

Running head: ADVANCE CARE PLANNING

**Advance Care Planning: The Knowledge, Attitudes, and Experiences of Medical-Surgical
Nurses in Winnipeg, Manitoba, Canada**

by

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Abstract

Canadians are living longer, and are, therefore, dealing with the health care implications and related medical decision making linked to the management of disease and illness. Advance care planning (ACP) is defined as a process of open communication and information sharing between the health care team, the patient, and his/her family to enable patient wishes for future care and medical treatment to be explored and supported. A number of healthcare organizations have identified that there is a clear role for nursing in ACP. The purpose of this study was to investigate the knowledge, attitudes, and experiences of medical-surgical nurses working in Winnipeg, Manitoba, Canada in relation to ACP. This cross-sectional descriptive study involved the use of a questionnaire developed and used in Singapore and assessed for face validity by local experts. A sample of 218 registered nurses responded to the web-based survey. Nurses in this study were found to: have a sound understanding of foundational ACP concepts; have communal and also varied attitudes toward ACP; and report variable levels of involvement in ACP with patients and families. The results of this study provide valuable insights, adding to the growing literature in this area. These findings can be used to support, inform, and direct essential change and development within educational and clinical settings alike.

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Chapter 1: Introduction

Advance care planning (ACP) is defined as a process of open communication and information sharing between the health care team, patients, and their families. This process of communication is meant to allow a patient's wishes for future care and medical treatment to be shared, explored, and supported (Baughman et al., 2013; Baughman et al., 2012; Minto & Strickland, 2011; Zhou, Stoltzfus, Houlding, Parks, & Swan, 2010). The study described in this document examined medical-surgical unit nurses' knowledge of, attitudes toward, and experiences with ACP in one regional health authority in Manitoba, Canada. In this chapter, the background to the problem will be outlined, definitions of terms will be provided, and the purpose of the study will be identified. In addition, the guiding conceptual framework will be described.

History of Advance Care Planning

Advance directives were first introduced in the United States in the late 1960s (Sabatino, 2010). An advance directive is a legal document that allows people's anticipatory medical treatment wishes to be indicated in writing, in advance of a time when, due to ailment or illness, they cannot speak for themselves. The intended purpose of an advance directive, or living will as it was first introduced, was to guide clinical care ensuring an individual's right to autonomous decision-making was protected, even during times of incapacitation or unconsciousness (Sabatino, 2010).

In the early 1990s, Canada took note of the need for legislation to legally protect the autonomous decision-making rights of Canadians in the health care arena (Manitoba Law Reform Commission, 1991). In Canada, health care directives or advance directives are regulated at the provincial level, with each province or territory charged with outlining laws and

regulations specific to their own jurisdiction (Brown, 2003; Dunbrack, 2006). In 1993 in Manitoba, the *Health Care Directives Act* was created to address this concern. The *Health Care Directives Act* provides legal protection and support to the autonomous decision-making rights of Manitobans (Manitoba Health, n.d.). This legislation allows individuals to document in advance their wishes for future medical care as well as designate a proxy or proxies to make medical decisions on their behalf if unable to do so for themselves (Dunbrack, 2006).

In recent years, supporting patients in autonomous medical decision making has shifted away from a reliance and emphasis on legal documentation alone to embracing instead an ongoing process of communication known as advance care planning (Baughman et al., 2012; Brown, 2003; Canadian Hospice Palliative Care Association, 2012; Sabatino, 2010). This shift was influenced by the Study to Understand Prognosis and Preferences for Outcomes and Risks of Treatment, also known as the SUPPORT study (Teno, Lynn, & Wenger, 1997). This was a large-scale study that investigated the impact of advance directives on communication and medical decision-making of hospitalized patients. The control group in this study received assistive services of nurse clinicians whose aim was to facilitate and support communication around the use of advance directives in the management of clinical patient care. This was done by enhancing communication pathways and interactions between patients, their families, and health care team members by engaging in discussions specifically around patient preferences, treatment options, and clinical care planning. Findings from this wide-scale study did not support the initial hypothesis that facilitating the use of advance directives in the clinical practice environment would foster improvements to treatment decision-making processes of patients. Furthermore, this study noted that the use of an ongoing process of communication around patient preferences, treatment options, and clinical care planning, known as advance care

planning, may well be more beneficial than a reliance on advance directive documents in isolation (Teno et al., 1997).

As noted above, advance care planning (ACP) is defined as a process of open communication and information sharing between the health care team, patients, and their families. This process of communication is meant to allow a patient's wishes for future care and medical treatment to be shared, explored, and supported (Baughman et al., 2013; Baughman et al., 2012; Minto & Strickland, 2011; Zhou et al., 2010) and is carried out in a manner that facilitates informed medical decision making by the patient (Baughman et al., 2013; Black & Emmet, 2006; Samanta & Samanta, 2010; Seymour, Almack, & Kennedy, 2010; Stewart, Goddard, Schiff, & Hall, 2011; Yee et al., 2011; Zhou et al., 2010).

ACP can occur in a variety of clinical care settings, such as primary care (Davidson, Banister, & de Vries, 2013; Minto & Strickland, 2011), acute care (Boddy, Chenoweth, McLennan, & Daly, 2013; Ceccarelli, Castner, & Haras, 2008; Zhou et al., 2010), the community (Badzek et al., 2006; Baughman et al. 2012; Baughman, Aultman, Ludwick, & O'Neil, 2014; Baughman, Ludwick, Palmisano, Hazelett, & Sanders, 2015; Boot & Wilson, 2014; Kazmierski & King, 2015; Seymour et al., 2010), and residential care facilities (Baron, Hodgson & Walshe, 2015; Jeong, Higgins, & McMillan, 2011; Stewart et al., 2011; Stone, Kinley, & Hockley, 2013). ACP discussions are meant to inform patients' thinking about what treatment options they may or may not want and the direction of care they would like to pursue. The categories of care used in Winnipeg are resuscitation (R), medical care (M), and comfort care (C) (Winnipeg Regional Health Authority [WRHA], 2011). Information related to the patient's health status, disease burden, expected trajectory of disease, available treatment options, and expected outcomes of said treatment options are meant to be discussed in ACP (WRHA, 2011, p. 3). As outlined by

the WRHA (2011) in a regional policy on this intervention, ACP “shall be initiated whenever future treatment options or Goals of Care need to be considered or revised” (p. 3), further elaborating that “such discussions shall be completed in advance of anticipated deterioration or acute illness” (p. 3). Ultimately ACP is meant to support patients, in collaboration with the health care team that serves them, as the leaders of their own medical care, and is embraced as a patient-centered approach to clinical care (Canadian Hospice Palliative Care Association, 2012; Health Canada, 2008).

Background to Study

A number of organizations have recognized that there is a clear role for nursing in the ACP process in Canada (Canadian Hospice Palliative Care Association, 2012; Canadian Nurses Association, 2008; WRHA, 2011). Being a regulatory body for health care services and delivery in Manitoba, the WRHA (n.d._a) oversees health care provided in Winnipeg as well as several neighbouring regions. As outlined by the WRHA (2011) in a written policy, ACP is to be carried out by health care team members providing direct clinical care to patients. The discipline of nursing is a major part of the interdisciplinary team providing direct clinical care to patients (Canadian Nurses Association, 2008), and the profession is ideally positioned at the bedside 24 hours a day, 7 days a week to contribute to meeting the ACP needs of various patient populations (Baughman et al., 2013; Ceccarelli et al., 2008; Minto & Strickland, 2011; Samanta & Samanta, 2010; Zhou et al., 2010).

While nursing is well placed to play an important role in discussions with patients about future care, current literature depicts the discipline of nursing as having variable or limited involvement in ACP practices (Badzek et al., 2006; Baughman et al., 2013; Baughman et al., 2012; Ceccarelli et al., 2008; Hu et al., 2010; Stewart et al., 2011; Yee et al., 2011; Zhou et al.,

2010). For example, Yee et al. (2011) used a questionnaire they developed to evaluate the ACP practices of various health care workers including nurses, medical social workers, and physicians working in the field of nephrology (N = 546) in Singapore. These authors noted that despite recognizing ACP as an important and valuable tool for clinical care, 90% of nurses surveyed (n = 461 nurses within the larger sample of health care providers) indicated they “occasionally or never discussed ACP with their patients” (Yee et al., 2011, p. 236). Furthermore, nurses in this study reported participating in ACP-related discussions less frequently than the physicians and social workers surveyed, often deferred ACP-related discussions to physicians or other health care team members, and did not believe ACP communication to be a part of their clinical scope of practice. Similarly, Baughman et al. (2012) used focus groups in one mid-western American state to explore community-based care managers’ roles in the ACP process and found that the nursing (n = 25) and social work (n = 37) care managers favored maintaining a limited role in ACP. The participants saw their roles as those of educator or coach, including providing information to clients regarding the ACP process, preferring that ACP-related discussions be conducted between patients and their physicians (Baughman et al., 2012, p. 729).

Currently, there is a paucity of literature that investigates the ACP practices of nurses in Canada. Literature from Singapore (Yee et al., 2011), the United States (Badzek et al., 2006; Baughman et al., 2012; Baughman et al., 2013; Baughman et al., 2014; Baughman et al., 2015; Black & Emmet, 2006; Black, 2007; Ceccarelli et al., 2008; Zhou et al., 2010), Australia (Boddy et al., 2013; Jeong et al., 2011), United Kingdom (Baron et al., 2015; Boot & Wilson, 2014; Kazmierski & King, 2015; Minto & Strickland, 2011; Seymour et al., 2010; Stewart et al., 2011; Stone et al., 2013), New Zealand (Davidson et al., 2013), and Taiwan (Hu et al., 2010) does provide some insight into the practices and perspectives of nurses in ACP. This gap in research

from Canada causes a reliance on international sources to represent or depict the practices of Canadian nurses in ACP. This could be problematic given differences in legislation related to health care directives and our health care systems in Canada and possible differences in nurses' scope of practice across countries (Brown, 2003; Canadian Hospice Palliative Care Association, 2012; Dunbrack, 2006; Schuklenk, Downie, Upshur, & Weinstock, 2011).

Purpose of the Study

A gap in the literature in relation to studies carried out in Canada on the topic of nurses and advance care planning was identified. The purpose of this cross-sectional, descriptive study was to explore knowledge of, attitudes toward, and experiences with ACP in registered nurses working on medical-surgical units in hospitals within the WRHA.

Definitions of Terms

Advance care planning. Advance care planning is a process of open communication and information sharing between the health care team, the patients, and their families, often occurring over time. This process of communication is meant to allow a patient's wishes for future medical care and treatment to be shared, explored, and supported (Baughman et al., 2013; Baughman et al., 2012; Minto & Strickland, 2011; Zhou et al., 2010) in a manner that facilitates informed decision making for the patient (Baughman et al., 2013; Black & Emmet, 2006; Samanta & Samanta, 2010; Seymour et al., 2010; Stewart et al., 2011; Yee et al., 2011; Zhou et al., 2010). In some instances, this process can occur with a substitute decision maker when a patient is not competent to make decisions for himself/herself (Canadian Hospice Palliative Care Association, 2012; Dunbrack, 2006; Manitoba Health, 1993; Manitoba Law Reform Commission, 1991).

Health care directive. A health care directive is a legal document that allows an individual to outline his/her wishes for or against specified future medical care and medical treatments. This legal document is meant to serve as a record for clinical management in patient care if the individual becomes incapacitated and unable to speak for himself/herself. In Manitoba, a proxy (i.e., a legal substitute decision maker) or proxies can also be named in this document (Manitoba Health, 1993).

Registered nurse. According to legislation in Manitoba, a registered nurse is defined as an individual who has graduated from an approved nursing education program or a program that meets the requirements set out in regulations, has passed a national registered nurse examination, meets the requirements of an annual continuing competence program, and maintains the required number of annual practice hours (College of Registered Nurses of Manitoba, 2005). Such individuals may hold valid registration with the regulatory body upon providing evidence that these criteria have been met and paying a registration fee.

Knowledge. In the dictionary, knowledge is defined as “facts, information, and skills acquired through experience or education; the theoretical or practical understanding of a subject” (“Knowledge”, 2014).

Attitude. In the dictionary, attitude is defined as “a settled way of thinking or feeling about something” (“Attitude”, 2014).

Experiences. Experiences are defined as “practical contact with and observation of facts or events” (“Experiences”, 2014).

Guiding Conceptual Framework

Ineffective and inconsistent practices in ACP are issues noted across Canada (Canadian Hospice Palliative Care Association [CHPCA], 2012; Schuklenk et al., 2011). In 2012, the

CHPCA released a collaborative document meant to address and mitigate this concern.

Developed by national organizations and ACP interest groups, “Advance Care Planning in Canada: National Framework” is a comprehensive document integrating legislative, ethical, and clinical practice considerations to establish a framework for successful operationalization of ACP across Canada (CHPCA, 2012, p. 1).

Stakeholders, the individuals whose work and participation in ACP are integral to the overall success of the process, are described in this framework to be “governments at all levels, the non-governmental sector, and health-care, legal, and social services professionals” (CHPCA, 2012, p. 1) whose actions are centered around the needs of the patient and family. This framework was designed to instruct ACP practices as well as inform and shape ACP-related educational and legislative initiatives (CHPCA, 2012). This national framework for ACP involves four areas of focus, all operating in connection with the patient and family as the nucleus of this framework. The four areas are: engagement to actively involve stakeholders in “planning for, and implementing advance care planning in Canada” (CHPCA, 2012, p. 12); education to train and inform relevant stakeholders in ACP-related content and skills; system infrastructure to establish and maintain formalized systems within health care and legislative sectors that support the connection, involvement, and immersion of stakeholders in ACP; and continuous quality improvement “to evaluate all advance care planning initiatives in Canada based on structure, process, and outcomes indicators” (p. 30).

Two areas of focus in the framework are of particular interest to this study as these foci provide rationale for carrying out the study and illustrate how findings from this research can be used. With regards to engagement of stakeholders for planning and implementing ACP, at present we have limited knowledge of nurses’ participation in and experiences with ACP,

particularly in Canada. Given nurses' proximity to patients (Peter & Liaschenko, 2004), it can be expected that patients in a variety of clinical settings will ask nurses questions about their illness trajectory. Patients rely on the knowledge and expertise of health professionals, including nurses, to inform, guide, and support them through the process of decision making for future clinical care. There is evidence that the nursing discipline in other countries is falling short of this expectation, displaying limited engagement in ACP practices (Baughman et al., 2012; CHPCA, 2012; Yee et al., 2011). The CHPCA (2012) framework identifies a need for further research in this area.

With regards to the education component of the framework, the CHPCA (2012) advocates the use of "emerging" research to inform and direct ACP initiatives in Canada (p. 10). The results of this study help identify possible facilitators and barriers to the engagement of nurses in the ACP process. In addition, the results assist in identifying knowledge gaps, misconceptions, held beliefs, and practices of nurses in ACP, all information that may be used to inform and support education and future initiatives organized under the guidance of this national framework.

Significance of the Problem

Canadians are living longer (Statistics Canada, 2013). Millions of Canadians are coping with chronic disease and illness (Health Canada, 2008), and ongoing advances in clinical technology provide Canadians with more and more medical treatment options in the management of disease and illness (CHPCA, 2012). Under such circumstances, Canadians are dealing with the health care implications and related medical decision making linked to the management of disease and illness (Dunbrack, 2006; Health Canada, 2008; Schuklenk et al., 2011). As such,

ACP becomes an integral component of the clinical management of Canadians in the hospital setting.

Advance care planning is important because it is meant to ensure patients' involvement in medical decision-making and clinical care and preserve patient autonomy (Baughman et al., 2013; Jeong et al., 2011; Minto & Strickland, 2011; Samanta & Samanta, 2010; Seymour et al., 2010; Yee et al., 2011; Zhou et al., 2010). When ACP is done effectively it has been shown to increase satisfaction with care and minimize levels of depression and anxiety in family members (Detering, Hancock, Raede, & Silvester, 2010; Simpson 2012), decrease the prevalence of ethical dilemmas and moral distress amongst health care team members (Simpson, 2012), support greater adherence to patients' wishes for future medical care and treatments (Simpson, 2012), and lower the experience of burden on health care team members and family members (Health Canada, 2008). It has also been shown that ACP does not have a negative impact on patients' hope (Davison & Simpson, 2006; Simpson 2012).

