introduce palliative care more than we do. (N2)

These are the cases where I feel my role is to reassure people that it's okay if they die having those advance care plans. I don't judge those advance care plans and I don't feel it's my job to bring them somewhere they're never going to get...We're never going to achieve perfect ACP with all people. (N1)

One [method] would be to see if we could get a religious person from that background involved because sometimes people have ideas but then if they have the priest or rabbi or somebody come, there can be some interpretation of that. I found sometimes that can be really impactful. (N3)

Chapter 5 - Discussion

With growing attention to the value of patient-centered care in Canada, our findings suggest systemic, organizational and personnel barriers that impact the ACP process for ethnocultural populations. There is a need for cultural competency education and training for health care providers to enhance ethnocultural knowledge, attitudes, and behaviours of personnel in ACP. We further discuss the need for organizational support within hospitals for meeting cross-cultural needs of patients and families, as well as the implementation of policies that support the movement of ACP across the illness continuum within the health care system. We identify through our findings cross-cultural facilitators that could be helpful for developing evidence-based tools enhance quality care across the illness continuum in ACP.

Respecting and Accepting Ethnocultural Beliefs and Values

The ruling for the Hassan Rasouli case in October 2013 was a landmark decision in Canadian health care when the Supreme Court of Canada ruled that family/surrogate decision-makers ultimately have the upper hand in making decisions to withdraw life-sustaining treatments (Barrett, 2013). With growing ethnocultural diversity, health care providers will increasingly face cross-cultural situations where patient/family wishes for care are inconsistent with what health care team members believe to be appropriate for the patient. Similar to the Rasouli case, religious values for the ‘sanctity of life’ and the push for aggressive treatments was the most frequent doctrine in our study that conflicted with physicians’ and nurses’ training, experience, and moral values for end-of-life care.

Considering the bioethical principles of Beauchamp and Childress (2009), it is not surprising that physicians and nurses are at times conflicted in situations where there is demand for MV for a seriously ill patient. Physicians that uphold values of beneficence and

malpractice often do not see a benefit in providing an invasive treatment that merely prolongs dying, and are likely to experience frustration when families/surrogates reject the idea of withholding or withdrawing treatment. Nevertheless, it is also wrongful to assume that all ethnocultural groups have or should have similar views as Western culture when it comes to quality of life and death.

Ethnocultural groups that use the notion of ‘sanctity of life’ often make medical decisions that override aspects of ‘quality of life’. With sanctity of life, available medical care and treatment should always be sought to give the patient a chance at health recovery – while the relief of pain and symptoms are important, life itself is considered invaluable and it is a foreign idea to weigh it otherwise. Physicians who discuss withholding or withdrawing MV with family members who advocate for these beliefs may be met with resistance, mistrust, and emotional distress. There is a wide disparity of ethnocultural views on the use of futile treatments, yet expectations for care remain underexplored. Cross-cultural studies that further explore disparities between what is expected for care and what is realistic may lend insight into solutions that work to bridge this gap.

Making medical decisions on behalf of a dying loved one is an important role with large responsibilities to guide care in the patient’s best interest. For some ethnocultural groups, this is a honourable duty for family members to collectively make decisions that fulfill perceived obligations for their loved one (Blackhall et al., 1995; Candib, 2002; Karim, 2003; Searight & Gafford, 2005). The foundation of ACP is built on the principle of patient autonomy, yet empowering patients to direct their own medical care contradicts directly with values for familial autonomy. All physicians and nurses in our study said they would respect a patient’s decision to withdraw from the decision-making process and defer medical information to family members. With patient-centered care at the forefront in Canada,

adjusting to patient preferences to defer from the decision-making process can be seen as an autonomous decision. Patient autonomy must be clarified with emphasis on patient-centered care to define the true meaning of this guiding principle.

Health care providers described their role in ACP as providing information and resources to empower patients and families to make informed decisions for care. While physicians emphasized on bringing the reality of mortality risk to patients/families through prognostic tools and data/evidence, nurses were more inclined to describe their role as educating and helping patients/families in interpreting different options for care. Although certainly ideal, physicians in our study describe time and resources as barriers for having conversations that relate to one's ethnocultural needs when there is pressure to dictate and deliver medical care. Responsibility of discussing ethnocultural aspects in ACP is often shifted to nurses, however, it is still important for physicians to be equipped with the skills to deliver and be accepting of diverse preferences for care.

Providing information on the risk of mortality and alternative options for care like palliative or hospice care is an important aspect of ACP, though the sole objective is not to succeed in convincing the patient and family to choose specific options for care. There seems to exist a wrongful perception among physicians and nurses who feel that ACP is a method used to move patients towards comfort care when outcomes look grave. Especially in cases concerning frail older adults, several nurse participants in our study discussed the urgency of having these conversations immediately upon ICU admission. Research shows that frail older adults are less likely to receive aggressive care with increasing age (Menec, Lix, Nowicki, & Ekuma, 2007). Ageism that exists among health care staff may be a factor for pushing ACP conversations to avoid MV withdrawal in seriously-ill older adults. There appears to be concern that frail patients experience more harm than good when MV is

initiated, and ultimately treatment is invasively withdrawn in the end when patient health is not restored.

This ageist approach, however, can have negative outcomes if older adult patients are pushed away from MV treatment that may actually have health benefits. As well, physicians and nurses who have objectives to change patient/family goals for care experience frustrations when they are unable to move frail older adults towards what is deemed appropriate care, most often comfort or palliative care. Feeling of ‘failure’ among health care providers in ACP appears to be linked to ethical/moral distress and negative caregiver attitudes, which research has shown can have adverse affects to job satisfaction, retention, and physical and psychological well-being (Dodek et al., 2013; Elpern et al., 2005).

The approach of shared decision-making is gaining prominence in health care policy, where “clinicians share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences” (Elwyn et al., 2010). However, based on some physicians’ responses to approaches in ACP, the concept of shared decision-making seems to extend beyond that of simply supporting deliberation. Physicians who described giving recommendations or opinions regarding MV to patients and families in our study may be acting in a paternalistic manner. Especially for some Asian cultures, physicians are viewed as authoritative figures and are obligated to comply with physician recommendations, pushing away from the true principles of patient-centered care (Kramer, Kwong, & Chung, 2002).

There is a difference between respecting and accepting ethnocultural beliefs and values that seems to be dictating these experiences for physicians and nurses. Health care providers must be open to diverse beliefs/values and varying preferences at the end-of-life to

be culturally sensitive in ACP, and should have awareness of their own values to separate this from the provision of care (Bicchi & Radcliffe, 1983). Health care providers who have the mindset to be accepting of diverse beliefs/values may experience less frustrations and negative attitudes that impact quality care.

Interestingly, ethical and moral distress with using MV was often linked to the notion of ‘suffering’ from a physical perspective for physicians and nurses. Though seldom discussed with regards to the patient, focus on psychological and existential components of suffering were often considered for family members who experience the grieving journey through the dying process and beyond death. One nurse provided a great example of an incident in which MV treatment was essential in avoiding psychological and existential suffering in the patient and family. Pushing for eternal life on earth was a strong belief for the patient’s wife, and the health care team was attentive to how this may impact her future grief. In working with community leaders, the decision to withdraw MV was eventually made when the time was appropriate. From an outsider’s perspective, this may seem like the wrongful approach was used with aggressive care, though in reality, the wife was satisfied with care and this was an appropriate approach for their situation.

As expressed by some participants and confirmed by research, these situations can be more difficult for bedside nurses who experience suffering with the patient and have little input for the direction of care (Dodek et al., 2013). Also interesting to note, the two physicians that experienced ethical/moral distress in such situations were both female, alluding to research findings that show female physicians display higher levels of empathic concern, values, and an array of negative feelings in clinical practice (Elpern et al. 2005). Physicians and nurses in our study describe seeking support from interdisciplinary health care team members in cross-cultural conflicts. While this is a great method for maintaining

continuity of care and a diffusion of knowledge between patients/families, colleagues, and other health professionals, this also highlights the need for cultural sensitivity training for end-of-life care.

A Canadian study conducted by Majumdar, Browne, Roberts, and Carpio (2004) showed long-term benefits of a cultural sensitivity training program that increased health care providers' open-mindedness, cultural awareness, improved understanding of multiculturalism, and ability to communicate with ethnocultural populations. Improving cross-cultural attitudes and awareness among health care providers through training and education can overcome personnel barriers in ACP and have positive outcomes for patients and families at the end-of-life.

Education and Support for Ethnocultural Assessments in ACP

Health care providers in this study recognize the strong influence of culture and religion on medical decisions and expectations for end-of-life care, and describe using a 'one size fits all' approach with patients and families to understand unique ethnocultural perceptions. There are many variations between and within ethnocultural groups and health care providers are aware that using this approach does not guarantee that all ethnocultural realms will be explored. Moreso, physicians and nurses in our study are aware that they may lack ethnocultural knowledge in aspects that should be further explored with patients/families which may act as a limitation in ACP. Yet a majority of physicians and nurses in the study feel confident with their skills in exploring and adjusting to diverse beliefs and values in ACP.

While the number of years in medical or nursing practice does not guarantee complete knowledge of all ethnocultural realms, our findings suggest an increase in confidence with engaging in ACP over time and with experience. Two nurse participants

described feeling 'uncomfortable' and 'intimidated' with approaching patients/families in a culturally sensitive manner due to potential gaps in ethnocultural knowledge. Despite one of these nurses having attended a cross-cultural workshop, having less than 10 years experience in nursing practice seemed to impact feelings of cultural competency in both nurses.

This is not to say, however, that having low confidence or less than 10 years experience translates into a lack of cultural competency; and vice versa, feeling confident or having more experience does not ensure that a health care provider is actually culturally competent. In a study by Watson & Day (2008), more than one-third of study respondents who identified themselves as being culturally competent were unable to correctly respond to a test of actual competency. There would be great value in providing health care providers with education and training on ethnocultural knowledge and effective cross-cultural communication skills in order to bridge potential gaps that may be unknown, harmful, or better improved. In fact, even respondents in our study that described feeling confident in ACP expressed desires for cross-cultural support and education pertaining to different methods for communicating across cultures.

Current postgraduate studies and training in Canada use the newly developed Triple C Competency-based Curriculum, which emphasizes the importance of patient-centered care within ethnocultural contexts (Tannenbaum et al., 2011). While efforts to improve patient-physician communication may have enhanced patient-centered care since the incorporation of this curriculum, a study by Johnson et al. (2004) found evidence that ethnic minorities are still more likely to perceive bias and a lack of cultural competency when seeking health care services in comparison to Caucasians. Targeting personnel barriers by enhancing culturally competent skills alone will not enhance patient-centered care; attention to systemic and

organizational barriers that facilitate the transferability of ACP can improve the provision of cross-cultural care.

Barriers Across the illness Continuum in ACP

Physician and nurse respondents describe ACP discussions as moving across the illness continuum from general beliefs, values, and goals for care towards the translation of those goals into treatment decisions when health outcomes look grave. As stated by physicians in our study as well as other research studies, this current approach to ACP works well with patients dealing with illnesses that experience a gradual and evident decline in health towards death, such as cancer (Fassbender et al., 2009). Unfortunately, physicians express difficulty with predicting timing of death in patients suffering from acute co-morbidities and this is commonly associated with the initiation of MV during serious deteriorations.

Patient preferences are often unknown in these situations when they are admitted to hospital and our respondents feel this is a non-optimal time to be exploring goals for care under timely pressure. Physicians in our study said they would initiate MV in these high-pressure situations with the expectation for physicians to reconvene goals of care. Aside from the obvious issue of potentially providing unwanted life-sustaining treatment, the initiation of MV is often the site where cultural or religious clashes occur. As previously stated, Jewish, Muslim, and Catholic religions allow the refusal of MV but forbid the withdrawal of life-sustaining therapies once they have been initiated (Jericho, 2011). Suicide is condemned in these three monotheistic religions and the act of MV withdrawal can be interpreted as an action that hastens death (Jericho, 2011).