When done effectively, the value of ACP is evident and a lack of involvement in this process on the part of health care providers jeopardizes the patient-centered approach to clinical care that ACP supports (Canadian Hospice Palliative Care Association, 2012; Health Canada, 2008). Recent Canadian literature, however, identified ACP practices in Canada to generally be poorly performed and inconsistently executed (Canadian Hospice Palliative Care Association, 2012; Schuklenk et al., 2011). As stated above, there is a need for further research to support improvements to the ACP process in Canada (Dunbrack, 2006; Easson, 2005; Schuklenk et al., 2011). Currently, literature to depict the ACP practices of nurses in Canada is limited. The significance of this study is that it contributes to our understanding of the knowledge, attitudes, and experiences of nurses working in a large regional health authority in Winnipeg, Manitoba,

Canada and provides research data that have the potential to contribute to improvements in the ACP practices of nurses in this country through, for example, education and policy development.

Chapter 2: Literature Review

In this chapter, a brief overview of the history of advance directives in the United States and Canada will be presented. This will be followed by an exploration of the literature related to nurses and advance care planning, with a particular focus on literature in the area of nurses' knowledge, attitudes, and experiences related to ACP.

Advance Directives

As stated above, the notion of advance directives (AD) was first introduced in the United States in the late 1960s (Sabatino, 2010). ADs serve as a record of anticipatory wishes for medical treatment and interventions documented in advance of a time when individuals may be unable to speak for themselves (Kirschner, 2006). These wishes are documented in what is known in some jurisdictions as a living will or durable power of attorney document (Kring, 2007; Prendergast, 2001). In Manitoba, these documents are referred to as health care directives.

The *Natural Death Act*, passed in California in the 1970s, was seminal legislation concerning planning for future clinical care. The legislation spoke to the protection of citizens' decision-making rights during incapacitation in the form of a living will (Kirschner, 2006). A living will, a formal document that captured preferences specific to "life-sustaining treatment" (Sabatino, 2010, p. 213), had limitations in its ability to depict comprehensive information related to various medical treatment options and interventions, and was often ineffective in guiding clinical care for an incapacitated patient as a result (Sabatino, 2010). Thus, the objective of effective planning for future clinical care was further expanded by the enactment of the *Durable Power of Attorney for Health Care* (DPAHC) legislation in some states in the United States (Sabatino, 2010). This legislation provided for the appointment of one individual by another to act on the person's behalf as principal medical decision maker in times of

incapacitation (Kirschner, 2006; Kring, 2007; Sabatino, 2010). Ultimately, the aim of an AD is to support the autonomous decision making rights of patients in the health care arena, seeking to ensure their wishes for clinical care are at all times observed and respected (Kirschner, 2006).

Another important piece of legislation in the United States is the federal *Patient Self-Determination Act*, which came into effect in the early 1990s. This act required medical facilities to advise patients of their independent rights to medical decision-making and ability to complete an advance directive (Sabatino, 2010). This legislation was meant to support autonomous decision making for hospitalized patients, promoting the need to plan for future clinical care and mitigate the occurrence of lengthy and costly court cases seen in the media over medical decision making on behalf of incapacitated patients (Pope, 2013; Prendergast, 2001).

AD legislation in Canada has followed a slightly different path than in the United States. In a report issued by the Law Reform Commission of Canada (1982) entitled “Euthanasia, Aiding Suicide and Cessation of Treatment”, the Commission argued against adopting “an equivalent to the Natural Death Act” in Canada (p. 69). At that time, the reason given for this stance was that such legislation:

would risk the reversal of the already-established rule that there should be no duty to initiate or maintain treatment when it is useless to do so. The living-will approach begins from the opposite principle, since it requires that the patient’s wishes be formally expressed in writing in order to authorize the physician not to prolong that patient’s agony and death. This approach may be arguable in the context of legal systems of California and other states, but we do not feel it is an arguable reform for Canada. (Law Reform Commission of Canada, 1982, p. 69)

It was not until the 1990s that AD legislation began to emerge in Canadian provinces, starting in Manitoba in 1992. In 2013, nine provinces and two territories had legislation related to ADs, proxies, and/or substitute decision-making (Irvine, Osborne, & Shariff, 2013).

Difficulties with advance directives. As noted above, ADs are meant to protect the autonomous decision-making rights of individuals and guide the delivery of clinical care to be in accordance with individuals' anticipatory medical decisions (Prendergast, 2001). Over time, however, ADs have been seen as widely underused and unsuccessful (Baughman et al., 2012; Black & Emmet, 2006, Fagerlin & Schneider, 2004; Wilkinson, Wegner, & Shugarman, 2007), for reasons described below.

Underuse of advance directives. In a review of AD literature from 2004 to 2007, Wilkinson et al. (2007) noted minimal uptake of ADs, with both well and ill persons displaying modest rates of AD completion. Fagerlin and Schneider (2004) reported equally low rates of advance directive completion in their report on the ineffectiveness of such documents, citing numerous reasons such as people's lack of understanding, the perceived difficulty of the task, people delaying or deferring completion, and people's perception that advance directives are only applicable to the "elderly or infirm" (Fagerlin & Schneider, 2004, p. 32). Other reasons for not completing an AD include anxiety about the morbid considerations of ADs, the perception that documented wishes would not be adhered to, and preferences to rely on others (e.g., physicians or loved ones) for medical decision making (Wilkinson et al., 2007). Two recent studies from Canada provide some information about AD completion. In a prospective study in one emergency department in Vancouver, researchers found that 19.3% of participants over 70 years of age (N = 280) indicated they had completed an AD (Gill, Fukushima, Abu-Laban, & Sweet, 2012), while approximately 44% of people in a telephone survey carried out in Alberta

(n = 1184, age range 18 to 96 years) indicated that they had completed an AD (Wilson et al., 2013). Gill et al. (2012) reported that close to 50% of those who had not completed an AD (n = 107) had never thought about doing so, 16% (n = 36) preferred to let family members decide for them, and 12% (n = 27) were not ready to make such decisions.

Directing clinical care. Fagerlin and Schneider (2004) noted various studies have reported that ADs were not successful in impacting the clinical care of incapacitated patients. These authors cited research that reported similar care occurred between groups of patients with and without ADs, also noting decision makers appointed in formal AD documentation were not always consulted or relied upon due to physical unavailability, being ill-equipped for substitute decision making, or emotional preoccupation with other concerns. Based on their review of the literature, these authors concluded advance directives “failed to offer people the means to articulate their preferences accurately” and found ADs to consistently be inaccessible or physically unavailable when needed (e.g., misplaced somewhere in the patient’s home) to guide or assist the actions of substitute decision makers (Fagerlin & Schneider, 2004, p. 38). Kring (2007) made the same observation that ADs were not physically accessible when needed and, therefore, were not useful in guiding clinical care.

In review articles on AD use, authors have highlighted that medical personnel were often unaware that their patients had completed an AD. In addition, some studies identified that physicians underestimated the clinical care wishes of their patients, while substitute decision makers overestimated the clinical care wishes of their loved ones. Some studies showed substitute decision makers did impact clinical care for incapacitated patients while other studies denied such influences, but when ADs were utilized they were found to be implemented extremely late in the course of illness (Wilkinson et al., 2007). Prendergast (2001) found “little

evidence that advance directives change treatment” (p. 35), citing studies that reported the lack of effect that formal AD documents had on impacting the direction or outcomes of clinical care.

Health care providers do find ADs can be helpful in stimulating conversations about clinical care with patients (Thompson, Barbour, & Schwartz, 2003), but acknowledge ADs can be limiting and potentially unreliable in portraying a patient’s real-time desires regarding clinical care (Kring, 2007; Thompson et al., 2003). Supporting the independent decision-making rights of patients is shifting towards employing a process of ACP and ongoing discussions about medical care and treatment options, rather than a reliance on formal ADs (CHPCA, 2012; Sabatino, 2010). Successful incidents of planning for future clinical care, based on high AD completion rates and corresponding compliance with outlined medical wishes, have been found in settings where an ongoing format of discussion about future pending medical care and treatment options is employed (Kring, 2007), and moving to a system of ACP rather than ADs is supported by national organizations like the Canadian Hospice Palliative Care Association (2012).

Advance Care Planning

ACP is complex and challenging work. Studies related to nurses and ACP have been carried out with nurses working in a number of areas, including home health care, nephrology, oncology, residential care facilities, community long-term care, acute care, community-based palliative care, and primary care. In this review of the literature related to ACP, CINAHL, PUBMED, and SCOPUS were searched with the primary search terms of *advance care planning, knowledge, attitude, experience, and nurse*. Derivatives of the term ACP (*advance care plan, advance care plan discussion, advance care planning discussion*) were used in combination with synonyms of the other primary search terms stated above. Articles published

before 2004 and articles with a paediatric focus were omitted. Three key topic areas were identified in this review of the literature in relation to nurses and ACP: knowledge of the ACP process; attitudes towards ACP; and experiences with ACP discussions with patients and families. Each of these topics is discussed below, with articulation of the major themes evident in this literature.

Knowledge. As with any skill in nursing practice, knowledge is required to effectively engage in the ACP process. Studies to date have examined how nurses understand and define ACP, nurses' knowledge of what shapes the process, such as legislation, and nurses' perception of their skills to contribute to the process. Researchers have found that nurses often struggle in their understanding of ACP and question their qualifications and preparedness to engage in the process.

How ACP is understood and defined. A recent American qualitative study conducted by Baughman et al. (2012) investigated how nurses understand and define ACP. Health care providers working in community long-term care were engaged in eight focus group sessions, each session sixty minutes in duration. Probing questions were presented to solicit perspectives of participants on their understanding and practices related to ACP. Through thematic analysis, the authors presented the study participants' (N = 62) understanding of ACP to be a collaborative process of social, legal, medical, and educational concerns. Socially, ACP was understood as the act of planning for one's future, planning for a time when clinical care needs would be changing and increasing. For some this was strictly related to end-of-life care, while others included planning for appropriate housing, identifying the need for clinical resources, and making funeral arrangements. Legal aspects of ACP were acknowledged as formal documentation that supported patients in autonomous medical decision making. The nurses (n = 25) and social

workers (n = 37) in this study identified their legal knowledge of ACP to be limited, refrained from completing ACP documentation for patients, and expressed a need for further training. The element of ACP perceived as medical was the aspect of relaying clinical information to patients and families. Participants recognized patients and families required detailed information related to their medical conditions, disease trajectory, and clinical treatment options as part of effective ACP. When reflecting on their own understanding of such information participants identified weaknesses in their scope of knowledge and expressed discomfort and avoidance about taking responsibility to relay this information to their patients. To promote ACP with patients, they encouraged patients to have such discussions with their doctors but restricted their own engagement in such discussions with patients to only the content they felt comfortable discussing, which for most study participants excluded information about “prognosis and medical options” (Baughman et al., 2012, p. 730).

Seymour et al. (2010) used an action research study design to investigate the perceptions and clinical care behaviours of community-based nurses in England related to ACP (N = 23). Study findings indicated that community nurses struggled with their understanding of the processes and proceedings of ACP. For this group of nurses, ACP was a fairly new concept, introduced to them within the previous two to three years through local education initiatives. A common perception of the participants, however, was an understanding of ACP as simply the legal formalization of clinical care planning that was already being done by health care team members (Seymour et al., 2010). The nurses also brought into question their colleagues’ knowledge of ACP; this was recognized as a limitation amongst the nurses manifested by nurses avoiding ACP discussions with their patients or asking others to conduct them in their place.

Researchers in the United Kingdom sought to investigate how residents of a nursing care home, their family members, and care home staff experienced ACP discussions. All individuals involved in a recent ACP discussion within the care home were asked to reflect on their experiences in semi-structured interviews with research team members (Stone et al., 2013). Through a qualitative descriptive study design one of the main findings of the study focused on how the participants understood ACP. The researchers identified staff at the care home (i.e., five nurses, one health care aid) did not have a clear understanding of ACP and understood the scope of the intervention differently from one another. Some believed ACP pertained to documented wishes for care, while others believed ACP pertained to routine care or funeral arrangements (Stone et al., 2013).

In an effort to demonstrate how nurses understand the need for ACP amongst their patients, a factorial survey design was used with health care professionals employed in long-term care in the community (Baughman et al., 2013). Factorial survey designs are meant to illicit judgements or conclusions from participants by asking them to answer questions based on the information provided in case-study-like scenarios presented to them (Baughman et al., 2013). The intention of presenting these scenarios to the social work (n = 299), nursing (n = 128), and allied health team members (n = 10) participating in the study was to better understand the factors or indicators health care professionals assessed for to determine a patient in need of ACP (Baughman et al., 2013). From this study, participants were found more likely to identify a need for ACP in patients who had limited or no social supports, were of elderly age (older than 75 years), and had a health condition in end-stage progression. These clinical factors had the most impact on how study participants understood or recognized a clinical need for ACP in patients (Baughman et al., 2013).

Knowledge and perception of skills in ACP. Several studies examined nurses' knowledge of various aspects of ACP with some studies also noting how nurses perceived their own abilities as contributing to effective future care planning with patients. As stated above, nurses struggle in their understanding of ACP and question their qualifications and preparedness to engage in the process.

A national study sought to investigate the knowledge, attitudes, and experiences of interdisciplinary renal health care providers (n = 546) in the country of Singapore (Yee et al., 2011). The authors developed a 41-item questionnaire, which incorporated questions from previous studies that were adapted with permission of the studies' authors. In total, 51 physicians, 461 nurses, 13 social workers, and 21 others responded to questions on the questionnaire. ACP knowledge was assessed using nine true/false format questions. ACP-related knowledge scores for nurses were the lowest of all study participants with an average score of 6.3 out of nine (230 responded); average scores for other participants were 8.0 for physicians (37 responded), 8.3 for medical social workers (13 responded), and 6.4 for other allied health team members (14 responded). The correct responses by study participants identified a clear knowledge of ACP as both an intervention that advocates for patient autonomy and necessitates effective skills of communication. The two questions with the highest number of people answering incorrectly were related to identifying ACP as a "legal document" and recognizing ACP as a process unrelated to the completion of an advanced directive (Yee et al., 2011, p. 234).

Concerns regarding limited knowledge were identified in nurse participants in a descriptive exploratory study on primary care nurses (N = 13) in New Zealand. Nurses were interviewed about their understanding of advance directives, considered in the New Zealand

culture to be the same as advance care plans. Nurses in this study were described as “unfamiliar with the terminology” of advance directives (Davidson et al., 2013, p. 30), and expressed difficulties with their understanding of legislative guidelines and the process of advance directive completion (Davidson et al., 2013).

A recent study used focus groups to solicit information on what multidisciplinary health care providers felt supported and impeded successful ACP, primarily within the acute care setting. Boddy et al. (2013) detailed findings on identified barriers to ACP as understood by the multidisciplinary health care providers (N = 41), which included seven acute care nurses. Findings from this study identified three major barriers described as patient, health care provider, and health care system-based barriers. Health care provider barriers included a lack of comprehensive knowledge in the “meaning, scope and associated administrative processes” of ACP (p. 42) and limited knowledge beyond one’s clinical role or clinical site. Similarly, Baughman et al. (2014) noted that the nursing (n = 25) and social work (n = 37) community care managers they interviewed felt their limited “knowledge and training” in ACP compromised their ability to implement ACP with their patients (p. 57).

Kazmierski and King (2015) conducted a broad interpretive phenomenological study on how planning for future care was experienced by community matrons, a position created to support community dwellers with high medical needs. This qualitative study focused on how ACP and do not resuscitate (DNR) decisions, or “do not attempt cardiopulmonary resuscitation (DNACPR)” as it is described in the United Kingdom, are made (Kazmierski & King, 2015, p. 20). It was identified that nurses in this study (N = 6) felt more comfortable completing formal DNACPR paperwork in collaboration with a fellow co-worker, which was not a required practice, rather than completing the form alone due to a personal lack of confidence. Nurses did

feel confident in their understanding of ACP and DNACPR, but still had reservations related to formal paperwork. This apprehension was identified as a barrier to ACP as it limited the nurses' involvement in related discussions with patients.