A Canadian study by Marcoux et al. (2007) shows that people often confuse withholding or withdrawal of life-sustaining treatments as acts of euthanasia, and some

misinterpret this as an active step towards death or believe they do not have rights to express such preferences for care. This may be a cause from recurring debates on euthanasia and physician-assisted suicide which have been at the forefronts recently in Canada, particularly with the landmark passing in June 2014 of Bill 52 in Quebec that now allows terminally ill patients the right to choose to die (Hivon, 2013). Respondents in our study described the involvement of non-denominational chaplains or spiritual care workers as helpful for patients/families in interpreting their medical situation within ethnocultural contexts.

However, a study by Abu Ras & Laird (2011) found that generic interfaith spiritual care workers find it challenging to address the needs of Muslim patients and non-denominational services are often rejected and refused. It would be interesting to assess patient/family satisfaction and effectiveness with using non-denominational chaplains in place of religious persons or community leaders. Collecting feedback and information from key informants in Canada's largest visible minority groups may help with tailoring support services to meet diverse cultural or spiritual needs.

Patients and families who do not have the support or skills to interpret important beliefs/values into goals for care not only burden themselves, but also make it difficult for health care teams to act on decisions that are not well informed. In such scenarios, physicians described keeping a seriously ill patient on the ventilator while discussions to withdraw MV occur with the family over a period of time. While nurses in this study, as well as other studies, find it more difficult to discuss MV withdrawal once it has already been initiated (Rubenfeld, 2004), physicians use this approach to instill trust with families and it is said to help with coming to terms with the reality of mortality risk as emerging health information is brought to the family.

Physicians are not obligated to provide care or treatment that is deemed medically futile, though assessing futility in some cases was said to be very difficult. Particularly in patients who experience intermittent episodes of serious decline (e.g. heart failure, pulmonary disease), physicians have a difficult time in judging whether MV would provide a health benefit or if this is the hospital admission in which the patient does not recover from. Interestingly, physicians who fought to withdraw MV from Mr. Hassan Rasouli argued that treatment was futile and they did not in fact require consent from the family to withdraw treatment (Barrett, 2013). However, Ontario law interprets ‘treatment’ broadly as palliative, therapeutic, preventative, diagnostic, or cosmetic care for the patient under different circumstances. For Mr. Rasouli, forestalling death was considered to be ‘therapeutic’ and ‘preventative’ purposes of treatment, therefore requiring consent under Ontario’s Health Care Consent Act (Barrett, 2013).

By providing clarification of Canada’s driving bioethical principles can work to address organizational gaps that make it difficult for physicians and nurses to enhance patient-centered care. However, these efforts must also be supported by a systemic structure that allows ACP discussions to move across the illness continuum with the patient to different health care settings. The implementation of an effective ACP framework in health settings that support different illness trajectories may serve as a valuable tool for avoiding unnecessary or unwanted MV treatment.

Implications of ACP in Long-Term Care

End-of-life is a hard topic to discuss for not only patients and their families, but health care providers as well who were not always comfortable with initiating the conversation. Especially when it comes to patients dealing with acute co-morbidities, there is no urgency to plan for end-of-life care and if the conversation could be delayed, physicians

and nurses in our study said they would. Only about one-third of long-term care facilities currently have policies for ACP and these discussions are not in routine practice (CHPCA, 2012). The implementation of routine ACP in organizational settings such as long-term care can be important for allowing patients in different stages of illness trajectories and their families to begin the consideration of important beliefs/values early in the disease course to guide how decisions should be made.

An increasing number of older adult patients from a wide range of demographics receive specialized care in long-term care or nursing facilities and about 63% of these patients are hospitalized in the last six months of life (Jayaraman & Joseph, 2013; Menec et al., 2004). Researchers have supported the implementation of ACP policies in long-term care to help patients, families, and health care providers plan for care in an environment that supports decisions to evolve over time (Cantor & Pearlman, 2004). The availability of social workers, clinical managers and nurses in the daily care of patients helps in advocating and regulating the consideration of important beliefs/values that are interpreted into goals for care.

As well, the advantage of having ACP discussions in long-term care settings is that most patients have the mental capacity to consider and express informed preferences for treatment and hospitalization. However, considering the number of patients affected by Alzheimer's disease and dementia is expected to rise significantly in Canada (ASC, 2010), there is significant need for evidence-based methods for engaging in ACP with cognitively impaired patients. Goals for care must be revisited as a patient moves through stages in an illness trajectory, and it is crucial for health care providers to be equipped with the tools, skills, and framework to obtain this information from frail older adults in long-term care.

These organizational efforts should be met with public health efforts that empower patients and families, and even the general population, to have effective ACP discussions.

Providing patients/families with informational resources early in the disease course that educate on euthanasia, palliative care, and end-of-life care treatment such as MV can work to avoid hospitalization and unwanted care (Cantor & Pearlman, 2004; Silveria, DiPiero, Gerrity, & Feudtner, 2000). However, generic materials and resources available in French and English only may not provide ethnocultural populations with the required support and skills for decision-making, and may be at a disadvantage in comparison to individuals who are able to take away valuable information. Researchers and stakeholders should explore whether current end-of-life resources meet the needs of diverse populations and identify ways to address any disparities.

Due to the current reality of end-of-life care for frail older adults and patients with acute co-morbidities, the implementation of ACP policies in long-term care and nursing facilities works to provide continued care within the health care system. However, there is a crucial need for an integrated ACP framework that moves with patients and families across the illness continuum through the health care system. Health care preferences are not stable over time and health care providers across health settings should be equipped with the education and skills to communicate with ethnocultural populations to ensure wishes are up to date and regularly revisited.

Recommendations

In light of our study findings that highlight systemic, organizational, and personnel barriers, we propose the following recommendations. First and foremost, cross-cultural education and culturally competent training must be provided to health care providers across health settings. Many organizations, such as the Speak Up campaign, are working to bring

increased focus to values/beliefs and patient-centered care to facilitate the interpretation of treatment preferences that can be misguided with advance directives. Incorporating training and education on ethnocultural realms, ethnocultural assessments, and cultural sensitivity into curriculums is a great initiative, though continued learning is crucial for ensuring on-going behaviours. In line with these efforts, how health care providers' views on patient autonomy and concepts of suffering should also be addressed in training workshops to support a patient-centered approach. The development of evidence-based online learning modules that are easily accessible to health care staff is a cost-effective tool that can be easily implemented into health care organizations.

In support of education initiatives, cross-cultural considerations should be incorporated into ACP frameworks. While findings from this study give insight into methods or guidelines used to find solutions for care, evidence-based research using various methodological approaches and from different stakeholder perspectives should be done on this topic. Future research studies should dive deeper into understanding patient/family expectations for cross-cultural care at the end-of-life and the reality of those expectations.

Lastly, Canadians need an integrated health system that emphasizes continued care. The importance of ACP in health settings should not be downplayed in the wake of an upcoming crisis for sustainable care. Physicians' expressed the great value that would come with having a central database or a unifying tool to facilitate the transferability of advance care plans or advance directives. Ontario's Local Health Integration Networks (LHIN) was developed to improve patient experience and access to health care services within a specified region; to utilize a developed system to implement a unifying jurisdiction for ACP is a feasible method for facilitating the transferability of ACP documents as patients/families move across the illness continuum between health settings.

Box 3 – Recommendations for knowledge-translation in health care

- Culturally competent education and training to enhance knowledge, attitudes, and behaviours of physicians and nurses
- Inclusion of evidence-based cross-cultural considerations in ACP frameworks
- Implementation of ACP policies in settings that support different illness trajectories

Reflection of the Researcher

With media attention to the topic of end-of-life and particularly patient cases where ethnocultural influences were causing friction in health care, I was driven to this research topic when I found myself torn on what an ethical approach to care would look like. As a Palestinian-Canadian from a Muslim background who has completed Health Ethics and Health Policy courses in my undergraduate degree, I was perplexed by the decisions I believe I would make if I was to balance my own beliefs and values with this knowledge. Having this ‘patient’ perspective in mind, I was emotionally driven to immerse the ‘health sciences’ side of me in research that aims to mediate an ethical solution.

As part of my research fellowship with the Technology Evaluation in the Elderly Network, I was privileged to have a patient/family support system voice to ensure that major themes from the interview dataset could be discussed with patient/family perspectives in mind. In conclusion of my research, I stand stronger in saying that there is no guaranteed approach and policies dictating a one way road will only present conflicts. The solution comes from efforts on both sides; my belief is that the Canadian health system needs to mediate through education and training efforts on a widescale to ensure these conversations are effectively being had in advance.

Limitations

There are a few limitations and methodological weaknesses in our study that should be acknowledged. While the use of a multi-institutional approach helps to establish validity with results, recruitment was limited to acute-care hospitals within the Ottawa region. Though the strength and consistency of major themes suggest they may be generalizable, our findings need to be confirmed with health care providers' experiences with cross-cultural ACP in hospitals elsewhere in Ontario. Participants were only recruited from ICU and palliative care units with consults in other various acute-care settings. Advance care planning occurs across the illness continuum and responses may vary depending on the health care unit. As well, ethnocultural demographics of patients/families within the research sites were not obtained and it is unknown whether certain hospitals present more cross-cultural scenarios than others, influencing responses to culturally competent care. In cases where only one participant was recruited from a hospital setting, this limitation was strengthened by recruiting from hospitals with the same over-arching policies under the Ottawa Hospital Network.

It is also possible that some participants had social desirability bias in their responses to sensitive questions regarding attitudes and behaviours towards cross-cultural care (Kirk & Miller, 1986). Descriptions of approaches to care may not be the same as the care that was actually delivered. To strengthen this limitation in accordance with our time and resources, the interview guide was designed in a manner that allows cross-validation of knowledge, attitudes and proposed behaviours. There was no indication that participants were hesitant or reluctant with their answers, however, there could be more certainty by using a different methodological approach. Future research studies on this topic should cross-validate

information collected from health care providers with responses from patient and family members. Using a comparative approach that measures potential disparities in the way care is received would be a good way to assess culturally competent care.

Conclusion

In conclusion, methods for managing ethnocultural diversity in ACP are essential to the provision of patient-centered care. An ACP framework that integrates systemic, organizational, and personnel aspects as a working unit can have significant improvements on the success of advanced planning. Cross-cultural education and skills training for health care providers alone will not ensure a culturally-sensitive and dignified death for patients and families. Efforts to structure an ACP process that supports patients/families in different illness trajectories may be effective for ensuring advance consideration of goals of care, as well as the continued provision of culturally competent care across the illness continuum. Ultimately, strengthening the application of ACP in different tiers within the Canadian health system can prove to be a valuable tool for reducing economic, financial, and social burden at the end-of-life.

References

- Abu Ras W. & Laird L. (2011). How Muslim and Non-Muslim Chaplains Serve Muslim Patients? Does the Interfaith Chaplaincy Model Have Room for Muslims' Experiences? *J Relig Health*, 50(1), 46-61.
- Alberta Heritage Foundation for Medical Research. (2005). *Advance Directives and Health Care Costs at the End of Life*. Alberta, Canada. Retrieved from: <http://www.assembly.ab.ca/lao/library/egovdocs/2005/alhfm/150236.pdf>
- Ali, N.S., Khalil, H.Z., & Yousef, W. (1993). A comparison of American and Egyptian cancer patients' attitudes and unmet needs. *Cancer Nurs*, 16(3): 93-203.
- Alzheimer's Society of Canada. (2010). *Rising Tide: The Impact of Dementia on Canadian Society*. Toronto, Ontario: Alzheimer's Society of Canada. Retrieved from: http://www.alzheimer.ca/~media/Files/national/Advocacy/ASC_Rising_Tide_Full_Report_e.pdf
- Baker, M.E. (2002). Economic, political and ethnic influences on end-of-life decision-making: A decade in review. *J Health Soc Policy*, 14(3), 27-39.
- Balboni, T.A., Paulk, M.E., Balboni, M.J., Phelps, A.C., Loggers, E.T., Wright, A.A...Prigerson, H.G. (2010). Provision of spiritual care to patients with advanced cancer: associations with medical care and quality of life near death. *J Clin Oncol*, 28(3), 445-452.
- Barrett, J. (2013, October 18). Doctors can't end Hassan Rasouli's life support without consent, Supreme Court rules. *National Post*. Retrieved from: <http://news.nationalpost.com/2013/10/18/supreme-court-upholds-right-to-demand-life-support-against-advice-doctors-cant-end-aid-without-consent/>

- Beauchamp, T., & Childress, J. (2009). *Principles of biomedical ethics (6th ed.)*. New York: Oxford University Press.
- Biocchi R. & Radcliffe S. (1983). *A shared experience: bridging cultures* (pp 10-16). London, Ontario: London Cross-Cultural Learner Centre.
- Bito, S., Matsumura, S., Singer, M.K., Meredith, L.S., Fukuhara, S., & Wenger N.S. (2007). Acculturation and end-of-life decision making: Comparison of Japanese and Japanese American focus groups. *Bioethics*, 21(5), 251-262.
- Blackhall, L. J., Murphy, S.T., Frank, G., Michel, V., & Azen, S. (1995). Ethnicity and attitudes toward patient autonomy. *JAMA*, 274(10), 820-825.
- Bowman, K. (2004). What are the limits of bioethics in a culturally pluralistic society? *J Law Med Ethics*, 32(4), 664-669.
- Bowman, K.W., & Singer, P.A. (2001). Chinese seniors' perspectives on end-of-life decisions. *Soc Sci Med*, 53(2001), 455-464.
- Bravo, G., Dubois, M.F., & Wagneur, B. (2008). Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. *Soc Sci Med*, 67(7), 1122-1132.
- Brown, R.L., & Suresh, U. (2004). Further Analysis of Future Canadian Health Care Costs. *North American Actuarial Journal*, 8(2):1-10.
- Bullock, K. (2006). Promoting advance directives among African Americans: a faith-based model. *J Palliat Med*, 29(1), 183-195.
- Campinha-Bacote, J. (2009). A culturally competent model of care for African Americans. *Urologic Nursing*, 29(1), 49-54.
- Campinha-Bacote, J. (2011). Delivering patient-centered care in the midst of a cultural

conflict: the role of cultural competence. *OJIN*, 16(2). Retrieved from:

<http://www.nursingworld.org/MainMenuCategories/ANAMarketplace/ANAPeriodicals/OJIN/TableofContents/Vol-16-2011/No2-May-2011/Delivering-Patient-Centered-Care-in-the-Midst-of-a-Cultural-Conflict.html>

Canadian Association of Critical Care Nursing Working Group. (1999). CACCN Position Statement. Advance directives. *Cdn Assoc Crit Care Nurs*, 10(2), 10-1.

Canadian Hospice Palliative Care Association. (2012). *Advance Care Planning in Canada: A National Framework*. Ottawa, Ontario. Retrieved from:

<http://www.advancecareplanning.ca/media/40158/acp%20framework%202012%20eng.pdf>

Canadian Institute of Health Information. (2010). *National Health Expenditure Trends, 1975 to 2010*. Ottawa, Ontario. Retrieved from:

http://secure.cihi.ca/cihiweb/products/NHEX_Trends_Report_2010_final_ENG_web.pdf

Canadian Nurses Association. (2002). *Code of ethics for registered nurses*. Ottawa,

Ontario: CNA. Retrieved from: <https://cna-aaic.ca/~media/cna/files/en/codeofethics.pdf>

Canadian Nurses Association. (2004). *Position statement: Promoting culturally*

competent care. Ottawa, ON: Retrieved from: http://cna-aaic.ca/~media/cna/page-content/pdf-fr/ps73_promoting_culturally_competent_care_march_2004_e.pdf

Canadian Medical Association. (2007). Euthanasia and assisted suicide. *CMA Policy*.

Retrieved from: <http://policybase.cma.ca/dbtw-wpd/Policypdf/PD07-01.pdf>

Canadian Medical Association. (2008). *Achieving Patient-Centered Collaborative Care*.

- Ottawa, Ontario: CMA Policy Document. Retrieved from:
<http://policybase.cma.ca/dbtw-wpd%5CPolicypdf%5CPD08-02.pdf>
- Canadian Nurses Association. (2008). Providing nurse care at the end of life. Ottawa, Ontario: CNA Position Statement. Retrieved from: http://www2.cna-aiic.ca/CNA/documents/pdf/publications/PS96_End_of_Life_e.pdf
- Candib, L.M. (2002). Truth telling and advance planning at the end of life: Problems with autonomy in a multicultural world. *Fam Syst Health*, 20(3), 213-228.
- Cantor, M.D., & Pearlman, R.A. (2004). Advance care planning in long-term care facilities. *J Am Med Dir Assoc*, 5: S73-S80.
- Carmel, S., & Mutran, E.J. (1999). Stability of elderly persons' expressed preferences regarding the use of life-sustaining treatments. *Soc Sci Med*, 49(3), 303–311.
- Chambers, T. (2000). Cross-cultural issues in caring for patients with cancer. *Cancer Treat Res*, 140:23-37.
- Charmel, P.A., & Frampton, S. (2008). Building the business case for patient-centered care: patient-centered care has the potential to reduce adverse events, malpractice claims, and operating costs while improving market share. *Healthcare Financial Management*. Retrieved from:
http://findarticles.com/p/articles/mi_m3257/is_3_62/ai_n24942366/?tag=content:coll
- Clarfield, A.M., Gordon, M., Markwell, H., & Shabbir, M.H.A. (2003). Ethical Issues in End-of-Life Geriatric Care: The Approach of Three Monotheistic Religions—Judaism, Catholicism, and Islam. *J Am Geriatr Soc*, 51(8), 1149–1154.
- Con, A. (2007). *Cross-Cultural Considerations in Promoting Advance Care Planning in Canada*. CIHR Cross-Cultural Palliative NET. BC Cancer Agency. Retrieved from:

http://www.bccancer.bc.ca/NR/rdonlyres/E17D408A-C0DB-40FA-9682-9DD914BB771F/28582/COLOUR030408_Con.pdf

Coolen, P.R. (2012). *Cultural Relevance in End-of-Life Care*. Seattle, Washington:

University of Washington. Retrieved from:

<http://ethnomed.org/clinical/end-of-life/cultural-relevance-in-end-of-life-care>

Cook, D., Ricker, G., Marshall, J., Sjøkvist, P., Dodek, P., Griffith, L...Guyatt G.

(2004). Withdrawal of Mechanical Ventilation in Anticipation of Death in the Intensive Care Unit. *N Engl J Med* 349:1123-32.

Cooley, M.E., & Jennings-Dozier. K. (1998). Cultural assessment of black American men treated for prostate cancer: clinical case studies. *Oncol Nurs Forum*, 25(10), 1729-36.

Council on Ethical and Judicial Affairs. (1991). Guidelines for the appropriate use of do-not-resuscitate orders. *JAMA*, 265, 1868–71.

Crawley, L.M. (2005). Racial, cultural, and ethnic factors influencing end-of-life care. *J Palliat Med*, 8(1), S58-S69.

Crawley, L., Payne, R., Bolden, J., Payne, T., Washington, P., & Williams, S. (2000). Initiative to Improve Palliative and End-of-Life Care in the African American Community. *JAMA*, 284(19):2518-2521.

Creswell, J.W. (1998). *Qualitative inquiry and research design: Choosing among five traditions*. Thousand Oaks, CA: Sage Publications.

Creswell, J.W. (2006). *Five Qualitative Approaches to Inquiry*. SAGE Publications.

Retrieved from: http://www.sagepub.com/upm-data/13421_Chapter4.pdf

Creswell, J.W., & Miller, D.L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-131.

- Deraspe, R. (2011). *Canada's Aging Population and Public Policy: 3. The Effects on Health Care*. Ottawa, Ontario: Parliament of Canada. Retrieved from:
<http://www.parl.gc.ca/Content/LOP/ResearchPublications/2011-122-e.htm>
- Dodek, P.M., Hamric, A., Ayas, N., Dhingra, V., Heppell, L., Keenan, S... Rodney, P. (2012). Moral distress in ICU professionals is associated with profession and years of experience. *Am J Respir Crit Care Med*, 185:A1607
- Dodek, P.M., Norena, M., Ayas, N., & Wong, H. (2013). Moral distress is associated with general workplace distress in intensive care unit staff. *Am J Respir Crit Care Med*, 187: A5331
- Dunbrack, J. (2006). *Advance care planning: the Glossary project – Final Report*. Ottawa, Ontario: Health Canada. Retrieved from: <http://www.hc-sc.gc.ca/hcs-sss/pubs/palliat/2006-proj-glos/index-eng.php>
- Educating Future Physicians in Palliative and End-of-Life Care. (2008). *Facilitating Advance Care Planning: An Interprofessional Educational Program: Curriculum Materials*. Ottawa, Ontario: Health Canada. Retrieved from:
https://www.afmc.ca/efppecc/docs/pdf_2008_advance_care_planning_curriculum_module_final.pdf
- Ellerby, J.H., McKenzie, J., McKay, S., Garipey, G.J., & Kaufert, J.M. (2000). Bioethics for clinicians: 18 Aboriginal cultures. *Can Med Assoc J*, 7(163), 845-850.
- Elpern, E.H., Covert, B., & Kleinpell, R. (2005). Moral distress of staff nurses in a medical intensive care unit. *Am J Crit Care*, 14(6), 523-530.
- Elwyn, G., Coulter, A., Laitner, S., Walker, E., Watson, P., & Thomson R. (2010). Implementing shared decision making in the NHS. *BMJ*, 341: c5146.

Emanuel, E.J., & Emanuel, L.L. (1992). Proxy decision making for incompetent patients.

An ethical and empirical analysis. *JAMA*, 267(15), 2067–2071.

End of life Care Network. (2011). Key definitions of end of life care. *Cumbria and*

Lancashire End of Life Network. Retrieved from:

http://www.endoflifecumbriaandlancashire.org.uk/info_patients_carers/definitions.php

Eues, S. (2007). End-of-life care: improving quality of life at the end of life. *Prof Case*

Manag, 12(6), 339-344.

Fassbender, K., Fainsinger, R.L., Carson, M., & Finegan, B.A. (2009). Cost Trajectories

at the End of Life: The Canadian Experience. *J Pain Symptom Manage*, 38(1), 75-80.

Fero, L.J., Witsberger, C.M., & Hoffman, L.A. (2009). Critical thinking ability of new

graduate and experienced nurses. *J Adv Nurs*, 65(1), 139–148.

Fowler, R., & Hammer, M. (2013). End of life care in Canada. *Clin Invest Med*, 36(3),

E127-E132.

Fritsch, J., Petronio, S., Helft, P.R., & Torke, A.M. (2013). Making decisions for

hospitalized older adults: Ethical factors considered by family surrogates. *J Clin Ethics*,

24(2), 125-134.

Fukuda-Parr, S. (2004). *Human Development Report 2004: Cultural liberty in today's*

diverse world. New York: United Nations Development Programme.

Gibson, D., & Zhong, M. (2005). Intercultural communication competence in the health

care context. *Intern J Intercult Rel*, 29(5), 621-634.

Giger, J., Davidhizar, R., & Fordham, P. (2006). Multicultural and multiethnic

considerations and advanced directives: developing cultural competency. *J Cult Divers*,

13(1), 3-9.

- Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *BDJ*, 204(6), 291-295.
- Gillick M, Berkman S, & Cullen L. (1999). A patient-centered approach to advance medical planning in the nursing home. *J Am Geriatr Soc*, 47(2), 227–230.
- Goldstein, D., Thewes, B., & Butow, P. (2002). Communicating in a multicultural society II: Greek community attitudes towards cancer in Australia. *Intern Med J*, 32(7), 289-296.
- Gregg, J., & Saha, S. (2007). Communicative competence: a framework for understanding language barriers in health care. *J Gen Intern Med*, 22(2), 368-270.
- Guion, L.A., Diehl, D.C., & McDonald, D. (2002). Triangulation: Establishing the Validity of Qualitative Studies. IFAS Extension: University of Florida. Retrieved from: <http://edis.ifas.ufl.edu/fy394>
- Guo, B., & Harstall, C. (2004). *Advance Directives for End-of-Life Care in the Elderly – Effectiveness of Delivery Modes*. Edmonton, Alberta: Alberta Heritage Foundation for Medical Research. Retrieved from: <http://www.ihe.ca/documents/ip20.pdf>
- Gysels, M., Shipman, C., & Higginson, I.J. (2008). Is the qualitative research interview an acceptable medium for research with palliative care patients and carers? *BMC Med Ethics*, 9:7. Retrieved from: <http://www.biomedcentral.com/1472-6939/9/7>
- Hamel C.F, Guse L.W, Hawranik P.G, Bond J.B Jr. (2002). Advance directives and community-dwelling older adults. *West J Nurs Res*, 24(2), 143-58.
- Hanson, L.C., Danis, M., & Garrett, J. (1997). What is wrong with end-of- life care? Opinions of bereaved family members. *J Am Geriatr Soc*, 45(11), 1339 –1344
- Health Canada. (2003). *What determines Health?* Ottawa, Ontario: Health Canada. Retrieved from: <http://www.hc-sc.gc.ca/hppb/phdd/determinants/determinants.html>

- Health Canada. (2008). *Implementation Guide to Advance Care Planning in Canada: A Case Study of Two Health Authorities*. Retrieved from: http://www.hc-sc.gc.ca/hcs-sss/alt_formats/pdf/pubs/palliat/2008-acp-guide-pps/acp-guide-pps-eng.pdf
- Health Canada. (2009). *Palliative and end of life care*. Retrieved from: <http://www.hc-sc.gc.ca/hcs-sss/palliat/index-eng.php>
- Health Law Institute. (2009). *A Summary of Canadian Legislation Concerning Advance Directives*. Halifax, Nova Scotia: Dalhousie University. Retrieved from: http://as01.ucis.dal.ca/dhli/cmp_advdirectives
- Heyland, D.K., Frank, C., Groll, D., Pichora, D., Dodek, P., Rocker, G., & Gafni A. (2006). Understanding Cardiopulmonary Resuscitation Decision Making* Perspectives of Seriously Ill Hospitalized Patients and Family Members. *Critical Care Medicine*. *CHEST*, 130(2), 419 -428.
- Heyland, D.K., Rocker, G.M., O'Callaghan, C.J., Dodek, P.M., & Cook, D.J. (2003). Dying in the ICU: perspectives of family members. *Chest*, 124(1), 392– 397.
- Higginbottom, G.M.A., Richter, M.S., Mogale, R.S., Ortiz, L., Young, S., & Mollell, O. (2011). Identification of nursing assessment models/tools validated in clinical practice for use with diverse ethno-cultural groups: an integrative review of the literature. *BMC Nursing*, 10:16-26.
- Higginson, I.J., Finlay, I.G., Goodwin, D.M., Hood, K., Edwards, A.G., Cook, A...Normand, C.E. (2003). Is there evidence that palliative care teams alter end-of-life experiences of patients and their caregivers? *J Pain Symptom Manage*, 25(2), 150-168.
- Hivon, V. (2013). *Bill 52: An Act respecting end-of-life care*. Quebec, Canada: National

Assembly of Quebec. Retrieved from:

http://www.google.ca/url?sa=t&rct=j&q=&esrc=s&source=web&cd=2&sqi=2&ved=0C DUQFjAB&url=http%3A%2F%2Fwww.assnat.qc.ca%2FMedia%2FProcess.aspx%3FMediaId%3DANQ.Vigie.Bll.DocumentGenerique_72865en&ei=QcoIVPWhBpOjyASbvoCwDQ&usg=AFQjCNFxmE5DO3sdacMPBma8TYdEHWIIQ&bvm=bv.74649129.d.aWw

Hudelson P, Perron N.J & Perneger T.V. (2011). Measuring physician's and medical students' attitudes toward caring for immigrant patients. *Eval Health Prof*, 33(4), 452-472.

Hudelson, P., Perron, N.J., & Perneger, T.V. (2011). Using clinical vignettes to assess doctors' and medical students' ability to identify sociocultural factors affecting health and health care. *Med Teach*, 33(10), e564-571.

Jackson, V.A., Mack, J., Matsuyama, R., Lakoma, M.D., Sullivan, A.M., Arnold, R.M... Block, S.D. (2008). A qualitative study of Oncologists' approaches to end-of-life care. *J Pall Med*, 11(6), 893-906.

Jacobs, L.M., Burns, K., & Bennett Jacobs, B. (2008). Trauma death: views of the public and trauma professionals on death and dying from injuries. *Arch Surg*, 143(8): 730-735.

Jayaraman J. & Joseph J.K. (2013). Determinants of place of death: a population-based retrospective cohort study. *BMC Palliative Care*, 12(19).

Jericho, B. (2011). End-Of-Life Issues: Withdrawal of Life-Sustaining Therapy-Religious Perspectives. *American society of anaesthesiology*, 128:1-9. Retrieved from: <http://www.icaa.ir/Portals/0/End-Of-Life%20Issues%20Withdrawal%20of%20Life-Sustaining%20Therapy-Religious%20Perspectives.pdf>

- Johnson, B. R. (1997). Examining the validity structure of qualitative research. *Education, 118*(3), 282-292.
- Johnson R.L, Saha S, Arbelaez J.J, Beach M.C, Cooper L.A. (2004). Racial and Ethnic Differences in Patient Perceptions of Bias and Cultural Competence in Health Care. *J Gen Intern Med, 19*(2), 101-110.
- Johnstone, M.J., & Kanitsaki, O. (2009). Ethics and Advance Care Planning in a Culturally Diverse Society. *J Transcult Nurs, 20*(4), 405-16.
- Kachingwe, A., & Huff, R. (2007). The ethics of health promotion intervention in culturally diverse populations. In M. Kline & R. Huff (Eds.), *Health Promotion in Multicultural Populations* (2nd ed., pp. 40-56). Los Angeles, London, New Delhi, Singapore: SAGE.
- Kagawa-Singer, M., & Backhall, L. (2001). Negotiating cross-cultural issues at end of life. *JAMA, 286*(23), 2993-3001.
- Karim, K. (2003). Informing cancer patients: Truth telling and culture. *Can Nurs Prac, 2*(3), 23-31.
- Kirk, J. & Miller, M. (1986). *Reliability and validity in qualitative research*. Beverly Hills, CA: Sage.
- Koenig, B.A., & Gates-Williams, J. (1995). Understanding cultural differences in caring for dying patients. *West J Med, 163*(3), 244 –249
- Kramer, E.J., Kwong, K., & Chung, H. (2002). Cultural factors influencing the mental health of Asian Americans. *West J Med, 176*(4), 227-231.
- Krefting, L. (1991). Rigor in Qualitative Research: The Assessment of Trustworthiness. *The American Journal of Occupational Therapy, 45*(3), 214-222.

- Krippendorff, K. (1980). *Content Analysis: An Introduction to Its Methodology*. Newbury Park, CA: Sage.
- Kwak, J. & Haley, W.E. (2005). Current research findings on end-of-life decision making among racially or ethnically diverse groups. *Gerontologist*, 45(5), 634–41.
- LeClaire, M.M., Oakes, J.M., Weinert, C.R. (2005). Communication of prognostic information for critically ill patients. *Chest*, 128, 1728 –1735.
- Legard, R., Keegan, J., & Ward, K. (2003). In-depth interviews. *Qualitative research practice: a guide for social science students and researchers*. pp 139-169. London: Sage Publications.
- Leininger, M.M. (1985). Nature, rationale and importance of qualitative research methods in nursing. In M. M. Leininger (Ed.), *Qualitative research methods in nursing* (pp. 1-28). New York: Grune & Stratton.
- Lewis, S. (2009). *Patient centered care: an introduction to what it is and how to achieve it*. Saskatoon, Saskatchewan: Saskatchewan Ministry of Health. Retrieved from: <http://www.health.gov.sk.ca/Default.aspx?DN=49372758-a388-4e95-8fe2-043c18362458>
- Lincoln, Y.S., & Guba, E.A. (1985). *Naturalistic Inquiry*. Beverly Hills, CA: Sage.
- Lynn J & Adamson D.M. (2003). Living well at the end of life. Adapting health care to serious chronic illness in old age. Washington: Rand Health.
- Maciejewski, P.K., Phelps, A.C., Kacel, E.L., Balboni, T.A., Balboni, M., Wright, A.A... Prigerson, H.G. (2012). Religious coping and behavioral disengagement: opposing influences on advance care planning and receipt of intensive care near death. *Psychooncology*, 21(7), 714–723.

Majumdar B, Browne G, Roberts J, & Carpio C. (2004). Effects of cultural sensitivity training on health care provider attitudes and patient outcomes. *J Nurs Scholarship*, 36(2), 161-166.

Mallery, L., Hubbard, R.E., Moorhouse, P., Koller, K., & Eeles, E.M.P. (2011). Specialist Physician Approaches to Discussing Cardiopulmonary resuscitation for Frail Older Adults. *J Pall Care*, 27(1), 12-19.

Marcoux, I., Mishara, B.L., & Durand, C. (2007). Confusion between euthanasia and other end-of-life decisions: influences on public opinion poll results. *Can J Public Health*, 98(3), 235-239.

Marshall, C., & Rossman, G.B. (1999). *Designing qualitative research – 3rd edition*.

SAGE Publications. Retrieved from:

<http://www.jeffreylonghofer.com/resources/Dissertation-Seminar/Required-Readings-PDFS/building-the-conceptual-framework.pdf>

Mayring, P. (2000). *Qualitative content analysis*. Forum: Qualitative Social Research,

1(2), 20. Retrieved from: <http://www.qualitative-research.net/index.php/fqs/article/viewArticle/1089/2385>

McNamara, C. (2009). *General guidelines for conducting interviews*. Retrieved from:

<http://managementhelp.org/evaluatn/intrview.htm>

McPherson, C.J., Higginson, I.J., & Hearn, J. (2001). Effective methods of giving information in cancer: a systematic literature review of randomized controlled trials. *J Public Health Med*, 23(3), 227-234.

Menec, V.H., Lix, L., Nowicki, S., & Ekuma, O. (2007). Health Care Use at the End of Life

- Among Older Adults: Does It Vary by Age? *J Gerontol A Biol Sci Med Sci*, 62(4): 400-407.
- Menec, V., Lix, L., Steinbach, C., Okechukwu, E., Sirski, M., Dahl, M., & Soodeen, R.A. (2004). *Patterns of health care use and cost at the end of life*. Winnipeg, Manitoba: Manitoba Centre for Health Policy. Retrieved from: http://mchp-appserv.cpe.umanitoba.ca/reference/end_of_life.pdf
- Meleis A.I & Jonsen A.R. (1983). Ethical crises and cultural differences. *West J Med*, 138(6):889-893.
- Merriam, S.B. (2014). *Qualitative Research: A guide to design and implementation*. San Francisco, CA: Jossey-Bass.
- Mirza, A., Kad, R., & Ellison, N.M. (2005). Cardiopulmonary resuscitation is not addressed in the admitting medical records for the majority of patients who undergo CPR in the hospital. *Am J Hosp Palliat Care*, 22(1), 20–25.
- Mitchell, A.M., Gale, D.D., Matzo, M.L., McDonald, M.C., & Gadmer, N. (2002). Critique of transcultural practices in end-of-life clinical nursing practice. *Nursing Forum*, 37(4), 24-31.
- Molloy, D.W., Guyatt, G.H., Russo, R., Goeree, R., O'Brien, B.J., Bedard, M...Dubois, S. (2000). Systematic implementation of an advance directive program in nursing homes: a randomized controlled trial. *JAMA*, 283(11), 1437-44.
- Moore, R.J., & Spiegel, D. (2004). *Cancer, culture and communication*. New York: Kluwer Academic/Plenum.
- Morse, Janice M. (1994). Designing funded qualitative research. In Norman K. Denzin & Yvonna S. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp.220-35).

Thousand Oaks, CA: Sage.