Silvester et al. (2013) performed a small scale, pre-intervention assessment on nursing (n = 17) and managerial staff (n = 28) working in residential aged care facilities in Victoria, Australia. In part, the purpose of this study was to provide baseline data on care providers' understanding of ACP and their related practices. When questioned on knowledge of ACP, 44% answered four out of seven questions correctly and 27% answered five out of seven correctly. The highest percentage of incorrect answers was noted on a question concerning the designation of a substitute decision maker (over 70% incorrect, n = 33). Of the nine questions posed to participants inquiring about their confidence in ACP-related tasks, participants were least confident about their understanding of pertinent local ACP legislation, the function of the substitute decision maker, and troubleshooting discussions of care between patients and family members (Silvester et al., 2013). In terms of perception of skills related to ACP, more than half surveyed reported minimal or no confidence in four of those nine ACP-related tasks, however, the majority of individuals (n = 27 out of 41) still reported feeling "comfortable or very comfortable" when asked about engagement in ACP discussions with patients and families (Silvester et al., 2013, p. 354). Half of respondents (21 out of 42) described themselves to be "skilled or very skilled" in ACP discussions (Silvester et al., 2013, p. 354). The study authors acknowledged the "apparent discrepancy" between self-reported comfort levels and "limited ACP knowledge and lower ratings of skill and confidence" (Silvester et al., 2013, p. 355), indicating the need for further study in this area. Confidence in ACP discussions was also addressed in a factorial survey design study by Baughman et al. (2013), which identified social

work, nursing, and allied health practitioners to have strong levels of “confidence and comfort” related to discussing ACP with patients and families (pp. 720-721).

Further limitations in the knowledge of nurses were documented in a recent American study that identified the potential for oncology-based advanced practice nurses (APN) to enhance the care of patients through effective ACP (Zhou et al., 2010). A descriptive cross-sectional study was conducted to investigate the knowledge, attitudes, and experiences of APNs working in oncology medicine (N = 300). Twelve multiple choice and true/false format questions were asked, covering knowledge of ACP-related legislation, communication, and professional practice responsibilities. The average score for all participants on the knowledge items was 67% correct, reflecting what the researchers described as participants being “somewhat knowledgeable” (Zhou et al., 2010, p. 405). Incorrect responses identified a lack of understanding that documentation and communication are both integral to the clinical care wishes of patients being accurately conveyed to others in ACP, and also showed some inexperience among participants regarding formal ACP documentation, in this case the Physician Order for Life-Sustaining Treatment (POLST) form, which details specifics to the end-of-life clinical care patients wish to receive.

The “Advance Care Planning Nurse Inventory” is a questionnaire developed by researchers for an American study investigating the academic knowledge of home care nurses (N = 519) related to ACP (Badzek et al., 2006, p. 58). Utilizing the self-developed questionnaire, researchers sought to test “perceived knowledge versus actual knowledge related to ACP” amongst this nursing population (Badzek et al., 2006, p. 56). On average, respondents had close to seven years of clinical experience working specifically as a home care nurse with more than half employed full time at the time the study was conducted. The nurses reported their knowledge of ACP being enhanced or supplemented by ACP literature they were exposed to

through their clinical work. When questioned how they perceived their personal level of ACP comprehension, the data reflected a positive and confident outlook as subjects overwhelmingly identified themselves to be well informed to conduct ACP with their respective patient populations and well versed in the policies and regulations that inform and shape ACP interventions (Badzek et al., 2006). Adeptness in ACP was indicated by respondents answering yes or no to various ACP-related questions of competence regarding engaging in ACP and understanding ACP legislation. Responses were overwhelmingly affirmative with 90% (n = 467) stating they understood “the concept of ACP” and 60-79% stating expertise in various laws that regulate the process. Results from the questionnaire that tested actual academic knowledge in ACP indicated much less proficiency. As a group, the nurses incorrectly responded to almost half of the knowledge-based questions that tested academic knowledge in ACP, with significant knowledge gaps related to legislation. This indicates significant limitations in the knowledge nurses have in ACP and calls into question the information that guides them in their ACP interactions (Badzek et al., 2006).

Ninety-five research subjects took part in a study in northeast England to investigate the opinions and practices of health care system personnel working in palliative care or with older adults with dementia. Robinson et al. (2013) wanted to solicit experiences from a wide variety of health care system personnel to expand collegial knowledge of ACP beyond the current research focus on distinct clinical disciplines. Nursing personnel included in this study were community nurses and mental health nurses (n = 17) grouped with allied health professionals (n = 22) and 5 palliative care specialists (i.e., consultants and clinical nurse specialists). Other study participants included physicians (n = 10), psychiatrists (n = 10), social workers (n = 6), ambulance service personnel (n = 15), solicitors (n = 3), and health care volunteers (n = 7).

Researchers in this study found study participants had concerns regarding their lack of clear understanding of the various legal and non-legal aspects of planning for future clinical care, were not well versed on ACP-related documentation and forms, and used terms related to planning for future clinical care incorrectly (Robinson et al., 2013). Among the various personnel involved in this study, palliative care specialists tended to have more divergent perceptions than others, displaying self-assurance in their ability to understand the legal foundation of the ACP process and in their ability to conduct ACP successfully. Additionally, palliative care specialists, along with a limited number of physicians and community nurses, perceived ACP as part of their scope of practice to a greater degree than the majority of others surveyed, who doubted their ability to carry out ACP with their patients and did not believe ACP was part of their scope of clinical practice responsibilities (Robinson et al., 2013).

Doubting clinical competence to engage in ACP was a finding also noted in a recent study involving nurses in Australia. In part, this study aimed to investigate oncology nurses' perceptions of what inhibits their ability to conduct ACP with patients (Samara, Larkin, Chan, & Lopez, 2013). Using a pre- and post-implementation audit design, an education program was provided to a group of nurses and physicians working in oncology. As part of the study, a sample of 25 nurses participated in a focus group interview exploring barriers to and strategies for implementing ACP. Although not explained in depth, concerns were expressed about limited skills as to the legal foundations of ACP and possessing less clinical knowledge regarding patient care than physicians. Nurses also felt ACP should be the responsibility of other health care professionals like physicians, "social workers or care coordinators" (Samara et al., 2013, p. 112).

To address knowledge gaps for nephrology nurses in ACP, educational seminars were organized by the American Nephrology Nursing Association to enhance understanding and

engagement of nurses in ACP. Ceccarelli et al. (2008) reported on the subjective feedback of nurses' experiences with ACP obtained from participants following their participation in these educational seminars. The nurses expressed concern about their knowledge and this translated into a reluctance to conduct ACP. Nurses felt they were not equipped with the right information to conduct ACP discussions with patients, questioned their clinical boundaries regarding what should actually be discussed with their patients, and felt they lacked the necessary skill of communication to support them in effective ACP with patients. These limitations were seen as being potentially detrimental to patients, having the potential to contribute to miscommunication and misunderstanding of clinically sensitive information relayed in such discussions.

A very recent longitudinal study conducted in Greater Manchester, England, within the nursing care home setting, highlighted the value of formal ACP-related training and education (Baron et al., 2015). The ACP educational program administered in the nursing care home setting was formatted specifically around the identified learning needs of the nursing care home staff and implemented over a maximum six week period. A questionnaire assessing ACP knowledge was administered to participants (N = 265, 12% were nurses) up to 14 months after the intervention had occurred, and results from participants identified a consistent increase in knowledge scores amongst staff that had received the educational program (Baron et al., 2015). This study also noted an increase in formal ACP documentation (identified as completed advance care plans) in four out of the six nursing homes that had received the educational program and a mean increase from 24% to 43% completion of ACP documentation, when all care homes that had received the educational program were considered.

These studies assessed nurses' ACP knowledge in a variety of ways. Nurses' understanding of ACP was dynamic and nurses were able to recognize the limitations that exist

in their comprehensive knowledge of the process. It is clear that this is an area for potential improvement among the nursing discipline to strengthen their comprehensive knowledge in ACP, supporting their role and work in this valued intervention.

Attitudes. In the literature, the emotional work of ACP, its impact on nurses, and nurses' attitudes are explored. These aspects of the literature are discussed below.

Emotional work of ACP. The work of nurses in ACP involves communicating with patients and families about morbidity, mortality, and end-of-life care, which can be difficult and emotional subjects for individuals to discuss openly (Badzek et al., 2006; Jeong et al., 2011; Stewart et al., 2011). In some studies, nurses believe ACP discussions have the potential to be upsetting and emotionally stressful for patients and families and several studies noted anxiety among nurses about engaging in ACP. Ceccarelli et al. (2008) noted nurses have a prominent sense of apprehension regarding ACP discussions with patients and families. Nurses judged the sensitive content of ACP discussions to be a distressing experience for patients and families often manifested by emotional or negative outbursts that nurses would rather avoid. Zhou et al. (2010), in their cross-sectional descriptive study of advanced practice oncology nurses, found nurses had similar concerns of not wanting to cause distress in patients or their family members and this limited their participation in ACP. The same concern was also voiced by nursing care home staff (n = 5 nurses, n = 1 nursing assistant) in a qualitative study conducted in southeast England. Staff identified they were concerned about distressing residents or their family members with ACP discussions, with researchers describing care home staff's experience of ACP as "intimidating," with their apprehension having influence over ACP actions (Stone et al., 2013, p. 553).

A 2014 study conducted by Boot and Wilson utilized a qualitative approach with palliative care clinical nurse specialists (CNS) and described ACP for this group as “taking a risk and requiring courage” (p. 10). The CNS group in this study (N = 8) needed to be in tune with their patients and required an emotional sensitivity to expertly assess what their patients may or may not be willing and open to discussing related to planning for future care (p. 11). Similarly, sentiments experienced by health care providers in a secondary narrative analysis by Baughman et al. (2014) described the experiences of the nursing (n = 25) and social work (n = 37) care managers working with patients in the community as “a common feeling of discomfort, fear, or inadequacy” (p. 59) pertaining to care managers’ experiences with ACP.

In a national study in Singapore, the attitude scores of nurses (n = 461) reflected a greater degree of preoccupation with the potential for ACP discussions to be upsetting and harmful to patients than physicians, medical social workers, and other allied health team members (Yee et al., 2011). In this study, nurses consistently scored highest or amongst the highest on questions assessing the perception of ACP discussions having adverse effects on their patients’ emotions and decision-making (Yee et al., 2011). Comparably, in a review of ACP literature from 2002-2011, Cohen and Nirenberg (2011) examined how ACP was carried out within the United States by health care professionals. These authors reported nurses struggled to overcome their own “discomfort” about engaging in ACP discussions and had concerns of contributing to a patient’s loss of hope if such conversations took place (Cohen & Nirenberg, 2011, p. 549).

Further to the concern that ACP can cause emotional strain for patients, nurses also questioned the negative impact such strain or negative emotion could have on the therapeutic relationships they had developed with patients (Ceccarelli et al., 2008) and the adverse impact the emotional strain and mental burden of ACP could have on the health care provider (Jeong et

al., 2011; Minto & Strickland, 2011). Stone et al. (2013) outlined that a prior familiarity and rapport between health care provider and patient was seen as beneficial or helpful to ACP discussions. These therapeutic relationships provided an underpinning or starting point from which such conversations could take place, providing confidence to the health care provider that these conversations could be navigated (Stone et al., 2013). This sentiment was also shared by nurses in a recent qualitative study by Boot and Wilson (2014). The clinical nurse specialists (N = 8) in this study believed a pre-existing relationship with a patient was a necessary foundation for engagement in ACP. However, nurses in this study also felt that ACP discussions had the potential to negatively impact those relationships and would consider the potential harm of a discussion prior to engaging in ACP with patients. Nurses also had concerns in an interpretive phenomenological study of community-based nurses (N = 6) that ACP discussions, particularly pertaining to the topic of ‘do not resuscitate,’ had the potential to be misunderstood or misinterpreted by patients and that such discussions could be received in a negative way by patients (Kazmierski & King, 2015).

“Practitioner sensitivity” was identified as a barrier to ACP in a multidisciplinary study conducted by researchers in Australia (Boddy et al., 2013, p. 42). Utilizing a qualitative approach, social workers (n = 10), occupational therapists (n = 7), speech therapists (n = 4), physiotherapists (n = 6), dieticians (n = 4), nurses (n = 7), and doctors (n = 3) were interviewed regarding their understanding of barriers to ACP. *Practitioner sensitivity* was described as including “their own discomforts relating to death and dying, the belief that discussion could lead to emotional distress, and difficulties concerning timing and appropriateness in hospital settings” (Boddy et al., 2013, p. 42).

In a phenomenological study, Minto and Strickland (2011) investigated the ACP experiences of physicians (n = 3) and nurses (n = 3) working with the palliative care population at a primary care facility in England. Utilizing a semi-structured interview approach these researchers reported the emotional impact the work of ACP had on the health care providers they interviewed. In this study the clinicians shared accounts of times when encounters with patients resulted in periods of emotional upset or distress for clinicians, or feelings of helplessness, sadness, and devastation. The intricacies of engaging in ACP with patients and providing care for a population dealing with a life-limiting health condition caused mental and emotional strain for clinical providers. Researchers described participants in this study as becoming “quite distressed when applying ACP to their patient” (Minto & Strickland, 2011, p. 280). These experiences were summarized as the “emotional labour of ACP” experienced by physicians and nurses alike (p. 280).

The emotional struggle of nurses in ACP was further illustrated in a case study design research investigation that evaluated the ACP experiences of registered nurses (N = 13) working with older adults in personal care homes in Australia. It was identified by the researchers that nurses go through phases (i.e., pre-transition, transition, post-transition) when supporting patients throughout the ACP process. In the pre-transition phase, when contemplating the initiation of ACP, nurses had feelings of “ambivalence and emotional turmoil” and were unsure when end-of-life ACP-based clinical decisions were appropriate to initiate with any particular patient (Jeong et al., 2011, p. 169). In the transition and post-transition phases nurses were noted to experience more positive feelings about ACP as they recognized the intervention supported the successful provision of care congruent with a patient’s wishes; a sense of emotional relief was expressed by participants when this occurred (Jeong et al., 2011). Similar feelings of turmoil or conflict were

expressed in the Baughman et al. (2014) study, where secondary analysis of data utilizing a narrative approach led to the identification of a recurring theme of conflict between professional and moral responsibilities related to ACP for nurse (n = 25) and social work (n = 37) care managers working in the community. In this study it was identified that the nurses and social workers felt a substantial responsibility to meet and support the diverse needs of their community-based patients when planning for future anticipatory care (e.g., health, finances, social supports).

Positive attitudes towards ACP. It is evident from the literature that attitudes of nurses towards ACP tend to be very positive. Nurses recognize the clinical value of the intervention (Baughman et al., 2012; Stewart et al., 2011; Yee et al., 2011; Zhou et al., 2010) and application of the process in protecting patient autonomy in medical decision making (Jeong et al., 2011; Seymour et al., 2010; Stewart et al., 2011). In a study of advanced practice clinical oncology nurses in the eastern United States study participants favoured the use of ACP, seeing benefits such as the interventions' capacity to "improve patients' and families' satisfaction about end-of-life care" (Zhou et al., 2010, p. 408), a valuable attribute when providing care for individuals dealing with a life-limiting cancer. Although not typically elaborated on, positive attitudes towards ACP are seen in numerous studies on nursing and ACP (Baughman et al., 2012; Silvester et al., 2013; Stewart et al., 2011; Yee et al., 2011; Zhou et al., 2010).

Nurses feel ACP contributes to patient autonomy in the health care arena in a variety of ways. Nurses view ACP as providing a platform for patients to direct the course of their clinical care by explicitly providing them the opportunity for their clinical condition to be discussed and treatment options explored (Yee et al., 2011). This sentiment is echoed by Seymour et al. (2010), whose community nursing research subjects ascribed ACP and its related documentation

as contributing to patients' requests for future clinical care being adhered to by health care professionals. In a qualitative study in London, England utilizing semi-structured interviews, residential care home facility managers, nurses, and health care aids were found to believe the process of ACP to be beneficial in assisting patients to make informed decisions for clinical care (Stewart et al., 2011) and felt it supported patients' ability to self-govern the medical care and treatments they received. This is a valuable characteristic of the ACP process, recognized by nurses in a variety of clinical settings (Seymour et al., 2010; Stewart et al., 2011; Yee et al., 2011; Zhou et al., 2010).