Ngo, H.V. (2008). *Cultural Competence: A Guide to Organizational Change*. Alberta,

Canada: Citizenship and Immigration Canada. Retrieved from:

<http://www.albertahumanrights.ab.ca/documents/pubsandresources/CulturalCompetencyGuide.pdf>

Nishimoto, P.W., & Foley, J. (2001). Cultural beliefs of Asian Americans associated with terminal illness and death (review). *Semin Oncol Nurs* 17(3), 179-189.

O'Higgins, F. (2003). *An introduction to mechanical ventilation in the intensive care*

unit. Update. *Anaesthesia* 16(9). Retrieved from:

www.nda.ox.ac.uk/wfsa/html/u16/u1609_01.htm

Ontario Health Quality Council. (2007). *2007 Report on Ontario's Health System*.

Toronto, Ontario, Canada: Queens' Printer for Ontario. Retrieved from:

<http://www.hqontario.ca/portals/0/Documents/pr/qmonitor-full-report-2007-en.pdf>

Ontario Medical Association. (2014). *Palliative Care : Backgrounder*. OMA's End-of-Life

Care Strategy. Toronto, Ontario. Retrieved from :

<https://www.oma.org/Resources/Documents/PalliativeCare.pdf>

Orr, R.D., & Genesen, L.B. (1997). Requests for "inappropriate" treatment based on

religious beliefs. *J Med Ethics*, 23(3), 142-147.

Papadopoulos I. & Lees S. (2004). Cancer and communication: similarities and

differences of men with cancer from six different ethnic groups. *Eur J Cancer Care*,

13(2), 154-62.

Pargament, K.I., Koenig, H.G., & Perez, L.M. (2000). The many methods of religious

- coping: development and initial validation of the RCOPE. *J Clin Psychol*, 56(4), 519-543.
- Payne S, Chapman A, Holloway M, Seymour J.E, & Chau R. (2005). Chinese community views: Promoting cultural competence in palliative care. *J Pall Care*, 21(2), 111-116.
- Perkins, H. S. (2000). Time to move advance care planning beyond advance directives. *Chest*, 117, 1228–1231.
- Phelps, A.C., Maciejewski, P.K., Nilsson, M., Balboni, T.A., Wright, A.A., Paulk, M.E...Prigerson, H.G. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *JAMA*, 301(11), 1140-1147.
- Purnell, L. (2002). The Purnell Model for Cultural Competence. *J Transcult Nurs*, 13(3), 193-196.
- Quinlan, C., & O'Neill, C. (2009). *Practitioners' perspectives on patient autonomy at the end-of-life*. Retrieved from: <http://hospicefoundation.ie/wp-content/uploads/2013/06/Practitioners-Perspectives-on-Patient-Autonomy-at-End-of-Life.-Quinlan-O-Neill-2009.pdf>
- Raymont, V., Bingley, W., Buchanan, A., David, A.S., Hayward, P., Wessley, S., & Hotopf, M. (2004). Prevalence of mental incapacity in medical inpatients and associated risk factors: cross-sectional study. *Lancet*, 364(9443),1421–1427.
- Reid, C., Gibbins, J., Bloor, S., Burcombe, M., McCoubrie, R., & Forbes, K. (2013). Healthcare professionals' perspectives on delivering end-of-life care within acute care hospital trusts: a qualitative study. *BMJ Support Palliat Care*. Retrieved from: <http://spcare.bmj.com/content/early/2013/11/19/bmjspcare-2013-000468.abstract>

- Rose, T.A. (2007). The special needs of adult transcultural cancer patients. *CJMRT*, 38(2), 10-16
- Rubinfeld, G.D. (2004). Principles and practice of withdrawing life-sustaining treatments. *Crit Care Clin*, 20(3), 435-451.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Adv Nurs Sci*, 8(3), 27-37.
- Schuye, P.M. (2007). Language differences as a barrier to quality and safety in health care: the Joint Commission perspective. *J Gen Intern Med*, 22(2), 360-361.
- Searight, H.R., & Gafford, J. (2005). Cultural diversity at the end of life: issues and guidelines for family physicians. *Am Fam Physician*, 71(3), 515-522.
- Sidani, S. (2008). Effects of patient-centered care on patient outcomes: an evaluation. *Res Theory Nurs Pract*, 22(1), 24-37.
- Silveira, M.J., DiPiero, A., Gerrity, M.S., Feudtner, C. (2000). Patients' knowledge of options at the end of life: Ignorance in the face of death. *JAMA*, 284(19), 2483-2488.
- Siegert, E.A., Clipp, E.C., Mulhausen, P., Kochersberger, G. (1996). Impact of advance directive videotape on patient comprehension and treatment preferences. *Arch Fam Med*, 5(4), 207-12.
- Smucker, W.D., Ditto, P.H., Moore, K.A., Druley, J.A., Danks, J.H., & Townsend A. (1993). Elderly outpatients respond favourably to a physician-initiated advance directive discussion. *J Am Board Fam Pract*, 6(5):473-482.
- Social Research Methods. (2006). Nonprobability Sampling. *Research Methods Knowledge Base*. Retrieved from:
<http://www.socialresearchmethods.net/kb/samprnon.php>

- Stacy, K. (2012). Withdrawal of life-sustaining treatment: A case study. *Critical Care Nurse*, 32(3), 14-23.
- Statistics Canada. (2005). *Population Projections of Visible Minority Groups, Canada, Provinces and Regions, 2001- 2017*. Catalogue no. 91-541-XIE. Retrieved from: <http://publications.gc.ca/collections/Collection/Statcan/91-541-X/91-541-XIE2005001.pdf>
- Statistics Canada. (2008). *Canada Ethnocultural Mosaic 2006 Census*. Catalogue no. 97-562-X. Retrieved from: <http://www12.statcan.ca/census-recensement/2006/as-sa/97-562/pdf/97-562-XIE2006001.pdf>
- Statistics Canada. (2010). *Population projections for Canada, provinces and territories 2009-2036*. Catalogue no. 91-520-X. Retrieved from: <http://www.statcan.gc.ca/pub/91-520-x/91-520-x2010001-eng.pdf>
- Statistics Canada. (2014). *Leading Causes of Death, By Sex (both sexes) 2011*. CANSIM Table 102-0561. Retrieved from: <http://www.statcan.gc.ca/tables-tableaux/sum-som/101/cst01/hlth36a-eng.htm>
- Sullivan, M.A., Muskin, P.R., Feldman, S.J., & Haase, E. (2004). Effects of religiosity on patients' perceptions of do-not-resuscitate status. *Psychosomatics*, 45(2), 119-128.
- Sulmasy, D.P. (2006). Spiritual issues in the care of dying patients: “. . . it's okay between me and god”. *JAMA*, 296(11), 1385-1392.
- Tannenbaum D, Konkin J, Parsons E, Saucier D, Shaw L, Walsh A. (2011). Triple C competency-based curriculum. *Report of the Working Group on Postgraduate Curriculum Review—Part 1*. Mississauga, ON: College of Family Physicians of Canada. Retrieved from:

www.cfpc.ca/uploadedFiles/Education/PDFs/WGCR_TripleC_Report_English_Final_18Mar11.pdf

Taylor-Powell, E., & Renner, M. (2003). *Analyzing Qualitative Data*. Program

Development and Evaluation: Madison, Wisconsin. Retrieved from:

<http://learningstore.uwex.edu/assets/pdfs/g3658-12.pdf>

Teno, J.M., Lynn, J., Phillips, R.S., Murphy, D., Youngner, S.J., Bellamy, P...Knaus,

W.A. (1994). Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. *J Clin Ethics*, 5(1), 23–30.

Teno, J.M., Fisher, E.S., Hamel, M.B., Coppola, K., & Dawson, N.V. (2002). Medical

care inconsistent with patients' treatment goals: association with 1 year Medicare resource use and survival. *J Am Geriatr Soc*, 50(3), 496–500.

Tierney, W.M., Dexter, P.R., Gramelspacher, G.P., Perkins, A.J., Zhou, X.H., &

Wolinsky, F.D. (2001). The effect of discussions about advance directives on patients' satisfaction with primary care. *J Gen Intern Med*, 16(1), 32-40.

Trill M.D & Holland J. (1993). Cross-cultural differences in the care of patients with

cancer: a review. *Gen Hosp Psychiatry*, 15(1), 21-30.

True, G., Phipps, E.J., Braitman, L.E., Harralson, T., Harris, D., Tester, W. (2005).

Treatment preferences and advance care planning at end of life: the role of ethnicity and spiritual coping in cancer patients. *Ann Behav Med*, 30(2), 174-179.

Watson C.M & Day D. (2008). Health care providers' perceived versus actual cultural

competency levels with Latino patients: A pilot study. *Wichita State University*.

Retrieved from:

<http://www.allhealth.org/briefingmaterials/grasphealthproviderscompetencywithlatinos-1285.pdf>

Werner, P., Carmel, S., & Ziedenberg, H. (2004). Nurses' and social workers' attitudes and beliefs about and involvement in life-sustaining treatment decisions. *Health and Social Work, 29*(1), 27-35.

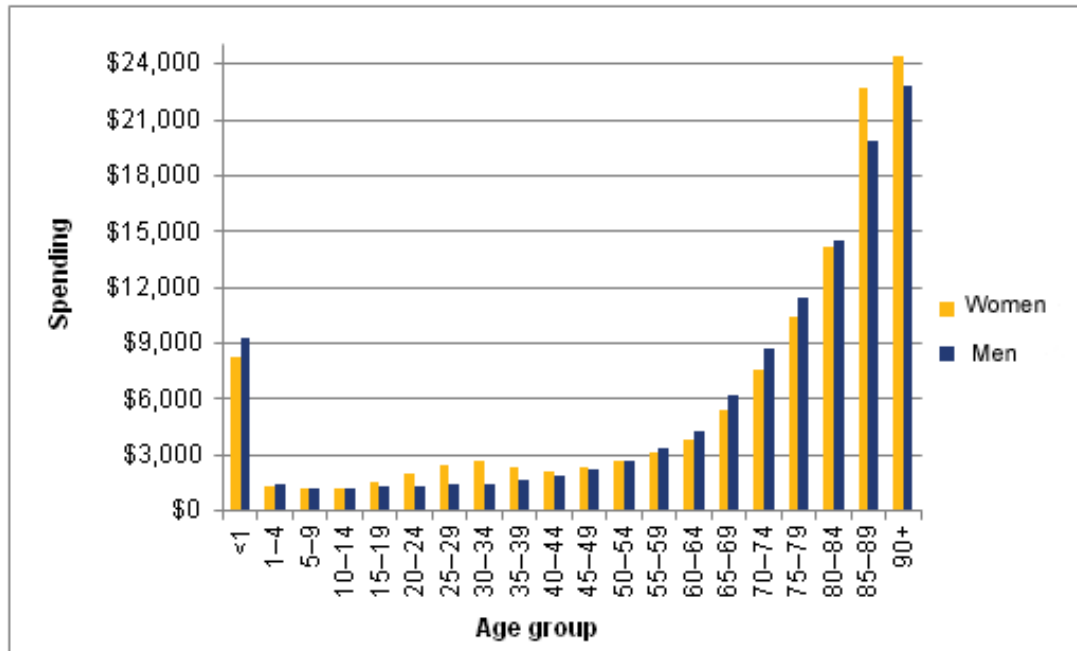
Workshop Scientific Committee. (2004). *Building collaborative communities for cross cultural cancer research and care*. Vancouver, British Columbia. Retrieved from: <http://www.bccancer.bc.ca/NR/rdonlyres/E25C74F6-6C62-438F-AB9A-F6898D8BBC8E/7605/BuildingCollaborativeCommunitiesPart1Sept04.pdf>

You, J.J., Dodek, P., Lamontagne, F., Downar, J., Sinuff, T., Jiang, X....Heyland, D.K. (2014). What really matters in end-of-life discussions? Perspectives of patients in hospital with serious illness and their families. *Canadian Medical Association Journal*. Retrieved from: <http://www.cmaj.ca/content/early/2014/11/03/cmaj.140673>

Appendices

Appendix A

Figure 1. Public health care spending per person per age group (2008)



Note: Retrieved from “Canada’s Aging Population and Public Policy: 3. The Effects on Health Care” by R. Deraspe (2011) and “National Health Expenditure Trends, 1975 to 2010” by Canadian Institutes of Health Information (2010), Ottawa, Ontario.