Also supportive of ACP as an intervention that fosters patient autonomy were primary care nurses in a qualitative study conducted in New Zealand. Nurses in this study (N = 13) believed patients' wishes for clinical care should be paramount, always adhered to and respected (Davidson et al., 2013). Further to this point, nursing (n = 25) and social work (n = 37) care managers working in the community setting in the United States expressed that despite conflict with the care perspectives of others involved in anticipatory care planning (e.g., family members, care managers), patients have the right to decide for themselves what their wishes for care will be and that right needs to be respected (Baughman et al., 2014).

Experiences. The literature related to nurses' experiences with ACP focuses on three aspects of the process: impact of families on the process; nurse engagement in ACP; and the influence of experiences on nurses' engagement in ACP. Each of these areas will be discussed.

Impact of family. A patient's loved ones can have a profound impact on the ACP process (Baughman et al., 2012; Jeong et al., 2011; Minto & Strickland, 2011; Seymour et al., 2010; Stewart et al., 2011). Nurses find patients do not make clinical care decisions in isolation and will often look to a loved one for assistance when involved in ACP discussions and

decisions. Jeong et al. (2011) noted reports from study participants that the perspective of patients' loved ones and their related wishes for the direction of future care are reflected upon and taken into consideration by the patient. Decisions were ultimately made by the patient but done so only after consultation with loved ones (Jeong et al., 2011). Seymour et al. (2010) noted that patients do not make decisions for clinical care in isolation but rather take into account the circumstances they are in with loved ones, such as housing, which weigh into decisions made regarding the setting for clinical care.

Nurses have reported both positive and negative effects of family members on ACP. A recent qualitative study conducted in England assessed the ACP experiences of patients and their family members. For nurses, family members could impact ACP negatively when their influences dictated the direction of care as opposed to the patient directing the care for himself/herself. Family was also noted to have a more positive impact when they were involved in the process of ACP in a manner of consultation, helping to outline what their loved ones' wishes for clinical care might be (Stewart et al., 2011).

Boot and Wilson in their 2014 study of clinical nurse specialists (N = 8) working in palliative care made note that difficulties can arise with family members when their wishes for care do not align with the patients' wishes or what is in "the patients' best interests" (p. 13) and described family dynamics in ACP to be, at times, difficult. Furthermore, a study conducted in southeast England also identified that apprehensions towards a family member of a patient can impact how or if the provider engages in ACP with a patient (Stone et al., 2013).

Zhou et al. (2010) commented on the potential for family members to act as a barrier to the ACP process by being unwilling to discuss ACP considerations due to personal denial or fears about their loved one's clinical condition. ACP encompasses discussions about end of life

and nurses found family members of patients were often quite reluctant to discuss such matters openly; nurses in this study named family members as the leading barrier to initiating ACP discussions with patients (Zhou et al., 2010). Family members' resistance to such discussions is a finding affirmed by other authors (Baughman et al., 2012; Jeong et al., 2011; Stewart et al., 2009).

A study carried out by Baughman et al. (2012) with both nursing and social work clinical care managers in the community setting reported findings on how family members and patients can influence the success of ACP. Participants in this study felt strongly about the ability of patients and family members to impede the ACP process by their lack of baseline knowledge about important ACP terms and the implications of those terms. This knowledge deficit delayed care planning outcomes because participants needed to first work on addressing knowledge gaps before ACP interventions could be conducted.

Engagement in ACP. Zhou et al. (2010) and Baughman et al. (2012) noted nursing to have inconsistent ACP practices with patients. Zhou et al. (2010) found advanced practice oncology nurses were comfortable to discuss plans for future clinical care with patients but reported their ACP practices as only "somewhat routine" (p. 407). Baughman et al. (2012) found that despite being clear supporters of ACP, study participants did not like engaging in these discussions, preferring instead to encourage that ACP discussions be conducted with patients' respective physicians (Baughman et al., 2012). This qualitative study also found participants did not perceive formal ACP documentation to be within their scope of clinical practice, again deferring this responsibility to physicians (Baughman et al., 2012). This is a sentiment echoed by Yee et al. (2011), who in their study of nephrology clinical team members reported nurses engaged with patients in ACP discussions much less than other health care providers surveyed,

with 66.2% of nurse respondents stating they “never” had discussions of anticipatory clinical care planning with their patients (p. 235). Nurses in this study also did not consider ACP to be within their scope of clinical practice and, as noted by Baughman et al. (2012), preferred instead to refer such discussions to other health care team members (e.g., physicians or medical social workers). And oncology nurses (n = 25) surveyed in a recent study on nurses and ACP reported that they categorized the work of ACP as best suited for other members of the health care team such as physicians, social workers, and case coordinators (Samara et al., 2013).

In contrast to these findings, Davidson et al. (2013) identified New Zealand nurses (N = 13) in the primary healthcare setting felt they were well positioned to successfully engage in ACP with their patients. They believed that the therapeutic relationships that developed over time in the community setting provided an effective foundation for “such sensitive discussions” (p. 30). These nurses also believed “involvement in advance care planning was part of their professional obligation” (p. 30) and valued teamwork in ACP, seeking physician involvement and collaboration in ACP.

Researchers from a 2007 study of health care professionals working with the older adult population found nurses (n = 74) to be less involved in future care planning discussions than social workers (n = 29), but slightly more involved than physicians (n = 32) (Black, 2007). Low rates of nursing (n = 128) and social work (n = 299) engagement were found in a 2013 study investigating how health care providers determine a patient’s need for ACP (Baughman et al., 2013). Using a quasi-experimental research design, almost half of the study participants reported engaging in anticipatory clinical care discussions with less than one quarter of their patients, and only one fifth of the research subjects reported “discussing ACP with over 75% of the consumers in their caseload” (Baughman et al., 2013, p. 720).

Silvester et al. (2013) also reported minimal engagement in ACP in a study that involved a small-scale pre-intervention assessment of residential aged care facilities in Australia. The nursing (n = 17) and managerial staff (n = 28) study participants were asked to detail their level of engagement in ACP with care home residents over the previous six months. Study results noted 35.8% of all respondents (n = 16) reported they had not conducted an ACP discussion in the last six months and 40% (n = 18) stated they had had ACP discussions with “very few/no residents” in the last six months (p. 354). Further to this, study participants identified as having “little or no experience in holding such discussions” (Silvester et al., 2013, p. 353) and 53% of them stated ACP at their care facility was “poorly” or “very poorly” done (p. 354).

A research study conducted out of the United States asked local nursing (n = 125), social work (n = 286), and a group categorized as “other” (n = 12) community care managers about the frequency of ACP discussions with their patients (Baughman et al., 2015). Participants were from nine different medical agencies in one midwestern state in the United States. Scores were high for two of the nine agencies with 81.2% and 59.1% of care managers reporting engaging in ACP discussions with at least 50% of their patients; however, results for other agencies were as low as 8.8% (for engagement in ACP discussions with 50% of patients or more). In response to a question about having been part of an ACP discussion with a patient within the past month, the responses for sites ranged from a high of 83.6% at one site to a low of 20.5% at another. Care managers from agencies that reported the most frequent engagement in ACP (with 50% of their patients or more) were also reported to have “higher levels of overall self-efficacy and feeling comfortable discussing ACP with consumers” when compared to managers at other sites (Baughman et al., 2015, pp. 512-513).

Impact of personal experiences on engagement in ACP. Personal experiences related to death and dying influence how nurses engage in ACP (Black, 2007; Baughman et al., 2013; Minto & Strickland, 2011). Black (2007) conducted a quantitative research study specifically investigating the impact health care providers' past experiences and personal beliefs about death and dying had on how these clinicians engaged in discussions of planning for future clinical care with patients. This study utilized several questionnaire assessment tools and studied American nurses (n = 74), physicians (n = 32), and social workers (n = 29). Using the "Death Attitude Profile-Revised," the "Advance Directive Communication Practices", and yes/no questions formatted by the researchers the health care professionals' personal perceptions of death and dying, advance directive communications with patients and families, and personal exposures to death and dying were studied. By assessing for differences amongst study participants who had and had not dealt with certain elements of death and dying in their personal lives, such as the loss of a loved one, researchers noticed that health care providers who had "recent personal experiences with terminal illness" (Black, 2007, p. 569) had enhanced practices of communication when compared with participants who had not had this experience. This was specifically related to the frequency of informing or advising patients and families regarding their rights related to planning for future clinical care. It indicated to the researchers that health care providers who themselves had dealt with concerns of death and dying had a greater awareness of patients and families need to be fully informed.

Further to this, a descriptive exploratory research study was conducted amongst New Zealand nurses (N = 13) to investigate their knowledge, opinions, and experiences around advance directives, considered the same as an advance care plan in New Zealand. Researchers stated that for primary health care nurses "reflection on personal experience contributed to an

understanding of their potential role with advance directives in primary care” (Davidson et al., 2013, p. 28). Participation in the clinical care or course of treatment for a loved one that had passed away, as well as having an awareness of one’s own anticipatory clinical care wishes, provided the nurses with insights for how they might engage in ACP with their patients. Nurses in this study had very little professional experiences with ACP and thus they drew from their past experiences to inform their ACP roles with patients (Davidson et al., 2013). Similar findings regarding drawing from related past personal experiences to inform ACP practices with patients were noted in a study by Baughman et al. (2014) where the community care managers also considered their own personal experiences with ACP to inform current ACP situations with their patients.

A study conducted in England investigated the experiences of nurses and physicians when implementing ACP for patients diagnosed with terminal illness (Minto & Strickland, 2011). This study found that the participants’ past experiences with ACP had influence over how nurses (n = 3) experienced ACP with their patients. This study reported that observing other professionals engaged in ACP fostered professional growth for nurses, supporting and informing future ACP discussions with their patients, and reduced nurses’ anxieties about engaging in such discussions.

Utilizing the “Advance Directives Communication Practices Instrument”, a 39-item questionnaire tool, authors of an American study sought to investigate the communication practices of full-time nurses working in the acute care hospital setting (Black & Emmet, 2006). Authors of this study worked with a definition of ACP that encompassed advance directives and found an association existed between nurses who started advance directive discussions with patients and nurses who had personal experiences as a proxy at some point in their personal

lives. This indicated for the researchers that first-hand experiences with the process of ACP influence the ACP practices of nurses.

Summary

There is evidence in the literature that nurses support the intervention of ACP and there is an identified need for their involvement in the process. Limitations in nurses' ACP knowledge are evident in some studies and the emotional work involved in ACP has been identified as a barrier to potential progress with ACP discussions. A review of the literature found nurses have an awareness of the impact family can have on the ACP process and outlined the variable and restricted level of engagement nurses have demonstrated in ACP practices in studies to date. More research is needed on this topic to better understand the work of nurses in ACP.

Chapter 3: Research Design and Methods

In this chapter, the research design and methods used for this study will be explored. A survey design was utilized for this study. With a survey design there is no manipulation of variables, rather its purpose is to assemble information on the variables under study in the population of interest (Gillis & Jackson, 2002). This approach to research “provides a quantitative or numerical description of trends, attitudes or opinions of a population” (Creswell, 2014, p. 155) and is commonly used in nursing research (Gillis & Jackson, 2002). The specific survey design methodology used in this study was a cross-sectional descriptive design.

Cross-sectional survey designs have been noted as successful in the investigation of “knowledge, attitudes, and behaviors in a specific population” (Supino & Borer, 2012, p. 9). Descriptive survey designs are recognized as useful in uncovering seminal information about populations where limited research inquiry exists and allow for characteristics and properties of the variables under study to be described and explained (Supino & Borer, 2012; Wood & Ross-Kerr, 2011). Descriptive survey designs are also beneficial in the identification of relationships between study variables (Gillis & Jackson, 2002; Wood & Ross-Kerr, 2011) and allow for correlations between variables (e.g., age or years of experience and knowledge, attitudes, or experiences) to be examined.

Setting and Sample

A population is all the individuals fitting the criteria for investigation that the researcher seeks to study (Gillis & Jackson, 2002; Wood & Ross-Kerr, 2011). The study was carried out in one regional health authority in the province of Manitoba. This particular regional health authority, the Winnipeg Regional Health Authority, was selected because it has had a policy on ACP for a number of years (i.e., since 2003 and revised in 2011) which addresses the role of the

nurse, as a member of the health care team, in this process. The population of interest for this study was practicing registered nurses on the register of the College of Registered Nurses of Manitoba (CRNM) who self-identified as working on medical-surgical units in hospitals and living in Winnipeg, Manitoba. Based on documentation from the CRNM, at the time of recruitment there were 1,400 registered nurses who self-identified as working on medical-surgical units in hospitals in Winnipeg (K. Mitchell, personal communication, March 2015). These registered nurses could be employed on a full-time, part-time, or casual basis. Medical-surgical nurses were selected as appropriate subjects for this study because in this clinical care setting nurses encounter patients with diverse and complex medical care needs and provide care to individuals across a continuum of acute illness, chronic illness, and end of life (Lee & Hughes, 2009; Lees, Myers, Obiols Albinana, Oswald, & Percival, 2013). Medical-surgical settings present opportunities for nurses and other health care providers to engage in the ACP process.

Studies carried out by my supervisor using a similar approach to recruitment obtained response rates between 14 and 22% (see, for example, Edwards, Thronson, & Girardin, 2013). Other cross-sectional descriptive research studies utilizing nurse participants from a specific nursing organization or association and electronic questionnaire distribution have seen response rates of 19% (O'Mara, Bauer-Wu, Berry, & Lillington, 2007) and 27% (Chapman, Pincombe, Harris, & Fereday, 2012), which would reflect a potential response rate in this study of 266 and 378 participants respectively. As Sue and Ritter (2007) identify, margin of error and confidence levels provide a gauge for "how well a sample represents a population" (p. 9). Margin of error decreases as the sample size grows. Sue and Ritter (2007) provide a guideline for sample sizes: a minimum of 272 participants is required to meet a 90% confidence level with a 5% margin of error. This would provide sufficient data for extrapolation to the wider population under study.

Instrumentation

The questionnaire used in this study was modified from an original instrument created by Yee et al. (2011) titled “Questionnaire Survey on Renal Health Care Professionals of Advance Care Planning in End-Stage Renal Disease”. The original questionnaire was utilized in a national survey in Singapore seeking to capture the ACP-related knowledge, attitudes, and experiences of health care professionals (i.e., physicians, nurses, medical social workers, and allied health care professionals) working with the end-stage renal patient population. The survey was both adapted and used in this study with permission from the original authors.

When developing the questionnaire, Yee et al. (2011) adapted, with permission, questions from three existing questionnaires (Duke & Thompson, 2007; Lipson, Hausman, Higgins, & Burant, 2004; Perry, Swartz, Smith-Wheelock, Westbrook, & Buck, 1996). Parallel to the objective of this research study, these various studies sought to investigate the knowledge, attitudes, beliefs, practices, and experiences of health care professionals specific to planning for future clinical care or, more specifically, ADs. The Yee et al. (2011) survey tool consists of 2 questions taken from the Duke and Thompson (2007) questionnaire, 14 questions taken from the Lipson et al. (2004) questionnaire, and 12 taken from the Perry et al. (1996) questionnaire, with the remaining 13 questions developed by Yee et al., who are nephrology, palliative care, and medical health professionals.

Duke and Thompson’s (2007) 40-item survey, “The Update on Advance Directives Questionnaire”, has a Cronbach’s alpha of 0.55. An expert panel was employed to confirm content validity in the tool and literature appraisal, discussions with clinical nurses, and assessment of pertinent legislation were utilized to develop the survey questions. Similarly, content validity with the Lipson et al. (2004) questionnaire was established by an expert panel

consisting of nurses, lawyers, and unspecified “topic experts,” and it was pilot tested (p. 787) and has a Cronbach’s alpha score of .69. The 45-item questionnaire developed by Perry et al. (1996) was developed by use of an expert panel of nephrology experts from clinical care, research, and administration.

The questionnaire used in this study (Appendix A) is comprised of four sections and contains 51 items. The questionnaire begins with 10 demographic questions to allow for description of the sample. Knowledge of ACP is measured using 12 true/false format questions requiring participants to select the correct response. The knowledge items are about, for example, the relationship between ACP and completing an advance directive, the timing of ACP discussions, who can initiate ACP discussions, and the role of documentation and communication skills in ACP. Attitudes towards ACP are measured using 17 Likert-scale items (i.e., a five-point scale ranging from strongly agree to strongly disagree) assessing nurses’ perceptions and emotions about engaging in ACP discussions with patients and families and perceptions of patients’ and families’ feelings and reactions to such discussions. These items explore feelings of adequacy, skill, emotional strength, hope, competency, support, and efficacy of ACP as a clinical intervention. Items in this section of the questionnaire include the following: “I favor the use of ACP”, “I don’t have the skills to discuss ACP”, and “Discussing ACP will make patients lose hope”. To assess experiences with ACP, 12 questions were posed, including questions about completing a personal advance directive (i.e., yes/no), whether or not the nurse considers ACP discussions part of his/her role (i.e., definitely, no, undecided), how often the nurse discusses ACP with patients (i.e., very often, often, occasionally, never), and whether or not the nurse was exposed to ACP information or training in his/her nursing education program (i.e., yes/no). The questionnaire concludes with an open-ended question: “Is

there anything else you would like to say about ACP?” Language used in the questionnaire was modified to reflect legislation found in Manitoba and demographic questions were altered to be more reflective of a Canadian context. For example, the term “advance medical directive” was modified to read health care directive. Furthermore, questions inquiring as to a participants’ “country of practice” and “institution of practice” (e.g., private practice, Voluntary Welfare Organisation in the original questionnaire) were respectively changed to inquire as to participants’ type of practice facility (i.e., teaching hospital, community hospital) and type of unit currently employed on (i.e., medicine, surgery, medical/surgical).

The modified questionnaire was assessed for face validity by nine nursing, advanced practice nursing, and medical professionals each with extensive experience with, exposure to, or knowledge of the ACP process. These health care professionals were asked to: a) review the questionnaire for its clarity and ease of completion; and b) assess each question, evaluating whether it supports the detection/discovery of elements related to its respective variable (i.e., knowledge, attitudes, experiences). This approach is in accordance with direction from Gillis and Jackson (2002) on assessing and substantiating face validity in a questionnaire. The expert opinions and feedback received from these nine health care professionals were then used to make adjustments or improvements to the questionnaire. Revisions made encompassed three types of modifications. One type of modification was wording changes. For example, in the Attitudes section, the word *favor* was changed to *support* in the statement “I favor the use of ACP.” A second type of modification was relocating questions or items from one section of the questionnaire to a better-suited section. For example, the item “I don't really understand what ACP really is” was moved from the Attitudes section to the Knowledge section. The third type of modification was adding questions to the questionnaire, an example being “Do you have

resources in your practice setting to support ACP with patients and families?” As the questionnaire is not seeking to measure specific constructs or characteristics of the variables under study and instead seeks to express self-reported perceptions of the variables, no additional psychometric testing was deemed appropriate or necessary per discussions with a statistician (B. Default, personal communication, August 2014).

Data Collection

A Canadian online survey platform, FluidSurveys™, was used to administer the questionnaire to the sample. A web-based approach is known to have both advantages and disadvantages. The Internet became increasingly popular throughout the 1990s with more and more households gaining access to this resource (Balch, 2010). Since that time the use of the Internet has supported a new phase in clinical research, easing the process for both the researcher and research participants. The use of online surveys can prove to be more cost effective than paper-based approaches by removing costs such as printing and postage, streamlining the initial data collection process for researchers and offering a quick, easy, and accessible means for respondents to engage in survey completion (Rosenbaum & Lidz, 2007). Online surveys also remove the step of having participants return completed surveys through the postal system. Given the sophistication of survey platforms today, researchers have the ability to create visually appealing surveys and to download data directly into programs like Excel or the Statistical Package for the Social Sciences (SPSS).

Online surveys are not without limitations, with some described as incompatibility of software platforms between researcher and participant skewing visual representation of surveys, spam filters impeding participant access to surveys (Balch, 2010), and the requirement of access to a personal or public computer, which may be problematic for some populations (Rosenbaum

& Lidz, 2007). Potential participants may also have varying levels of computer skills, which may preclude some from participating.

Following approval by the Education/Nursing Research Ethics Board (Appendix B), permission was sought from the CRNM (Appendix C) to have them distribute an email on behalf of the researcher inviting all practicing RNs who self-identified as working on medical-surgical units in hospitals and living in Winnipeg to participate in the study. The link to the survey was contained within that email. The first email message outlined the purpose of the study, the types of questions participants would be asked, the time commitment required, and strategies for preserving confidentiality, and provided contact information for me and my advisor in case anyone had questions about the survey (Appendix D). This email message was followed by three reminder messages sent at the one week, two week, and three week mark by CRNM, each briefly outlining the purpose of the study and what was being asked of potential participants (Appendix E). All four messages contained a link to the survey. The survey remained active in terms of data collection for a period of 28 days. This time period was selected as it was felt to be a sufficient time frame to allow for both robust and expedient data collection.

Once potential participants clicked on the link within the email messages, they were taken to the first page of the survey. This was an information page detailing the particulars of the research study and the role of study participants. This page informed potential study participants that completion and submission of the questionnaire equates consent and that anonymity of all respondents will be maintained. A participation incentive, two \$50 gift cards for Unimor Healthwear and Homecare Products in Winnipeg Manitoba, was offered to participants. Participants had the option to input their email address at the end of the online questionnaire to enter into the draw. The draw was managed by a research coordinator with the

Manitoba Centre for Nursing and Health Research (MCNHR) at the University of Manitoba.

The list of individuals who opted to enter the draw was kept in a file entirely separate from all other data collected and operated solely by the MCNHR research coordinator assisting with the study. An email of notification was sent by the research coordinator to the two selected winners of the draw and these emails were subsequently deleted. Participation in the draw was voluntary and, aside from this process, no identifying information was requested or collected and email or Internet Protocol (IP) addresses were not saved.

Data Analysis

After a period of four weeks from the start of data collection, all data were removed from FluidSurveys and imported into the Statistical Package for the Social Sciences (SPSS) software. Data were organized and cleaned by the principal researcher under the guidance of an MCNHR research coordinator. Missing data were noted, largely participants that accessed the questionnaire but answered none or only a few demographic questions and omitted questions from all other sections of the questionnaire (i.e., knowledge, attitudes, experiences). For the demographic questions and in order to describe the sample, descriptive statistics were used, including means (e.g., age, years of experience), ranges (e.g., age), and percentages (e.g., community or teaching hospital). As per the Yee et al. (2011) study, responses to knowledge questions were analyzed to assess the number of correct responses (i.e., percentages correct) and average scores for the sample. The Likert-scale attitude items were scored at 5 for strongly agree down to 1 for strongly disagree. Mean scores were calculated and percentages used to report the number of respondents agreeing or disagreeing with statements or undecided about the statements. In addition, correlations were examined between attitude questions using the Pearson correlation coefficient (r). Correlational testing is valuable because it identifies if two

variables are associated with one another, and can identify a positive or negative relationship between them (Wood & Ross-Kerr, 2011). Percentages were calculated for the yes/no and frequency questions in the experience section of the questionnaire. Relationships between demographic variables (e.g., age, years of experience) and frequency of engaging in ACP discussions were assessed using Pearson correlation coefficient (r). The open-ended question was analyzed using content analysis, with responses coded by me and my thesis supervisor, followed by identification of categories, and then the collapsing of categories through a process of discussion and consensus (Elo & Kyngas, 2008).

Ethical Considerations

This research study was guided by the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010). This document is based on three core principles: respect for persons; concern for welfare; and justice. To ensure respect for persons and promote informed choice to participate in the study, information was provided in recruitment email messages and on the first page of the electronic questionnaire about the particulars of the research study and role of study participants, including the time commitment, the nature of the questions, how anonymity is preserved, and how data are protected (e.g., in password-protected computers) and will be confidentially destroyed five years after the completion of the study. Potential study participants were informed that completion and submission of the questionnaire equated consent and that anonymity of all respondents will be maintained. Participants were informed that they could exit the survey at any time they wished to or omit any questions they did not wish to answer free of any consequences. The nature of the data collected was numerical representations of responses

to true/false, Likert-scale, yes/no type questions and demographic questions, therefore, not identifiable with study participants and maintaining anonymity of study participants. As the link to the questionnaire was distributed by the CRNM and no email addresses or IP addresses were saved by me, participants were anonymous. Only me, my advisor, my committee members, and statisticians or research coordinators employed by the College of Nursing, University of Manitoba had access to the anonymized data, and it was stored on each of our respective password-protected computers. A pledge of confidentiality was signed by the research coordinator (Appendix F). No deception was used in this study.

A participation incentive, two \$50 gift cards for Unimor Healthwear and Homecare Products in Winnipeg Manitoba, was offered to participants. Participants had the option to input their email address at the end of the online questionnaire to enter into the draw. From the list of email addresses generated by manual random selection one individual was chosen to receive the first \$50 gift card. That winner's email address was then removed from the list and a second winner was selected from the remaining individuals, and received the second \$50 gift card. The gift cards were labelled with the winners email addresses and left for pick up at the Manitoba Centre for Nursing and Health Research reception desk. An email of notification to the winners was sent March 2, 2015 and, as stated above, this process was carried out by a research coordinator at the Manitoba Centre for Nursing and Health Research. The list of individuals entered in the draw was kept in a separate file by the research coordinator and deleted after winners were selected and notified. Email communications sent to inform the selected two winners were also deleted after being sent.

In terms of concern for welfare, this study is viewed as minimal risk. Anticipated benefits to participation are contributing to the discovery of new knowledge regarding the

population under study, contributing to related literature on this subject, and contributing to the development of possible future guidelines, interventions, or policies in this area. It was deemed unlikely that any of the questions would cause stress for research participants, but as some level of risk is always present in any form of research, it may be speculated that if any past experiences with ACP have been negative for participants, then reflecting on those experiences may have brought up similar feelings for participants. It was not anticipated that any such feelings would prove harmful to participants or require any sort of intervention. However, participants were informed that should any distress result from participation in this study, the services of the Employee Assistance Program, which offers free of charge counseling services to all WRHA employees, was available to them. Contact information for the Employee Assistance Program was provided in the survey.

The third core principle, justice, has to do with fair and equitable treatment. The inclusion criteria for this study were designed to include all registered nurses who self-identify as working on medical-surgical units in the WRHA. There was no known imbalance of power present between the researcher, or her committee, and potential participants. Participants could choose whether or not they wished to volunteer for the study and all participants remained anonymous.

Summary

A survey design was used for this study, with the population of interest being registered nurses self-identifying as working on medical-surgical units in hospitals and living in Winnipeg, Manitoba. The questionnaire used in this study was modified from one created by Yee et al. (2011) for a study on health care providers in Singapore working with patients with end-stage renal disease. An on-line survey platform was used to collect data. Appropriate statistical

procedures were used to analyze the data, and content analysis was used with the responses to the open-ended question. The study was guided by the core principles of the *Tri-council Policy Statement: Ethical Conduct for Research Involving Humans* (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, & Social Sciences and Humanities Research Council of Canada, 2010).

Chapter 4: Results

In this chapter, the results of the survey will be presented. A total of 311 nurses accessed the questionnaire on FluidSurveys™ and/or responded to at least one of the questions outlined in the questionnaire. Ninety-three nurses failed to respond to enough of the questions to be included in data analysis (e.g., responded only to demographic questions), with 218 completing all of the survey or at least portions of the knowledge, attitudes, and experience questions. The recruitment emails were sent out to 1,400 registered nurses, so this sample size represents 16% of that number.

Demographics

Of those who responded, 90.8% were female (n = 198) and 9.2% (n = 20) were male. The mean age of the nurses (n = 210) was 38.19 years, with a range from 20 to 67 years. The breakdown for age groups is provided in Table 1, with the highest percentage of participants falling in the 20 to 29 years range (32.9%).

Table 1

Nurses' Age By Groups

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	20-29 years	69	31.7	32.9	32.9
	30-39 years	50	22.9	23.8	56.7
	40-49 years	41	18.8	19.5	76.2
	50-59 years	38	17.4	18.1	94.3
	60-69 years	12	5.5	5.7	100.0
	Total	210	96.3	100.0	
Missing	System	8	3.7		
Total		218	100.0		

With regards to nursing education, 32.6% (n = 71) of nurses were diploma prepared, and 67% (n = 146) held a bachelor's degree in nursing. Some indicated they had received education outside of nursing: 19.7% (n = 42) had completed a diploma program other than in nursing and 22.1% (n = 47) had

completed a bachelor's degree program other than in nursing. The majority of respondents (96.8%) did not hold Canadian Nurses Association (CNA) certification in any designation.

In terms of employment, just over half of the respondents (55%, n = 120) identified they worked in a tertiary hospital, with 43.6% (n = 95) working in a community hospital. Of the three respondents who selected 'other' for this question, one described the work facility as acute care, another as a clinic, and the third as both a community and a tertiary hospital. Approximately half of the nurses (51.8%, n = 113) reported working on medical units, 33% (n = 72) on surgical units, and 11% (n = 24) on mixed medical/surgical units. Eight respondents selected other for this question, indicating they worked in a specific type of unit (e.g., cardiac medicine) or in more than one unit (e.g., the float pool). More than half of respondents 53.2% (n = 116) indicated they were employed part-time. Full-time nurses made up 39% of respondents (n = 85) and 7.8% (n = 17) were employed casually. Years of experience as a nurse ranged from zero years, meaning less than one full year, to 44 years, with a mean of 11.78 years (n = 210) and a median of 6.0 years. The majority of nurses indicated they were staff nurses (93.2%, n = 204), with 5.5% of the nurses indicating they were clinical resource nurses (n = 12).

Knowledge of Advance Care Planning

The items in this section of the questionnaire required respondents to indicate whether statements were true or false and can be grouped into four areas of investigation related to knowledge of ACP: legislation, procedure, and policy; communication; forms and documentation; and nurses' perception of personal knowledge and abilities. Analysis of responses in this section illustrate the nurses have a sound understanding of several foundational knowledge concepts in ACP. Ten items specifically tested academic knowledge of ACP and two assessed nurses' perception of personal knowledge related to ACP. The scores on the 10 academic knowledge items ranged from 4 to 10 correct, with a mean score of 8.57 (N = 218).

For the true/false questions relating to ACP *legislation, procedure, and policy* (see Table 2), 94%, 92.6%, and 90.7% of nurses respectively responded correctly to the statements "ACP discussions can only be initiated by doctors" (i.e., the statement is false), "ACP discussions can be initiated by nurses"

(true), and “my place of work has a policy on ACP” (true). In stark contrast, the fourth statement in this category, “the agreed upon ACP status must be documented as a physician’s order,” had the lowest percentage of nurses responding correctly, with only 28% of respondents identifying that this statement is false. A gap in knowledge for nurses is evident here as 72% of study participants believed the agreed upon ACP status must be written in the chart as a physicians’ order when in fact the WRHA written policy on ACP does not state/stipulate this. For the final item in this category, “the WRHA ACP ‘Goals of Care’ form related to ACP decision making is always an equivalent document to a HCD,” 73.4% of respondents answered correctly that this statement is false.

Table 2

Knowledge Questions: Legislation, Procedure, and Policy

	True	False
ACP discussions can only be initiated by doctors	6% (n=13)	94% (n=204)
ACP discussions can be initiated by nurse	92.6% (n=201)	7.4% (n=16)
My place of work has a policy on ACP	90.7% (n=195)	9.3% (n=20)
The agreed upon ACP status must be documented as a physician’s order	72% (n=154)	28% (n=60)
The WRHA ACP “Goals of Care” form related to ACP decision making is always an equivalent document to a HCD	26.6% (n=57)	73.4% (n=157)

Three true/false questions are categorized as relating to *communication* (see Table 3): “ACP discussions do NOT take into account the patient’s life values and preferences” (false); “it’s important to hold ACP discussions early in the course of illness, especially for those with a life limiting disease” (true); and “communication skills are essential for ACP” (true). All three were answered correctly by the majority of participants (i.e., 92.6%, 98.2% and 97.7% respectively), identifying awareness amongst the nurses as to the importance of early and effective communication in ACP as well as incorporation of a patients’ personal belief system and principles in the process.