Appendix B

Table 5. Overview of advance directive legislation in Canadian provinces and territories

Jurisdiction	Type of advance directive provided for in legislation	Instructional directive	Proxy directive	Proxy
Newfoundland and Labrador	Instructional and proxy	Advance Health Care Directive	Advance Health Care Directive	Substitute decision maker
Nova Scotia	Proxy directive	-----	Authorization	Guardian
Prince Edward Island	Instructional and proxy	Advance Health Care Directive	Advance Health Care Directive	Proxy
New Brunswick	Proxy directive	-----	Power of Attorney for Personal Care	Attorney for personal care
Quebec	Proxy directive	-----	Mandate	Mandatary [the maker of a Mandate is called the Mandator]
Ontario	Proxy directive	-----	Power of Attorney for Personal Care	Attorney for personal care
Manitoba	Instructional and proxy	Health Care Directive	Health Care Directive	Proxy
Saskatchewan	Instructional and proxy	Health Care Directive	Health Care Directive	Proxy
Alberta	Instructional and proxy	Personal Directive	Personal Directive	Agent
British Columbia	Proxy directive	-----	Representation Agreement	Representative
Yukon	Proxy directive	-----	Advance Directive	Proxy
Northwest Territories	Instructional and proxy	Personal directive	Personal directive	Agent

Note: Retrieved from “Advance care planning: the Glossary project- Final report” by J. Dunbrack (2006), Ottawa, Ontario: Health Canada.

Appendix C

Interview Guide:

Opening: Hello. Thank you again for taking the time to be a part of my research project. I will start by giving you some information on the structure of this interview.

I am interested in the topic of **advance care planning** (ACP): the process used for patients to describe their preferences, beliefs, and values for life-sustaining treatments in the event that he/she no longer has the ability to consent or refuse treatment.

I will be asking you a few questions to get insight on your experience with advance care planning for mechanical ventilation (MV) from a cross-cultural perspective. Two of the questions will be simulated scenarios; I will ask you to describe for me the approach you would take in a given scenario. The interview should last no more than 30-40 minutes.

Just a reminder that I will be audio-taping the interview and that information collected from you throughout the study will remain confidential. I will let you know when I begin audio-recording. You can stop me at any time if you no longer wish to proceed with the interview. I will start with a few basic questions to get to know you better.

Part I – Introduction

1. Please tell me your job title and the medical units you normally work in?
2. How long have you been practicing as a physician/nurse?
3. In what country did you complete your medical/nursing training/residency?

Part II –Advance Care Planning Across Cultures

Advance Care Planning

4. Are you normally involved in ACP discussions with patients/families?
 - a. If so, are you familiar with any frameworks or policies (published or unpublished) that help guide you through the process?
 - i. Based on your experience, what is your role in ACP?
 - ii. Who is often involved in the ACP discussion?
 - iii. At what point over the course of illness are you normally involved in the ACP conversation?
 - b. If no, are you able to describe for me how ACP takes place in your practice?
 - i. Is there anything specific that you do that supports or contributes to planning for end-of-life care?
 - ii. SKIP TO #8 + SIMULATED SCENARIOS
5. How comfortable are you discussing end-of-life care with patients and families?
6. Generally, what approach works best for you for planning end-of-life care with patients/families?
7. Briefly, what are some of the main points that you want to get from patients/families in an ACP discussion?

8. In your opinion, how important is it to discuss plans for MV treatment (invasive/non-invasive) in advance with patients/families?

Cross-Cultural Care

9. Do you feel that in your medical experience, you have managed care for patients from a variety of different ethnocultural backgrounds?
- a. If so, briefly what ethnocultural backgrounds have you cared for?
 - i. Have you ever participated in any form of cultural competency training or workshops?
 - ii. In your opinion, how important is the patient/family's ethnocultural background when it comes to end-of-life care?
 - iii. How confident do you feel providing care for a patient/family with an ethnocultural background that is different from your own?
 - b. If no, have you ever participated or taken part in cultural competency training or workshops?
 - i. In your opinion, how important is the patient/family's ethnocultural background when it comes to end-of-life care?
 - ii. How confident would you feel providing care for a patient/family with an ethnocultural background that is different from your own?
 - iii. SKIP TO SIMULATED SCENARIOS
10. Can you describe for me the general approach that works best for you for understanding different religious or cultural beliefs/values at the end-of-life?
11. Does your approach to ACP change when you are dealing with a patient/family from a different ethnocultural background?
- a. If so, can you describe for me what you do differently?

ACP for Mechanical Ventilation Cross-Culturally

12. Do you find that, at times, ethnocultural beliefs/values for MV use at the end-of-life are inconsistent with what you thought was appropriate for the patient?
- a. Do you experience ethical or moral distress in these situations?
 - b. What methods or skills do you find helpful for working with the patient/family to find a solution for care?
 - c. How does this method or approach change with different illness trajectories (progressive vs. acute)?
13. Are there any other sorts of challenges that you experience that hinder your ability to provide end-of-life care cross-culturally?
- a. If any, what methods do you use to overcome these challenges?
14. OPTIONAL: Can you think of an example where there was a cultural misunderstanding or a disagreement with regards to MV treatment?
- a. How did you find a solution for care?
15. Do you feel that you have the support (ex. organizational, systematic, material, etc.) to provide end-of-life care that matches ethnocultural needs of patients/families?
16. Overall, do you feel that ACP is effective for avoiding cross-cultural issues that may arise at the end-of-life?
- a. If not, in your opinion, how can the provision of cross-cultural care be improved in ACP?

Simulated Scenarios

For the last part of the interview, I am going to ask you to consider the following scenarios...

Consider the following scenario: In some cultures, discussing death and dying with a seriously, ill patient is considered offensive, taboo and inappropriate. In an attempt to develop an ACP for MV, the family pushes for familial autonomy and prefers to take responsibility for decision-making, despite the patient's capacity to make decisions:

- a. What are some important considerations that you would take into account?
- b. Can you describe for me how you would work with the patient/family to set a care plan in this situation?
- ~~e. How would your approach change if the patient were dealing with a gradual/progressive illness (ex. cancer) vs. an acute deterioration (ex. organ failure)?~~

Consider the following scenario: In some cultures, there is a strong value for the sanctity of life or the idea that human life is sacred and should be preserved at all costs. During an ACP discussion, a patient/family under your care express strong preferences for MV intubation, despite futility or minimal benefits of this treatment:

- a. What are some important considerations that you would take into account?
- b. Can you describe for me how you would work with the patient/family to set a care plan in this situation?
- ~~e. How would your approach change if the patient were dealing with a gradual/progressive illness (ex. cancer) vs. an acute deterioration (ex. organ failure)?~~

16. In your opinion, is there anything that should be changed or done that would improve your ability to provide end-of-life care cross-culturally?
17. Knowing what you now know about this topic, what advice would you give to researchers or fellow health care providers about how they should talk or think about this issue?

Part IV - Closing


18. Is there anything else that you would like to say or add to this discussion that I did not bring up in the interview?
19. Are there any reports or other literature that you would recommend that would be helpful to my research?
20. Could you suggest anybody who would be helpful in providing me with more information on ethnocultural considerations in ACP or might be interested in doing this interview with me?

Thank you, I will now turn off audio-recording.

Appendix D.1

Figure 2. Ethics Approval from Bruyère Research Institute (May 2013)

www.bruyere.org



Bruyère pour des soins continus.
Bruyère Is Continuing Care.

Hôpital Élisabeth-Bruyère Hospital
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Télec./Fax: 613-562-6367

Hôpital Saint-Vincent Hospital
60, rue Cambridge St. N.
Ottawa ON K1R 7A5
Tél./Tel.: 613-562-6262
Télec./Fax: 613-782-2785

Résidence Élisabeth-Bruyère Residence
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6262
Télec./Fax: 613-562-1223

Résidence Saint-Louis Residence
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Télec./Fax: 613-683-5001

Village Bruyère Village
879, ch. Hiawatha Park Rd.
Ottawa ON K1C 2Z6
Tél./Tel.: 613-562-6262
Télec./Fax: 613-683-5001


Centre de médecine familiale Bruyère
Bruyère Family Medicine Centre
75, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-241-3344
Télec./Fax: 613-241-1971

Centre de médecine familiale Primrose
Primrose Family Medicine Centre
35, rue Primrose St.
Ottawa ON K1R 0A1
Tél./Tel.: 613-230-7788
Télec./Fax: 613-230-7778

Institut de recherche Bruyère
Bruyère Research Institute
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6045
Télec./Fax: 613-562-4266

Fondation Bruyère Foundation
43, rue Bruyère St.
Ottawa ON K1N 5C8
Tél./Tel.: 613-562-6319
Télec./Fax: 613-562-6023

Affilié à / Affiliated with



uOttawa

May 8, 2013

Ms. Ayah Nayfeh
MSc Student, Faculty of Health Sciences
University of Ottawa

**Re: Advance Care Planning for Mechanical Ventilation: The
Cross-Cultural Approach in Long-Term Care.**
(Bruyère REB Protocol # M16-13-007)

Final Approval

Dear Ms. Nayfeh,

Thank you for your response to our conditional approval letter. With the revisions, the application has satisfied all ethical requirements.

As such, the Bruyère Continuing Care Research Ethics Board (REB) is pleased to give you ethical approval for the period May 8, 2013 to May 8, 2014.

Please submit a copy of the University of Ottawa REB approval letter once received.

Please be advised that any complaints made by participants must be reported to the REB.

All changes to the approved protocol must be approved by the REB.

Please complete an Annual Project Update/Notification of Termination form by the approval end date as noted above.

We wish you the best of luck with your research endeavors.

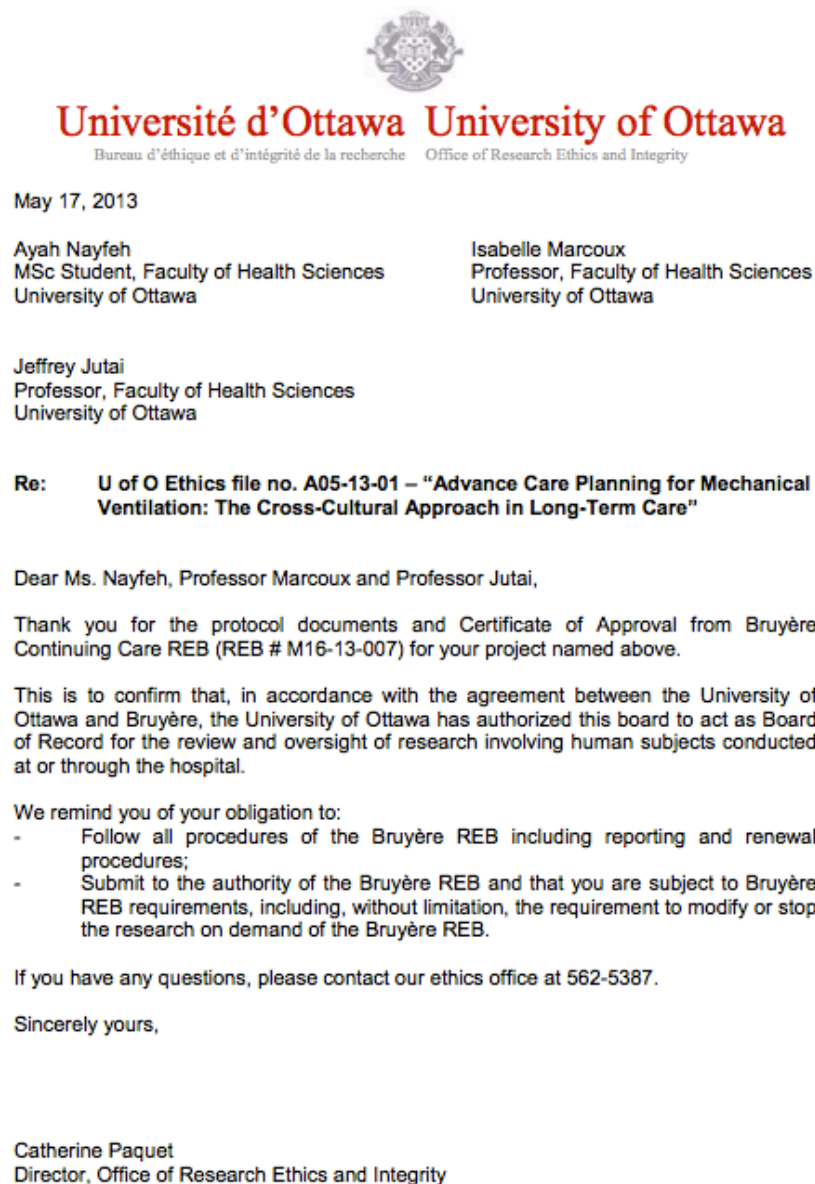
Sincerely,

Dorothy Kessler, M.Sc., O.T. Reg. (Ont), PhD Candidate
Chair, Research Ethics Board
Bruyère Continuing Care