Table 3

Knowledge Questions: Communication

	<u>True</u>	<u>False</u>
ACP discussions do NOT take into account the patient's life values and preferences	7.4% (n=16)	92.6% (n=201)
It's important to hold ACP discussions early in the course of illness, especially for those with a life limiting disease	98.2% (n=213)	1.8% (n=4)
Communication skills are essential for ACP	97.7% (n=213)	2.3% (n=5)

Knowledge of *forms and documentation* in ACP (see Table 4) was assessed by the nurses' responses to the statements "Advance Care Planning (ACP) discussions can be done without the patient filling out a Health Care Directive (HCD)" (true) and "documenting ACP discussions is NOT important" (false). The vast majority of nurses understood ACP could occur without the existence of a HCD (95.3% answered correctly) and identified the importance of documentation in ACP (98.6% answered correctly).

Table 4

Knowledge Questions: Forms and Documentation

	<u>True</u>	<u>False</u>
Advance Care Planning (ACP) discussions can be done without the patient filling out a Health Care Directive (HCD)	95.3% (n=204)	4.7% (n=10)
Documenting ACP discussions is NOT important	1.4% (n=3)	98.6% (n=214)

The last category of items in the knowledge section of the questionnaire related to nurses' *perception of personal knowledge* (see Table 5). The two statements in this section were: "I am well equipped with the clinical knowledge I need to discuss ACP with patients;" and "I don't really understand what ACP is." The distribution of true and false responses from participants for the statement about possessing the knowledge necessary for ACP discussions was more closely related than for any other question in this section. Forty-two percent of respondents questioned their professional preparedness to

engage in ACP and did not believe they had the necessary clinical knowledge to engage in ACP with their patients. Conversely, 58.1% (n=126), notably lower than scores for other affirmatively/positively worded questions in this section, believed their clinical knowledge was sufficient to support them in ACP. Only 3.7% of respondents indicated they did not understand what ACP is.

Table 5

Knowledge Questions: Perception of personal knowledge and abilities

	<u>True</u>	<u>False</u>
I am well equipped with the clinical knowledge I need to discuss ACP with patients	58.1% (n=126)	41.9% (n=91)
I don't really understand what ACP is	3.7% (n=8)	96.3% (n=210)

Attitudes Towards Advance Care Planning

Seventeen statements were presented to respondents in this section and they were asked to indicate their level of agreement or disagreement with the statements. This section of the questionnaire provided insights and appraisal to the general feelings and opinions held by the nurses on five basic categories of questions: potential barriers to ACP; personal outlook in ACP; concern with or for the patient and family; benefits to ACP; and autonomy and patients’ right to choice. Responses were scored using a 5-point Likert-scale with *strongly agree* (SA) representing a score of five sequentially to *strongly disagree* representing a score of one. The responses to the Likert-scale are represented using the following abbreviations: strongly agree (SA), agree (A), undecided (U), disagree (D) and strongly disagree (SD). Mean scores for all statements are found in Table 11 below.

Potential barriers to ACP. Four possible barriers to ACP discussions were examined in this section of the survey: patient readiness, communication skills of the nurse, emotional strength of the nurse, and time (see Table 6). Generally, nurses did not view patient readiness as a barrier to ACP, with 77% of nurses disagreeing with the statement “our patients are not ready for ACP discussions”. Communication skills also were not widely seen as a barrier to ACP for nurses, with 75.2% disagreeing

with the statement “I don't have the communication skills to discuss ACP.” In addition, almost 75% of the nurses disagreed with the statement “I don't have the emotional strength to support the patient through ACP discussions,” with a small percentage of nurses undecided (18.5%), and less than seven percent of respondents in agreement with the statement (SA = 6.2%, A = 0.5%). In comparison with the other potential barriers, time was identified as the most influential barrier based on responses of the sample. Almost 31% of nurses agreed with the statement “I don't have the time to discuss ACP” (SA = 4.3% A = 26.2%). More than half of respondents, however, did not see the constraint of time as a factor that limited their ability to carry out ACP (SD = 8.6%, D = 47.1%), and 13.8% were undecided as to how they felt time impacted their ability to engage in ACP.

Table 6

Attitude Questions: Potential Barriers to ACP

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
Our patients are not ready for ACP discussions	0.9% n=2	10.3% n=22	11.7% n=25	54% n=115	23% n=49
I don't have the communication skills to discuss ACP	0.9% n=2	8.0% n=17	16% n=34	54.5% n=116	20.7% n=44
I don't have the emotional strength to support the patient through ACP discussions	0.5% n=1	6.2% n=13	18.5% n=39	52.6% n=111	22.3% n=47
I don't have the time to discuss ACP	4.3% n=9	26.2% n=55	13.8% n=29	47.1% n=99	8.6% n=18

Personal outlook in ACP. All of the nurses supported ACP as a necessary intervention, with 86.4% strongly agreeing and 13.6% agreeing with the statement “I support the use of ACP.” Despite clear support for ACP, 25.5% of nurses indicated that they were undecided when considering the statement “I consider ACP discussions as part of my nursing role.” This was the highest percentage of undecided responses found in the data. Close to 65% of respondents agreed with this statement (SA = 16.5% and A = 48.1%), viewing ACP as part of their clinical scope of practice. Only 9.8% of nurses (SD = 1.9%, D = 8%) indicated that ACP was not part of their clinical nursing roles.

The statement “I feel confident in ACP discussions with patients and families” showed a range of participants’ responses (see Table 7). While close to 57% agreed with this statement, strongly disagree was selected by 1.9% of nurses, disagree by 18.5%, and 22.7% were undecided, the second highest scoring for undecided in the Attitudes section.

Table 7

Attitude Questions: Personal Outlook in ACP

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
I support the use of ACP	86.4% n=184	13.6% n=29	0% n=0	0% n=0	0% n=0
I consider ACP discussions as part of my nursing role	16.5% n=35	48.1% n=103	25.5% n=54	8% n=17	1.9% n=4
I feel confident in ACP discussions with patients and families	13.7% n=29	43.1% n=91	22.7% n=48	18.5% n=39	1.9% n=4

Concern with or for the patient and family. Various statements that explore nurses’ perceptions of how ACP can affect patients and their families in negative and positive ways were presented to study participants. Nurses had divided responses as to the potential for emotional distress to be experienced by patients as a result of ACP discussions, and the emotional well-being of patients in ACP discussions was a point of concern for nurses. Over 25% (SA = 0.5%, A = 24.6%) of nurses agreed with the statement “I worry I will upset the patient if I try to discuss ACP,” over 25% (SA = 0.5%, A = 24.6%), and another 16.1% were undecided about how they felt on this subject. The remaining 58.7% of nurses did not share this concern, selecting strongly disagree (10.4%) or disagree (48.3%) as their response.

Close to 62% of respondents disagreed (SD = 10%, D = 51.7%) with the statement “If I discuss ACP with the patient, the family may blame me for the patient’s choice.” However, the third highest percentage of undecided scores was noted with this statement at 21.3%, with 17% of nurses agreeing with the statement (SA = 15.6% and A = 1.4%). The majority of nurses did not believe that discussions of

death related to ACP would trigger or perhaps prompt patients to wish for death themselves. Close to 80% of nurses did not accept the statement “If I talk about death the patient may choose it” (SD = 20%, A = 59.7%). Only 7.1% of nurses (SA = 0.5%, A = 6.6%) agreed with this statement and another 14.2% identified as undecided. Furthermore, the majority of participants did not agree with the statements “Discussing ACP will make patients lose hope” (D = 67.8%, SD = 14.7%) and “Discussing ACP or HCD is advocating euthanasia” (D = 35.7%, SD = 61%). Only one individual agreed that ACP is advocating euthanasia, accounting for 0.5% of responses, with the remaining 2.9% of nurses identifying as undecided (see Table 8).

Table 8

Attitude Questions: Concerns for or with the Patient and Family

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
If I discuss ACP with the patient, the family may blame me for the patient’s choice	1.4% n=3	15.6% n=33	21.3% n=35	51.7% n=109	10% n=21
I worry I will upset the patient if I try to discuss ACP	0.5% n=1	24.6% n=52	16.1% n=34	48.3% n=102	10.4% n=22
If I talk about death the patient may choose it	0.5% n=1	6.6% n=14	14.2% n=30	59.7% n=126	19% n=40
Discussing ACP will make patients lose hope	0.5% n=1	5.7% n=12	11.4% n=24	67.8% n=143	14.7% n=31
Discussing ACP or HCD is advocating euthanasia	0.5% n=1	0% n=0	2.9% n=6	35.7% n=75	61% n=128

Perceived benefits of ACP. Two statements examined nurses’ attitudes regarding the benefits of ACP (see Table 9). The majority of nurses agreed with the statements “ACP helps in the medical care of the patient when he/she is seriously ill” (A = 36.7%, SA = 60.5%) and “ACP can decrease the burden of decision-making on family members” (A = 40.8%, SA = 48.8%).

Table 9

Attitude Questions: Perceived Benefits of ACP

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
ACP can decrease the burden of decision-making on family members	48.8% n=103	40.8% n=86	7.6% n=16	2.4% n=5	0.5% n=1
ACP helps in the medical care of the patient when he/she is seriously ill	60.5% n=127	36.7% n=77	1.0% n=2	1.4% n=3	0.5% n=1

Autonomy and patients’ right to choice. In this category, assessments are made as to nurses’ attitudes towards assertions that examine feelings and opinions related to patients’ right to choice and self-governance in medical decision-making. The second highest level of agreement amongst nurses (98.6%) was noted for the statement “ACP allows patients to have a sense of control over their lives.” This high percentage of agreement provides an indication that nurses are cognizant of the positive impact open discussions and communications with patients can have on patients’ sense of autonomy. The dynamic of patients’ right to choice bumping up against the idea of conserving life was presented to participants in the statement “prolonging life is more important than honoring a patient’s request to refuse life-sustaining treatment.” The vast majority of nurses disagreed with this statement, putting more value on an individuals’ right to choice than conserving life at all cost. Strongly disagree was selected by 63.2% and 30.7% disagreed (see Table 10).

Encompassed in ACP is the notion that it is patients’ values and beliefs that drive the course of treatment. Almost 98% of the nurses agreed with the statement “it is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions.”

Table 10

Attitude Questions: Autonomy and Patients' Right to Choice

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
ACP allows patients to have a sense of control over their lives	61.9% n=130	36.7% n=77	1% n=2	0.5% n=1	0% n=0
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	0.5% n=1	0.9% n=2	4.7% n=10	30.7% n=65	63.2% n=134
It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	78.2% n=165	19.4% n=41	0.5% n=1	0% n=0	1.9% n=4

Summary. Responses to statements in this section provide an array of opinions and perceptions related to five dynamics of the ACP process: potential barriers to ACP; personal outlook in ACP; concern with or for the patient and family; benefits to ACP and autonomy; and patients' right to choice. Attitudes varied for the sixteen statements presented to participants; only one statement, "I support the use of ACP," achieved 100% agreement amongst nurses. A diverse range of viewpoints is represented amongst the data. Some misgivings and objections are present for nurses' related to ACP and the nurses' role in this intervention with patients and families. When comparing the potential barriers of patient readiness, communication skills, and time, almost 30% of nurses viewed lack of time as a barrier to ACP discussions, while only 11% agreed that patients are not ready for these discussions and 9% agreed that they did not have the skills to engage in these discussions. All of the nurses supported the use of ACP, and close to 65% viewed ACP discussions as part of their nursing role. Interestingly, over 40% of nurses did not feel confident in ACP discussions. One quarter of the sample worried that they will upset patients when discussing ACP, but the vast majority agreed that ACP provides patients with a sense of control of their lives (98.6%), can decrease the burden of decision making for family members (89.6%), and help in the care of patients (97.2%).

Attitude Questions: Mean Scores Interpretation. Mean scores are “the average score of the sample” (Wood & Ross-Kerr, 2011, p. 254). For each statement in the Attitudes section of the questionnaire the mean score was computed and is reported below in Table 11. In congruence with the Likert scale (SA = 5, SD = 1) used to gauge participants’ level of agreement or disagreement to each statement, mean scores will fall between a score of 5 to 1. As discussed above, responses to most statements were varied, however, the mean score allows reflection on the average position of the sample on each statement when considered as a whole. From the table below, generally nurses were not concerned with patient readiness, communication skills, emotional strength, and time being impeding factors to ACP. Nurses showed strong support for ACP but displayed only modest levels of confidence related to engagement in this intervention and had limited levels of acceptance for ACP as part of the nursing role. Overall, the sample was not concerned with the potential for negative outcomes or consequences to patients and families related to ACP, saw significant benefits to ACP in terms of assisting patients and families with clinical care planning and substitute decision-making, and strongly supported the notion of autonomous decision making for patients and honoring patients’ clinical wishes.

Correlations

Assessment for correlations between questions is necessary to determine if a relationship exists between them and if that relationship is a positive or negative association. Pearson coefficient, represented by r , was used for this purpose. The intensity of the association is demonstrated by the coefficient score reported, which will be a value between negative one and positive one (Wood & Ross-Kerr, 2011). For this study the Pearson Coefficient (r) scores were categorized as very weak (0-0.19), weak (0.2-0.39), moderate (0.4-0.59), strong (0.6-0.79), and very strong (0.8-1.0) (British Medical Journal, n.d.). A statistical analysis was carried out of all attitude questions against one another, and this revealed numerous statistically significant relationships (see Appendix G).

Table 11

<i>Attitudes Towards Advance Care Planning</i>	Mean	n
<i>Potential Barrier to ACP</i>		
Our patients are not ready for ACP discussions	2.12	213
I don't have the communication skills to discuss ACP	2.14	213
I don't have the emotional strength to support the patient through ACP discussions	2.10	211
I don't have the time to discuss ACP	2.70	210
<i>Personal Outlook in ACP</i>		
I support the use of ACP	4.86	213
I consider ACP discussions as part of my nursing role	3.69	212
I feel confident in ACP discussions with patients and families	3.48	211
<i>Concerns for or with the patient and family</i>		
If I discuss ACP with the patient, the family may blame me for the patient's choice	2.47	211
I worry I will upset the patient if I try to discuss ACP	2.56	211
If I talk about death the patient may choose it	2.10	211
Discussing ACP will make patients lose hope	2.09	211
Discussing ACP or HCD is advocating euthanasia	1.43	210
<i>Perceived Benefits of ACP</i>		
ACP can decrease the burden of decision-making on family members	4.35	211
ACP helps in the medical care of the patient when he/she is seriously ill	4.55	210
<i>Autonomy and Patients' Right to Choice</i>		
ACP allows patients to have a sense of control over their lives	4.60	210
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	1.45	212
It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	4.72	211

The most significant correlation was identified between the statements “I don't have the communication skills to discuss ACP” and “I don't have the emotional strength to support the patient through ACP discussions.” Pearson coefficient (r) for this relationship is 0.641, n = 211, p < 0.001, identifying a strong positive relationship. In this case for ACP discussions, the more a nurse doubts her/his skills of communication in ACP, the more she/he is likely to also doubt her/his emotional strength to act as a support for patients in ACP discussions and vice versa.

The second strongest correlation, with a Pearson coefficient (r) score of 0.559, n = 210, p < 0.001, was noted between the statements “ACP allows patients to have a sense of control over their lives” and

“ACP can decrease the burden of decision making on family members.” This relationship is moderate in strength and demonstrates that as a nurses’ level of agreement with the statement “ACP allows patients to have a sense of control over their lives” strengthened across the Likert scale, that nurses level of agreement with the statement “ACP can decrease the burden of decision making on family members” was also noted to strengthen across the Likert scale.

The third and fourth strongest correlations identified in the data had to do with confidence. Nurses who responded that they were confident regarding engaging in ACP discussions with patients and families were less likely to report that they did not have the communication skills needed to discuss ACP ($r = -0.551$, $n = 211$, $p < 0.001$) or that they did not have “the emotional strength to support the patient through ACP discussions” ($r = -0.519$, $n = 211$, $p < 0.001$). So, as nurses’ level of confidence related to participating in ACP discussions increases, they/nurses are also more likely to hold higher personal opinions of their communication skills and emotional strength. Inversely, as a nurses’ level of confidence decreases, they are more likely to be uncertain or doubt the sufficiency of their communication skills and question if their emotional strength is adequate to support patients in ACP. These relationships were moderate in strength.

Two other statements that were positively associated were “I feel confident discussing ACP with patients and families” and “I consider ACP as part of my nursing role” ($r = 0.487$, $n = 211$, $p < 0.001$). The statement “I worry I will upset the patient if I try to discuss ACP” was moderately associated with “discussing ACP will make patients lose hope” ($r = 0.417$, $n = 211$, $p < 0.001$) as well as “I don't have the communication skills to discuss ACP” ($r = 0.407$, $n = 211$, $p < 0.001$). Nurses who indicated that “discussing ACP will make patients lose hope” were more likely to report that they did not have “the emotional strength to support the patient through ACP discussions” ($r = 0.407$, $n = 211$, $p < 0.001$). A moderate association was identified between the statements “prolonging life is more important than honoring a patient’s request to refuse life sustaining treatment” and “discussing ACP or a HCD is advocating euthanasia” ($r = 0.412$, $n = 210$, $p < .001$). A variety of other associations between statements were established with SPSS, with correlational significance at a level of 0.05 and 0.01 or higher, however,

these additional correlations had moderate to very weak linear associations with a Pearson's coefficient of 0.4 or less (see Appendix G).

Experiences with Advance Care Planning

Nurse respondents were asked to provide answers to questions regarding both their professional and personal practices and experiences related to HCDs and ACP discussions, and their education and training related to ACP.

Completion of a health care directive. The vast majority of nurse respondents identified as having provided care for a patient that had a HCD, however, the number of respondents who had completed a HCD varied by age group. Less than 30% (n = 57) of nurses had completed a HCD for themselves, and 37.7% (n = 79) identified having a family member with a completed HCD. Only 11 of the nurses (5.2%) had not cared for a patient with a HCD. Comparing age groups with completion rates of personal HCD, the oldest age group of nurses, 60-69 years of age, had the highest rates of completing a HCD (45.5%). The lowest rate was the youngest age demographic, 20-29 years old, with 24.2% having completed a HCD (Table 12).

Advance care planning. Nurses were asked to respond yes or no to questions that examined past life experiences and past professional experiences related to death and dying and their influence on ACP discussions. Slightly over half (52.2%, n = 109) of nurses surveyed reported that past personal experiences with death and dying influenced how they engaged in ACP with their patients. The remaining 47.8% (n = 100) did not believe the situations they had experienced in their personal lives related to death and dying had a bearing on how they handled ACP. The question related to nurses' past professional experiences yielded different results, with 80.7% (n = 171) of nurses responding *yes* to the question "my past professional experiences with death and dying influence how I engage in ACP with patients." The remaining 19.3% (n = 41) of respondents answered *no*.

Table 12

Completion of HCD by Nurses

			1. Have you completed a Health Care Directive (HCD) for yourself?		Total
			Yes	No	
Age Groups	20-29 years	Count	16	50	66
		% within Age Groups	24.2%	75.8%	100.0%
	30-39 years	Count	13	36	49
		% within Age Groups	26.5%	73.5%	100.0%
	40-49 years	Count	10	30	40
	% within Age Groups	25.0%	75.0%	100.0%	
	50-59 years	Count	13	25	38
		% within Age Groups	34.2%	65.8%	100.0%
	60-69 years	Count	5	6	11
		% within Age Groups	45.5%	54.5%	100.0%
Total		Count	57	147	204
		% within Age Groups	27.9%	72.1%	100.0%

Nurses were asked how frequently they discuss ACP with their patients. Of the 212 nurses who responded to this question, 3.3% (n = 7) selected very often, 17.5% (n = 37) often, 62.3% occasionally (n = 132), and 17% (n = 36) never. For those that identified being involved in ACP discussions with their patients (n = 175), 50.3% (n = 88) responded that they initiated the discussion, 19.4% (n = 34) indicated that patients initiated the discussion, and 17.7% (n = 31) stated the discussion was initiated by the family. Over 20 nurses identified that “others” initiated the ACP discussion, including physicians, the health care team, allied health professionals, or a combination of the categories above. Ten nurses indicated that physicians started the discussion. Two nurses further qualified that doctors were doing so only after prompting from nursing staff: “Doctors after being urged by the nurses” and “myself or residents given suggestion to by nurses.” Two others identified that the clinical resource nurse, in combination with

physicians, was responsible for ACP. The health care team was identified in two responses, with one nurse writing: “discussed first among HCP then will discuss to pt. and family.” Interestingly, only 56% (n = 116) of nurses answered *yes* to the question “Are nurses in your practice setting expected to be involved in ACP discussions?”

Nurses were also asked to agree or disagree (i.e., using a scale of strongly agree to strongly disagree) with the statement “family members have a positive effect on ACP.” A total of 120 nurses (56.6%) agreed (SA = 13.2%, A = 43.4%) with the statement, one third (n = 72) were undecided, and only 20 individuals (9.4%) disagreed.

Education, training, and resources. Exposure to ACP in practice was more common amongst the sample than training and education in basic foundational nursing curricula. However, half of nurses surveyed (50.5%, n = 105) reported not having access to ACP resources or print material in their respective work places.

The nurses were asked: “Did you have any exposure to ACP information or training in your basic/foundational nursing education?” Close to 55% of nurses (n = 114) responded that they had received some level of formalized ACP education during their undergraduate nursing education. Just over 65% of nurses (n = 137) indicated that they had been exposed to ACP information or training in their professional nursing practice. Over a third of nurses (34.4%, n = 72) denied experiencing any professional direction or instruction with ACP during their years of practice.

Access to assistive materials and resources for ACP in the clinical setting was a split experience for the sample (n = 208). When asked if they had access to “resources in your practice setting to support ACP with patients and families,” 49.9% (n = 103) said *no* and 50.5% (n = 105) responded *yes*.

Summary. Nurse respondents were asked a variety of questions regarding their experiences with ACP. Having the experience of providing care for a patient that had a HCD was common amongst nurse respondents (95%). Much less common, however, was having their own completed HCD (26.9%) or having a family member with a completed HCD (37.3%). Just over half of the nurses indicated they are expected to participate in ACP with their patients, and only 20% identified that they engage in ACP

discussions with patients often or very often. Of those who are discussing ACP with patients (176), approximately 50% indicated that it is the nurse who usually initiates the discussion with their patients. Approximately 56% of respondents identified family members as having a positive effect on ACP. It was identified that past experiences with death and dying, both personal and professional, have an influence on how they conduct ACP, with more nurses indicating that professional experiences influenced the discussions (80.7%) when compared to personal experiences (52.2%). In regards to nurses and their education and training with ACP, just over 50% of nurses reported receiving ACP training or information in their basic nursing education, and 65.6% reported receiving information or training in their practice. Approximately 50% of nurses reported having access to ACP resources in their practice setting.

Relationships Between Variables

Several relationships of interest were analyzed using Pearson Chi-square calculations in SPSS. Relationships between variables marked with an asterisk (*) had two cells of categorical data (25%) with an expected count less than five when Pearson Chi-Square analysis was computed. However, the strong evidence (p value $\leq .001$) to the relationships negated this finding and all associations were accepted (the null hypothesis was rejected).

Specifically, the frequency of reported ACP discussions with patients was analyzed and assessed against other variables. When assessed against demographic variables, no evidence of a relationship was found between frequency of reported ACP discussions and nursing position, type of practice facility, type of nursing unit, employment status, education, or gender. However, evidence of a relationship was discovered between reported frequency of ACP discussions and the variables age and years of nursing experience. The mean age of the sample was 38.19 years, thus the variable age was categorized into two groups, 38 years of age and younger and older than 38 years of age. Strong evidence of a relationship between age group and frequency of ACP discussions (Pearson Chi-square = 19.032, $n = 204$ degrees of freedom ($df = 3$, $p < 0.001$)* was identified. Nurses 38 years of age and older reported having ACP discussions with patients more frequently than nurses younger than 38 years of age. Similarly, 11.28 was the mean for years of experience for the sample, thus this variable was categorized into two groups,

nurses with up to and including 11 years of experience and nurses with more than 11 years of experience. A Chi-square test for independence revealed a significant relationship between increased years of nursing experience and rates of ACP discussions with patients (Pearson Chi-square = 17.224, $n = 211$, $df = 3$, $p = 0.001$)*.

When frequency of reported ACP discussions with patients was compared against knowledge variables, only one relationship could be established with strong evidence. Nurses who felt well equipped with the clinical knowledge needed to engage in ACP discussions also reported higher frequency of ACP discussions (Pearson Chi-square = 36.146^a, $n = 212$, $df = 3$, $p < 0.001$)*. Lastly, comparing frequency of ACP discussions against experience variables, three relationships were established. Nurses who reported receiving ACP education and training in their careers also reported engaging in ACP discussions with their respective patients more frequently than those who reported they had not received any education (Pearson Chi-square = 29.005^a, $n = 209$, $df = 3$, $p < 0.001$)*. A statistically strong association was evident between nurses reporting that past professional experiences with death and dying impacted how they engaged in ACP and higher frequency of ACP discussions with patients (Pearson Chi-square = 42.903, $n = 212$, $df = 3$, $p < 0.001$). The last relationship identified was an increased degree of reported ACP discussions amongst nurses who also reported working in a clinical environment where the expectation existed that nurses are to engage in ACP discussions with patients and families (Pearson Chi-square = 39.029, $n = 207$, $df = 3$, $p < 0.001$)*. Comparing reported frequency of ACP discussions to attitudes yielded no identified relationships between variables.

Content Analysis of Open-Ended Question

Inductive content analysis methodology (Elo & Kyngas, 2008) was used to analyze the participant responses to the open-ended question “Is there anything else you would like to say about ACP?” Sixty-five nurses answered the question. Fourteen responses were excluded because they contained only one word (e.g., yes, no, none), and one because it was an expression of frustration at receiving the reminder messages regarding the survey. A total of 50 responses were included in the inductive content analysis. All responses were copied verbatim and reviewed several times; each time in

the margin, notes that summarized or described each participant response, known as headings, were made. The headings were then compared and grouped for like characteristics and similarities and higher order categories were then identified from them. These categories were then inserted into the original document of participant responses, and category names were revamped and revised for the final time. My supervisor reviewed the comments independently, and with minor modifications (i.e., adding a comment to a second category, minor changes to wording of the categories), agreed with the categories and comments placed in those categories. A total of seven categories were identified, and one category had two sub-categories. More than one category could be represented in an individual participant’s response. Sentence segments were considered independently of an entire comment when appropriate.

Importance and Value of ACP. Nine nurses commented on the importance or value assigned to the ACP process; this value could be assigned either by them or by others (see Table 13). Comments that affirmed the importance of this intervention were noted as well as specific points made to the widespread application of ACP and the potential of this intervention to improve clinical care.

Table 13

Content Analysis Category: Importance and Value of ACP

“It is essential to have an ACP discussion with the patient and family especially if a patient has a debilitating condition”	
“I think it is an important topic to be discussed”	
“is important”	segment
“ongoing discussion with treatments regardless of what ACP level a patient is at”	
“I believe this is an important aspect of healthcare”	segment
“everyone above sixteen or older should have an ACP and HCD”	
“It is a great idea for everyone to fill one out”	
“Helps impact and reduce patient flow reduces admissions from nursing homes if this is dealt with at their sites”	
“Very important for hcp, patients, and families - it helps direct care plans in the right direction in most cases”	

Lack of Clarity in the ACP Process. Some of the comments (see Table 14) illustrated a lack of clarity in the ACP process currently in use on the nurses’ units, and these comments were grouped into two sub-categories: *lack of clarity regarding the ACP form* (4 comments) and *responsibility in ACP*,

whose role is it? (7comments). Study participants felt ambiguity existed with the ACP designated levels of care (R, M, C) and how they are interpreted and applied by clinical staff. For example, one nurse wrote:

Current ACP statuses used are not clear enough such as when patients do not want to be defibrillated or have chest compressions but would want to be intubated if respiratory status were to decline. In ACP M there is differing opinions if a code blue should be called in a patient that is declining and would need ICU support such as in shock where vasopressors are needed.

Another nurse identified that “*ACP m means something different among different facilities and physicians.*” Participants were expressing their overall impression of ambiguity or experiences that occur from various interpretations and applications of the levels of care currently used in ACP.

The second sub-category related to a lack of clarity in the process and was labelled as follows: Responsibility in ACP, whose role is it? This subcategory highlights the questioning of responsibility regarding ACP and exploration of various health care team members’ involvement in the process. Some responses had to do with the onus of ACP being placed on physicians alone. For example, one nurse wrote:

To me it seems like it is more of a physician’s responsibility. They are ultimately the ones in charge of a person’s medical treatment.

Other comments outlined clinical scenarios and factors that affect or impact who is able to take responsibility for the ACP discussions, including a change in patient status or the presence of a terminal illness. As one nurse noted:

Often it will be addressed again if there had been complications leaving the patient with permanent damage. In this case it is usually the surgeon or charge nurse to address a change in status, however, the staff nurses also engage in conversations about this.

Participant responses that explored different health care team members’ involvement in ACP identified that physicians, charge nurses, and staff nurses may be involved in the process. These statements allude to ACP being understood more as the responsibility of the health care providers as a

team rather than the onus being placed on one team member alone and also touched on nurses' experiences of different scenarios or factors that seem to have influence over how ACP is conducted on their units.

Table 14

Content Analysis Category: Lack of Clarity in the ACP Process

Lack of Clarity Regarding ACP Form	4 comments
“unclear treatment under ACP”	
“Current ACP statuses used are not clear enough such as when patients do not want to be defibrillated or have chest compressions but would want to be intubated if respiratory status were to decline. In ACP M there is differing opinions if a code blue should be called in a patient that is declining and would need ICU support such as in shock where vasopressors are needed.”	
“it is a very vague document”	
“ACP m means something different among different facilities and physicians”	
Responsibility in ACP, whose role is it?	7 comments
“To me it seems like it is more of a physician’s responsibility. They are ultimately the ones in charge of a person’s medical treatment.”	
“doctors should determine ACP with the patients”	
“ACP Status is always done by MD and family members”	
“Very Few Physicians fill out the ACP forms ... It is not looked upon as a need to discuss and they expect the nursing staff to do so”	duplicate
“Often it will be addressed again if there had been complications leaving the patient with permanent damage. In this case it is usually the surgeon or charge nurse to address a change in status, however, the staff nurses also engage in conversations about this.”	segment
“I let doctors discuss ACP status if it’s a terminal case”	
“For question ten the charge nurse is involved in ACP discussions during rounds or family meetings but the bedside nurse if often not there”	

Reluctance of Physicians to Engage in ACP. A point of contention for respondents was the perceived reluctance of physicians to engage in the ACP process with patients and families (5 comments).

One nurse stated:

doctors need to be more involved in ACPs with patients and families instead of what appears to be avoiding the issue.

Some of the comments in this category allude to nurses’ reliance on physicians to have ACP discussions with patients and families, rather than nurses engaging in these discussions themselves (see Table 15).

Table 15

Content Analysis Category: Reluctance of Physicians to Engage in ACP

“Often have to encourage and push physicians to get an ACP Status”	
“Physicians in an acute care setting are often very reluctant to bring up the ACP status until it was too late”	
“Doctors must write the order but avoid the conversation at times even in patients with poor prognosis”	
“I find that a lot of physicians are extremely reluctant to discuss ACP even with prompting from nurses”	
“doctors need to be more involved in ACPs with patients and families instead of what appears to be avoiding the issue”	

Need for Improvement in ACP. This category is a collection of participant responses (6 comments) that speak to an identified awareness that inconsistent and inappropriate practices exist in ACP and action needs to be taken to correct the current state of ACP locally (see Table 16). These comments relate to not being proactive, hesitancy to raise questions about future care, or not addressing ACP status. One nurse wrote:

There has been much advancement in discussions with patients and family over the years. The expectation is that every patient is asked the questions so that we can openly discuss the informed decisions of our patients. We are still not there yet and I am glad that there is research going on in this area. We should not ever be hesitant to discuss patients’ wishes and knowledge about their health which of course includes their death.