À Bruyère, nous vous promettons... bonté • sécurité • bienveillance
At Bruyère, we promise you... Kind • Safe • Care

Appendix D.2


Figure 3. Ethics approval from University of Ottawa (May 2013)



Appendix D.3

Figure 4. Ethics approval from l'Hôpital Montfort (February 2014)

713, chemin Montréal Road, Ottawa, ON K1K 0T2
Tel./Tel.: 613-746-4621 Téléc./Fax: 613-748-4934
hopitalmontfort.com



**Hôpital
Montfort**

Un hôpital d'enseignement
affilié à l'Université d'Ottawa
A teaching hospital affiliated
with the University of Ottawa

Avis d'approbation éthique
Comité d'éthique de la recherche de l'Hôpital Montfort

Le 13 février 2014 :

<p>Chercheur principal :</p> <p>Ayah Nayfeh Faculty of Health Sciences University of Ottawa</p>	<p>Co-chercheurs :</p> <p>Jeffrey Jutai Faculty of Health Sciences, University of Ottawa</p> <p>Isabelle Marcoux Faculty of Health Sciences, University of Ottawa</p>
--	--

Titre du projet : « Advance Care Planning for Mechanical Ventilation: Health Care Providers' Perspectives on Cross-Cultural Care »

Numéro du dossier : AN-20-01-13

Date de début : 13 février 2014

Date de fin : 12 février 2015

En concordance avec l'Énoncé de politique des trois conseils, le Conseil canadien des normes, les lois et règlements applicables en Ontario, je confirme que le Comité d'éthique de la recherche (CÉR) de l'Hôpital Montfort a étudié et approuvé votre demande d'approbation éthique pour une période d'un an pour les documents suivants :

- Lettre d'invitation (A & F) soumis les 7 et 10 février 2014
- Lettre de suivi à l'invitation (A & F) soumis les 7 et 10 février 2014
- Formulaire de consentement (F & A) soumis le 7 février 2014
- Guide d'entrevue (Interview guide) (A) soumis le 20 janvier 2014

Le protocole de l'étude ne peut être modifié sans une approbation préalable du CÉR sauf s'il est question de la sécurité immédiate des participants ou de logistique administrative comme un changement de numéro de téléphone. Vous devez aviser le CÉR immédiatement de tout changement, événement indésirable ou nouvelle information pouvant augmenter le risque de l'étude, modifier le cours de l'étude ou atteindre la sécurité des participants. Les modifications au projet et aux outils de recrutement doivent être soumises au CÉR.

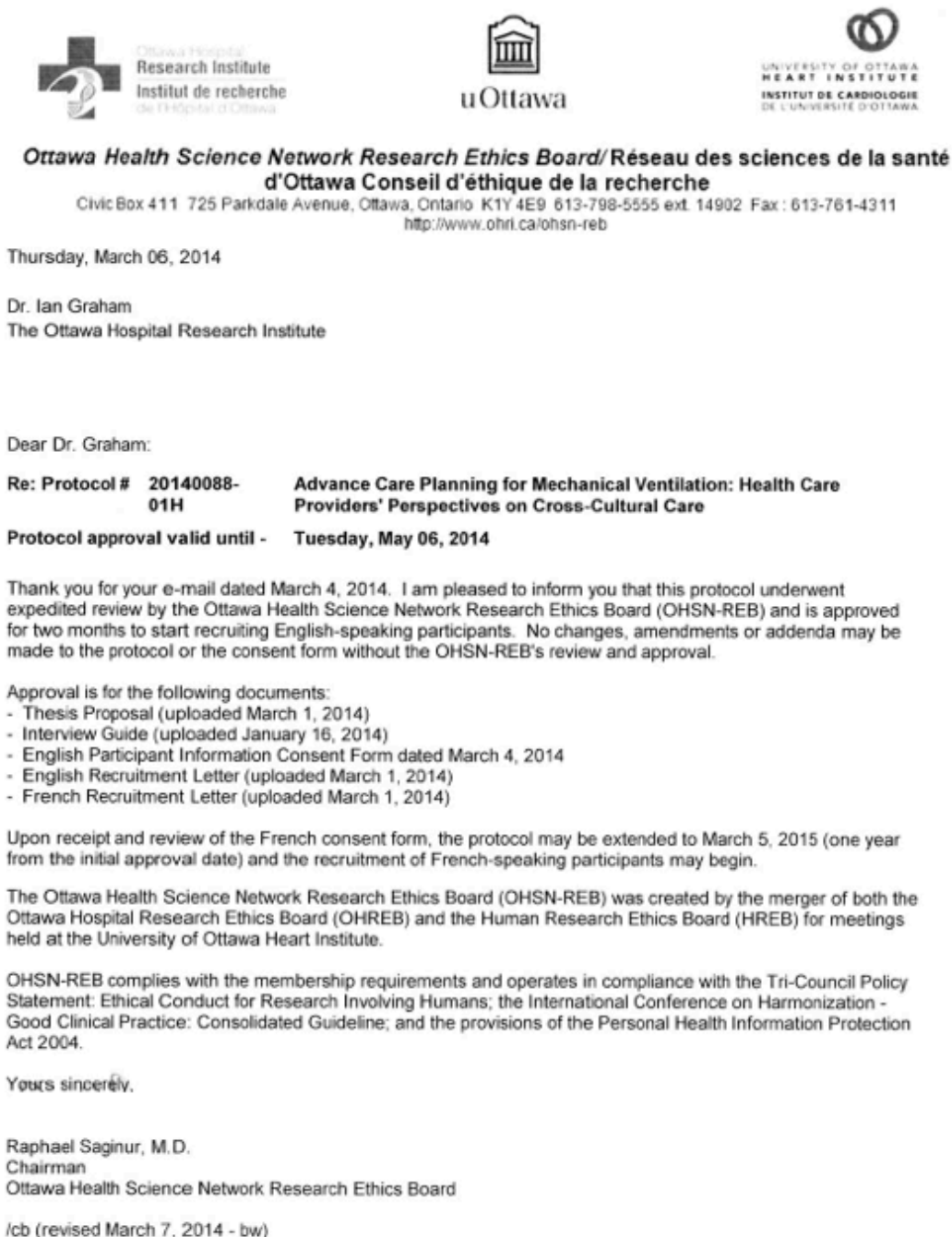
Veillez nous acheminer quatre semaines avant la date d'échéance de cet avis d'approbation, un rapport final afin de fermer le dossier ou de faire une demande de renouvellement du certificat éthique de l'étude.

Si vous avez des questions, vous pouvez communiquer avec Christian Bergeron, coordonnateur du CÉR de l'Hôpital Montfort, au 613-746-4621 poste 2221 ou par courriel à ethique@montfort.on.ca.

Lynn Casimiro, PhL, Ph. D.
Présidente du Comité d'éthique de la recherche — Hôpital Montfort

Appendix D.4

Figure 5. Ethics approval from Ottawa Hospital Research Institute (March 2014)




Appendix E.1

Figure 6. Bruyère Research Institute Information Consent form

www.bruyere.org/irb
www.bruyere.org/bri

SOINS CONTINUS
Bruyère
CONTINUING CARE



INSTITUT DE RECHERCHE
BRUYÈRE
RESEARCH INSTITUTE
*Affilié à l'Université d'Ottawa
Affiliated with the University of Ottawa*

Information Consent Form

*Adresse postale
Mailing Address
43, rue Bruyère St.
Ottawa ON K1N 5C8*

*Bureau central
Corporate Office
Tél./Tel.: 613-562-6045
Télex./Fax: 613-562-4266*

*Éducation et recherche en soins palliatifs
Palliative Care Education and Research
Tél./Tel.: 613-562-6262 poste/ext. 1352
Télex./Fax: 613-562-6371*

*Centre de recherche C.T. Lamont
en soins de santé primaires
C.T. Lamont Primary Health Care
Research Centre
Tél./Tel.: 613-562-6262 poste/ext. 1589
Télex./Fax: 613-562-6099*

*Recherche sur les soins aux aînés
Care of the Elderly Research
Tél./Tel.: 613-562-6262 poste/ext. 1434
Télex./Fax: 613-562-4266*

PROJECT TITLE: Advance Care Planning for Mechanical Ventilation: Health Care Providers' Perspectives on Cross-Cultural Care

PRINCIPAL INVESTIGATOR:
Ayah Nayfeh M.Sc. Candidate | Candidat à la maîtrise
Interdisciplinary School of Health Sciences | École interdisciplinaire des sciences de la santé
Faculty of Health Sciences | Faculté des sciences de la santé
University of Ottawa | Université d'Ottawa

CO-INVESTIGATORS:
Dr. Isabelle Marcoux:
Interdisciplinary School of Health Sciences
Dr. Jeffrey Jutai:
Interdisciplinary School of Health Sciences
Bruyère Research Institute


Funding Organization: Bruyère Research Institute and Technology Evaluation in the Elderly.

Dear Sir or Madam:

Thank you for your participation in this research study with Bruyère Research Institute and Interdisciplinary School of Health Sciences. The aim of this study is to explore advance care planning (ACP) for mechanical ventilation from a cross-cultural perspective in long-term and complex continuing care. Before providing your consent to participate in this research project, please take the time to read, and understand the following information.

We encourage you to ask the research investigator any questions you may have in order to clarify or explain information that does not seem clear.

Affilié à / Affiliated with



UNIVERSITÉ D'OTTAWA

La compassion et le savoir en harmonie
Blending Compassion with Knowledge

Purpose of Study

Advance care planning (ACP) is a method for patients to express in advance their preferences, beliefs and values for life-sustaining technologies at the end-of-life (ex. mechanical ventilation, dialysis, and nutrition). This process is used to ensure patients receive quality end-of-life care, avoid unwanted aggressive treatments, and reduce the burden of decision-making from families and health providers.

In a nation as diverse as Canada, ethnocultural patients and families with diverse beliefs and values will ultimately seek end-of-life care. The objective of this study is to identify the strengths and challenges with using current practices for ACP to set care plans for mechanical ventilation with ethnocultural patients and families.

Your participation will include one face-to-face interview that will last approximately 30-40 minutes. The interview will include open-ended questions and two simulated scenarios.

Voluntary Participation

Your participation in this research project is voluntary and will not impact your employment with Bruyère Continuing Care. You may withdraw from the study at any time by informing the research investigator.

If you decide to withdraw from the study, data that has been collected from you will not be used for research but will be kept on file to meet regulations. Research data will be destroyed five (5) years following the completion of this project.

Confidentiality

Information that is collected and recorded from you will be kept in an encrypted file in Dr. Jeff Jutai's lab at Saint-Vincent Hospital. Only the principal investigator and co-investigators involved in the study will have access to your information. The Research Ethics Board (REB) may also access your research file for audit.

The principal investigator will only collect information that is needed from you to meet the scientific objectives of the study. The interview will be audio-recorded and transcribed for data analysis. Audio-recordings will be destroyed once data analysis is complete.

Your research file may also include personal information such as your job title, gender, and number of years in clinical practice. This file will be destroyed five (5) years following the completion of this study. Paper documents will be shredded and disposed, and electronic copies will be destroyed as per University of Ottawa guidelines.

Information collected from you will remain strictly confidential. To protect your identity and confidentiality of your information, you will only be identified by an assigned code throughout the study. The code list linking your name to your research file will be kept in a locked cabinet in Dr. Jeff Jutai's research lab at Saint-Vincent Hospital, separate from the encrypted data. You have the right to review your research file to verify information for as

long as the research investigators possess this information.

Research findings may be published in scientific journals or shared during scientific discussions or conferences, and may be used to support the development of future research studies. No publication or scientific communication will disclose information that would allow you to be identified.

Benefits of Participating in the Study

Participation in this research study will provide valuable knowledge pertaining to the cross-cultural care at the end-of-life, specific to ACP for mechanical ventilation.

Risks of the Proposed Study

There are no known risks for participating in this research study.

Audio-Recording

Interviews will be audio-recorded using a voice-note recorder and transcribed for data analysis. Research files will be kept in an electronic encrypted file in Dr. Jeff Jutai's research lab at Saint-Vincent Hospital. Audio-recordings will be destroyed once data analysis is complete. You have the right to refuse audio-recording. Please select one of the following options:


I consent to audio recording: Yes _____ No _____

Appendix E.2

Figure 7. l'Hôpital Montfort Information Consent form


713, chemin Montréal Road, Ottawa, ON K1K 0T2
Tel./Tel.: 613-746-4621, Téléc./Fax: 613-748-4914
hopitalmontfort.com

Information Consent Form



**Hôpital
Montfort**

Un hôpital d'enseignement
affilié à l'Université d'Ottawa
A teaching hospital affiliated
with the University of Ottawa



uOttawa

PROJECT TITLE: Advance Care Planning for Mechanical Ventilation: Health Care Providers' Perspectives on Cross-Cultural Care

PRINCIPAL INVESTIGATOR:
Ayah Nayfeh MSc. Candidate
Interdisciplinary School of Health Sciences
Faculty of Health Sciences
University of Ottawa

CO-INVESTIGATORS:
Dr. Isabelle Marcoux
Interdisciplinary School of Health Sciences
Faculty of Health Sciences
University of Ottawa

Dr. Jeffrey Jutai
Interdisciplinary School of Health Sciences
Faculty of Health Sciences
University of Ottawa

FUNDING ORGANIZATION:
Bryère Research Institute and Technology Evaluation in the Elderly Network

CONFLICTS OF INTEREST(S):
There are no apparent or potential Conflicts of Interest(s) with the conduct of this study.

Dear Sir or Madam:

Thank you for participation in this Master's research study conducted by Ayah Nayfeh from the Interdisciplinary School of Health Sciences, with thesis supervisors Dr. Isabelle Marcoux and Dr. Jeff Jutai. The aim of this project is to explore advance care planning for mechanical ventilation from a cross-cultural perspective. Before providing your consent to participate in this study, please take the time to read and understand the following information.

We encourage you to ask the research investigators any questions you may have in order to clarify or explain information that does not seem clear.

Purpose of Study

Advance care planning (ACP) is a method used for patients to express in advance their preferences, beliefs, and values for life-sustaining technologies at the end-of-life (ex. mechanical ventilation, dialysis, nutrition, etc.). The purpose of this discussion is to ensure patients receive quality end-of-life care that meets their needs, and avoids the use of unwanted or unnecessary life-sustaining treatment.

In a nation as diverse as Canada, patients and families with diverse beliefs and values will ultimately seek end-of-life care. The objective of this study is to identify the strengths and challenges with setting care plans for mechanical ventilation with patients and families from different ethnocultural backgrounds.

Voluntary Participation

Your participation in this research study is voluntary and will not impact your employment with Hôpital Montfort. As a research participant, you will be involved in one face-to-face interview that includes open-ended questions and two simulated scenarios, and will last approximately 30-40 minutes. Please note that the interview is available in English only.

You may withdraw from the study at any time by informing the principal investigator. Research data that has been collected from you prior to withdrawal will not be used for research but will be kept on file to meet regulations. Data will be destroyed ten (10) years following the completion of the study.

Data Conservation

Information that is collected and recorded from you will be kept in an electronic encrypted file in Dr. Jeff Jutai's research lab at Saint-Vincent's Hospital. Only the principal investigator and co-investigators involved in the study will have access to your information. The Research Ethics Board (REB) may also access your research file for audit purposes.

The principal investigator will only collect information that is needed from you to meet the scientific objectives of the study. The interview will be audio-recorded and transcribed for data analysis. Audio-recordings will be destroyed once data analysis is complete.

Your research file will also include personal information such as your job title, gender, and number of years in medical practice. This file will be destroyed ten (10) years following the completion of the study. Paper documents will be shredded and disposed, and electronic copies will be destroyed as per University of Ottawa guidelines.

Confidentiality and Anonymity

Information that is collected from you will remain confidential. To protect your identity and confidentiality of your information, you will only be identified by an assigned code throughout the course of the study, and your identity will not be revealed to employers or medical directors within your unit. The code list linking your name to your research file will

be kept in a locked filing cabinet separate from the encrypted data, in Dr. Jeff Jutai's research lab at Saint-Vincent's Hospital. You have the right to review your research file to verify information for as long as the research investigators possess this information.

Notification of Research Findings

Research findings may be disseminated to Hôpital Montfort by means of a research report, copy of a scientific publication, or a workshop presented to the medical units involved in the study. Findings may also be shared during scientific discussions or conferences, and may be used to support the development of future research studies. No publication or scientific communication will disclose information that would allow you to be identified.

Benefits of Research Participation

Participating in this research study will provide valuable knowledge pertaining to cross-cultural care for patients and families at the end-of-life.

Risks of Research Participation

There are no known risks for participating in this research study.

Audio-Recording

Interviews will be audio-recorded using a voice-note recorder and transcribed for data analysis. Research files will be kept in an electronic encrypted file in Dr. Jeff Jutai's research lab at Saint-Vincent's Hospital. Audio-recordings will be destroyed once data analysis is complete. You have the right to decline to be audio recorded. Please select one of the following options:

I consent to audio recording: Yes _____ No _____

Appendix E.3

Figure 8. Ottawa Hospital Research Institute Information Consent form



Participant Information Consent Form

PROJECT TITLE: Advance Care Planning for Mechanical Ventilation: Health Care Providers' Perspectives on Cross-Cultural Care

PRINCIPAL INVESTIGATOR:
Dr. Ian Graham
 Ottawa Hospital Research Institute

CO-INVESTIGATORS:
Ayah Nayfeh (M.Sc. Candidate)
 Interdisciplinary School of Health Sciences

Dr. Isabelle Marcoux (Thesis Supervisor)
 Interdisciplinary School of Health Sciences

Dr. Jeffrey Jutai (Thesis Co-Supervisor)
 Interdisciplinary School of Health Sciences
 Bruyère Research Institute

FUNDING ORGANIZATION:
 Bruyère Research Institute and Technology Evaluation in the Elderly Network

You are being asked to participate in this research study from the Interdisciplinary School of Health Sciences at the University of Ottawa. The aim of this study is to explore advance care planning (ACP) for mechanical ventilation from a cross-cultural perspective. Before providing your consent to participate in this research study, please take the time to read and understand the following information.

We encourage you to ask the research investigator any questions you may have in order to clarify or explain information that does not seem clear.

Purpose of Study

Advance care planning (ACP) is a method for patients to express in advance their preferences, beliefs and values for life-sustaining technologies at the end-of-life (ex. mechanical ventilation, dialysis, and nutrition). This process is used to ensure patients receive quality end-of-life care, avoid unwanted and/or aggressive treatments, and reduce the burden associated with decision-making from families and health care providers.

Civic Campus Civic
 1053 av. Carling Avenue
 Ottawa, Ontario K1Y 4E9

General Campus Général
 501 chemin Smyth Road
 Ottawa, Ontario K1H 8L6

Riverside Campus Riverside
 1967 prom. Riverside Drive
 Ottawa, Ontario K1H 7W9

Page 1 of 4



In a nation as multicultural as Canada, patients and families from different ethnocultural backgrounds with diverse beliefs and values will ultimately seek end-of-life care. The objective of this study is to identify the strengths and challenges with using current practices for ACP to set care plans for mechanical ventilation with patients and families from different ethnocultural backgrounds.

Your participation will include one face-to-face interview that will last approximately 30-40 minutes. The interview will include open-ended questions and two simulated scenarios. It will be conducted at a time and place most convenient for you. Once the interview is over, your participation in this study is complete.

Risks of the Proposed Study

There are no known risks for participating in this study.

Benefits of Participating in the Study

Your participation in this study will provide valuable knowledge pertaining to cross-cultural care for patients at the end-of-life.

Do I have to participate? What alternatives do I have? If I agree now, can I change my mind and withdraw later?

Your participation in this study is voluntary. The alternative to this study is not to participate.

You may decide not to be in this study, or to be in the study now, and then change your mind later without affecting the employment or other services to which you are entitled or are presently receiving at this institution.

If you withdraw your consent, the study team will no longer collect your personal identifying information for research purposes, but will be kept on file to meet regulations.

Will I be paid for my participation or will there be any additional costs to me?

You will not be paid to participate in this study, nor will it cost you anything to participate.



Confidentiality

- All information collected during your participation in this study will be identified with a unique study number, and will not contain information that identifies you, such as your job title, gender, and number of years in medical practice..
- The link between your unique study number and your name and contact information will be stored securely and separate from your study records, and will not leave this site.
- Any documents kept in an encrypted file in Dr. Jeff Jutai's lab at Saint-Vincent's Hospital will contain only your unique study number.
- You will not be identifiable in any publications or presentations resulting from this study.
- Information that identifies you will be released only if it is required by law.
- For audit purposes only, your original study records may be reviewed under the supervision of Dr. I. Graham's staff by representatives from:
 - The Ottawa Health Science Network Research Ethics Board (OHSN-REB),
 - The Ottawa Hospital Research Institute.
 - University of Ottawa Health Sciences Research Ethics Board,
- Research records will be kept for 10 years, after this time they will be destroyed.
- The interview will be audio-recorded and transcribed for data analysis; audio-recordings will be destroyed once data analysis is complete.

Questions

If I have any questions about the research study, I am encouraged to contact Ayah Nayfeh at

If I have any questions about the rights of a research participant or ethical concerns about this study, I can contact the Chair of the Ottawa Health Science Network Research Ethics Board (OHSN-REB) at (613) 798-5555 ext. 16719, or the Protocol Officer for Ethics in Research at the University of Ottawa, Tabaret Hall, 550 Cumberland Street, room 159, Ottawa, ON, K1N 6N5, at (613) 562-5841 or ethics@uOttawa.ca.



Consent to Participate in Research

I understand that I am being asked to participate in a research study about exploring advanced care planning for mechanical ventilation.

- This study was explained to me by _____.
- I have read, or have had it read to me, each page of this Participant Information Consent Form.
- All of my questions have been answered to my satisfaction.
- If I decide later that I would like to withdraw my participation and/or consent from the study, I can do so at any time.
- I voluntarily agree to participate in this study.
- I will be given a copy of this signed Participant Information Consent Form.

I consent to audio recording: Yes _____ No _____

Participant's Printed Name Participant's Signature Date

Investigator or Delegate Statement

I have carefully explained the study to the study participant. To the best of my knowledge, the participant understands the nature, demands, risks and benefits involved in taking part in this study.

Investigator/Delegate's Printed Name Investigator/Delegate's Signature Date

Civic Campus Civic
1053 av. Carling Avenue
Ottawa, Ontario K1Y 4E9

General Campus Général
501 chemin Smyth Road
Ottawa, Ontario K1H 8L6

Riverside Campus Riverside
1967 prom. Riverside Drive
Ottawa, Ontario K1H 7W9