Another commented that “*very few physicians fill out the ACP forms... It is not looked upon as a need to discuss.*”

Table 16

Content Analysis Category: Need for Improvement in ACP

<p>“I feel we need to take a more proactive approach to ACP too often the conversation is taking place when an acute situation is occurring”</p>	
<p>“Quite often it is something that is not addressed More often than not ACP status stands as ACP to be determined which in my mind is not acceptable at all I am glad to see someone is choosing this topic for her thesis as I feel it is a very important part of the nursing care we provide especially in an acute care setting”</p>	
<p>“There has been much advancement in discussions with patients and family over the years The expectation is that every patient is asked the questions so that we can openly discuss the informed decisions of our patients We are still not there yet and I am glad that there is research going on in this area We should not ever be hesitant to discuss patients’ wishes and knowledge about their health which of course includes their death”</p>	
<p>“is important but often miss”</p>	
<p>“Very few physicians fill out the ACP forms at HSC It is not looked upon as a need to discuss”</p>	<p>duplicate</p>
<p>“ACP status is often never readdressed by physicians if the original discussion on admission does not result in the patient making a choice”</p>	

Importance of Timing in ACP. Evident in some of the nurses’ comments was a mindfulness or concern that a preferred or ideal timing for ACP exists (9 comments). Some of the statements emphasized the value that appropriate timing can have on the trajectory of ACP or on conducting ACP in general. There was value placed on conducting ACP early in an individual’s course in hospital and a sense that consequences can arise when the ideal timing for ACP is not accomplished. In five out of seven participant responses, ideal timing for ACP was specifically stated as on admission to a health care facility or related to admission by proximity of time. This is illustrated in these two examples: “ACP discussion should be initiated on admission” or “it is important that it be discussed with the patient and or family at the soonest opportunity when admitted to the hospital always.” Overall the construct of time and timing was viewed as a significant one in ACP and early initiated discussions were desired (see Table 17).

Table 17

Content Analysis Category: Importance of Timing in ACP

“need to be addressed FAR SOONER than it is in most cases”	
“Discussions that happen early on admission make it easier on families”	
“ACP discussion should be initiated on admission”	
“I definitely think the initial discussion should start when they are admitted”	
“it is important that it be discussed with the patient and or family at the soonest opportunity when admitted to the hospital always”	
“early discussion with patient and family”	
“... and I feel like acp should be done as soon as the patient knows they’re being admitted to the hospital”	segment
“I feel we need to take a more proactive approach to ACP too often the conversation is taking place when an acute situation is occurring”	duplicate
“I feel that nurses and doctors are often afraid to have this discussion and it often happens too far into an admission”	duplicate

Call for more education and supports. It was clearly and repeatedly identified in the open-ended comments that nurses feel more education, training, and supports are needed that will assist them in their roles and tasks related to ACP, and that continued and ongoing dialogue or exploration on the subject of nursing and ACP is needed (12 comments). Furthermore, some comments paid direct attention to the desire for specific aids and assistive materials (e.g., a video, guides) to address and inform what ACP is and the nurses’ role and scope of practice in this intervention. One nurse wrote:

It would be nice if there was a booklet available for nurses to better understand their role in discussing ACP and the variables that could warrant a review of ACP status and what each status usually represents.

Attention to education of the general public on ACP was also identified as an area that has need for supports to assist people to prepare for these conversations. Lastly, nurses’ responses touched on a feeling of unpreparedness to deal with ACP with the current level of knowledge and understanding they were equipped with (see Table 18).

Table 18

Content Analysis Category: Call for More Education and Supports

“need support on how to start acp discussion and what to say”	
“...and I think many of my coworkers need further education on ACP discussions”	segment
“New nurse hired last September who received no guidance regarding my role or responsibility with ACP statuses of my patients”	
“I would like to see some discussion as to how to implement this discussion on a short stay surgical unit as time preoperatively is incredibly brief”	duplicate
“we need more discussions on this topic”	
“It would be nice if there was a booklet available for nurses to better understand their role in discussing ACP and the variables that could warrant a review of ACP status and what each status usually represents”	
“a video for discussion”	
“make a guide on how to talk to patients about acp eg simple explanations of C M and R to tell patients how to bring it up”	segment
“There needs to be public information on this issue so that people are prepared for this conversation”	
“but nurses in my setting have not been equipped to have these discussions with patients”	segment
“I am unsure what resources we have available at our hospital regarding ACP status I do feel nurses at the hospital I am employed at need more training and resources in order to guide patients and their families in this very crucial and sensitive subject”	segment
“I feel like I need more experience to deal with ACP at my work place”	

Difficulties with and in ACP. This category (9 comments) details a variety of statements sharing articulation of various difficulties that intertwine with professional understanding and experiences in ACP. Difficulties or perceived barriers are diverse in this category, but again share the similarity of being obstructive to successful ACP. For example, the following two statements address the idea that personal emotions of the health care provider can be a barrier to timely ACP or an obstacle when conducting ACP in general: “I feel that nurses and doctors are often afraid to have this discussion and it often happens too far into an admission”; “Worry about what pts and family will think when ACP discussed”. Other comments touch on the way that the clinical setting (e.g., cardiac surgery, short-stay surgery) can have an impact on the process or outcome of an ACP conversation. Another difficulty

evident related to the feeling that nurses are limited in their ability to engage in a full ACP discussion by scope of practice and practice limitations. This is exemplified in the following comment:

As a nurse it's outside our scope to discuss prognosis co-morbidities and treatment options and side effects which play a large role in ACP talks. A patient may want to die when in the acute phase of an illness or pull out all the stops for something like cancer that will make their last days more uncomfortable for them and their families.

Lastly, this category includes statements that expressed frustrations with ACP that can exist for nurses in relation to family decisions contradicting with patient decisions, family members having difficulty “saying goodbye”, or feelings that patient wishes are not respected (see Table 19).

Table 19

Content Analysis Category: Difficulties with and in ACP

“I feel that nurses and doctors are often afraid to have this discussion and it often happens too far into an admission”	
“Worry about what pts and family will think when ACP discussed”	
“Often the ACP status is determined prior to a patient having cardiac surgery and they must agree to be ACP R before they have this surgery”	segment
“I would like to see some discussion as to how to implement this discussion on a short stay surgical unit as time preoperatively is incredibly brief”	duplicate
“As nurses we depend on physicians prognosis before discussing ACP”	
“as a nurse its outside out scope to discuss prognosis co morbidities and treatment options and side effects which play a large role in ACP talks A patient may want to die when in the acute phase of an illness or pull out all the stops for something like cancer that will make their last days more uncomfortable for them and their families”	
“nurses should be able to advocate for pt decision regarding acp especially if it contradicts family decision”	
“I find that sometimes family members make decisions for their incapable loved ones based on the fact that they are not wanting to say goodbye to their loved one even though it is in the best interest for them ACP discussion can sometimes be challenging”	segment
“hate it patient too often asking to die their wished are not respected”	

Summary. The open-ended responses to the request for additional comments provided insight into some of the varied concerns, frustrations, and struggles medical-surgical nurses have with ACP. For the nurses, ACP is a valuable intervention that supports clinical care, but the sentiment was also expressed

that change and improvements are needed in the way ACP is currently practiced and carried out in the medical-surgical environment. Nurses expressed a clear need and desire for ACP-related education, training, and instruction to support their work in ACP with patients. The open-ended responses revealed the importance of timing in ACP for these nurses and they expressed an emphasis on the need for earlier ACP practices, particularly ACP at time of admission. The responsibility of ACP as an intervention was experienced somewhat diversely for respondents, but frustrations were expressed at the role of the physician, with some respondents describing physicians as being evasive or avoiding ACP discussions with patients and families. These comments provide access to some of the insights and experiences of medical-surgical nurses' in ACP, highlighting the diverse context in which this intervention occurs.

Chapter 5: Discussion

In this chapter, the results of the survey will be discussed in relation to the literature on ACP and the findings of previous studies. Given that the Yee et al. (2010) instrument was used in this thesis project, particular attention will be paid to how the results of this study compare to Yee et al.'s (2010) results. The implications for practice, research, and education will be considered. In addition, limitations of the study will be identified.

Knowledge

Nurses in this study excelled at similar categories of knowledge as the nurses in the Yee et al. (2011) study, from whom this questionnaire was obtained and modified. Analysis of scores in this section illustrate nurses have a sound understanding of several foundational academic concepts in ACP with the majority of questions in this section answered correctly. Ten questions specifically tested academic knowledge of ACP and two questions tested nurses' perception of personal knowledge related to ACP. Respondents answered anywhere from 4 out of 10 questions correctly to 10 out of 10 questions correctly. The highest percentage of nurse respondents ($n = 214$) correctly answering a single question in this section was 98.6%; similarly, the highest percentage of respondents correctly answering a single question in the Yee et al. study was 97.3%. More questions were answered correctly on average by nurses in this study than the Yee et al. (2011) study, which outlined an average correct mean score of 6.3 out of nine amongst nurses respondents ($n = 230$), where this study had a mean score of 8.57 out of ten ($n = 218$).

Two of the highest scoring correctly answered questions in both studies pertained to communication skills being essential for effective ACP and the importance of early initiated ACP when an individual has a life-limiting condition. Awareness to the value of documentation in ACP was another strong area of understanding amongst study participants (*i.e.*, in the top three highest scores for correctly answered questions), more so than by nurses in the Yee et al. study (*i.e.*, not in the top three highest scores for correctly answered questions).

Generally speaking, nurses performed well in the knowledge section of this study, displaying an adequate to a strong understanding of ACP and some of the foundational concepts encompassed in the intervention. The sense from the literature review, however, is that nurses experience difficulties in their understanding of ACP concepts (Baughman et al., 2012; Baughman et al., 2014; Boddy et al., 2013; Davidson et al., 2013; Robinson et al., 2013) and can often question if their understanding of foundational concepts is enough to support productive engagement in the process (Baughman et al., 2012; Baughman et al., 2014; Ceccarelli et al., 2008; Robinson et al., 2013). Limitations for nurses related to policy and or legislative understanding of planning for future clinical care were identified in several studies throughout the literature review (Badzek et al., 2006; Baughman et al., 2012; Davidson et al., 2013; Robinson et al., 2013; Samara et al., 2013; Yee et al., 2011). Contrary to previous international studies, legislation, policy, and procedure questions generally were well understood by nurses in this study. Nurses excelled at three out of five legislative and policy-related questions, scored well on a fourth, with the remaining question being the only question in the knowledge section incorrectly answered by a significant number of nurses. Perhaps differences noted here are due to diversities in legislation across international regions and, furthermore, differences in what must be understood by nurses in order to execute and implement ACP effectively. When comparing knowledge proficiency of nurses from a single local health region in Manitoba, Canada to international nursing groups, foundational differences in legislation and policy must also be contemplated. Nonetheless, nurses taking part in this study do have gaps in their ACP knowledge of policy and legislation. It can be stated, however, that the results of this study illustrate a general understanding is present for this nursing group.

ACP requires open communication and dialogue between the health care team and patient and family (Minto & Strickland, 2011; Zhou et al. 2010). Several studies identified nurses doubted the proficiency of their communication skills and at times were critical of their abilities to adequately relay clinical information to patients and families (Baughman et al., 2012; Ceccarelli et al., 2008; Samara et al., 2013). Similarly, a significant number of nurses surveyed in this study believed their clinical knowledge was insufficient to support effective ACP discussions with patients and families. Nurses in this study did,

however, recognize the value of good communication in ACP, much like the participants in the Yee et al. study.

Attitudes

Attitudes varied for sixteen statements posed to participants, with one statement receiving 100% agreement amongst respondents. Findings based on mean scores in this study identify nurses working in Winnipeg who responded to the survey saw greater benefits to ACP, showed more concern for patient autonomy and respect for patient choice, were less preoccupied with perceived harmful effects of ACP on patients and families, and were influenced less by potential ACP barriers than the nurses in the Yee et al. study (see Table 20). In addition, these Winnipeg medical-surgical nurses, when compared to the nurses in the Yee et al. study, registered greater support for ACP as an intervention, believed more strongly in the potential for positive effects of ACP, and were less inclined to consider ACP as harmful or distressing to patients and families. It is noted that the sample size of nurses in the Yee et al. study ($n = 416$), a national study carried out in Singapore, is larger than that of this study ($n = 218$), which was focused on one health region in Manitoba, and this difference must be taken into consideration.

A notable finding from the data was the significant number of study participants unsure on their position or opinion on whether ACP was or was not within their scope of practice. One quarter of study participants ($n = 54$) could not provide a definitive response as to whether or not ACP was viewed as a responsibility of their nursing role within their respective clinical practice environments. The regional WRHA policy on ACP designates that health care providers providing direct care to patients in any WRHA facility are responsible for ACP (WRHA, 2011). Given that the majority of study participants were aware that their health care facility has a policy on ACP (90.7%, $n = 195$), this finding was surprising. Accounting for this discrepancy may be that nurses are aware that a written policy on ACP exists, but perhaps may not be knowledgeable of the specific details of that policy and their clinical role identified within it. Furthermore, perhaps nurses do not feel that they are required to partake in this intervention due to work culture or lack of role clarity within their respective clinical practice settings.

Table 20

	Mean	Mean (Yee)
<i>Comparison of Results for Attitudes Towards Advance Care Planning Items</i>		
<i>Potential Barriers to ACP</i>		
Our patients are not ready for ACP discussions	2.12	3.15
I don't have the communication skills to discuss ACP	2.14	3.29
I don't have the emotional strength to support the patient through ACP discussions	2.10	2.73
I don't have the time to discuss ACP	2.70	2.73
<i>Personal Outlook in ACP</i>		
I support the use of ACP	4.86	4.00
I consider ACP discussions as part of my nursing role	3.69	X
I feel confident in ACP discussions with patients and families	3.48	X
<i>Concerns for or with the patient and family</i>		
If I discuss ACP with the patient, the family may blame me for the patient's choice	2.47	3.09
I worry I will upset the patient if I try to discuss ACP	2.56	3.12
If I talk about death the patient may choose it	2.10	2.83
Discussing ACP will make patients lose hope	2.09	2.70
Discussing ACP or HCD is advocating euthanasia	1.43	2.78
<i>Perceived Benefits of ACP</i>		
ACP can decrease the burden of decision-making on family members	4.35	3.71
ACP helps in the medical care of the patient when he/she is seriously ill	4.55	3.87
<i>Autonomy and Patients' Right to Choice</i>		
ACP allows patients to have a sense of control over their lives	4.60	3.85
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	1.45	2.89
It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	4.72	3.76

Another notable finding related to nurses' confidence regarding ACP. When asked to respond to the statement "*I feel confident engaging in ACP with patients and families,*" 22.7% of nurses (n = 48) were undecided and 20.4% (n = 43) selected disagree or strongly disagree. Selection of undecided as a response could mean a variety of things (e.g., possibly ambivalence, doubt, or uncertainty in one's opinions), but suggests that confidence was lacking for this group of nurses in the sample. An individual's level of confidence in any task will inevitably influence willingness to participate and likely

the degree to which the person is comfortable while conducting the task. Therefore, nurses that lack confidence in their ability to discuss ACP with patients and families are at risk to avoid or minimize their engagement in the intervention. This has negative implications for the patients and families receiving care in various health facilities across the region. Furthermore, lack of confidence was associated with perceived lack of communication skills and inadequate emotional strength to support patients in ACP. These conditions have the potential to exacerbate this issue, grossly limiting a nurse's engagement in ACP, and these factors have powerful implications and potential consequences for patients.

Although concerning, these findings are not entirely unexpected as the related literature on nursing and ACP places focus on the interplay of nurses' emotions in relation to their involvement in ACP resulting in hesitancy in ACP engagement or variable levels of involvement in ACP by nurses. More specifically, a large aspect of this is that nurses deal with emotions generally described or identified in some way as difficult or distressing when involved in planning for future clinical care with patients and families (Baughman et al., 2014; Ceccarelli et al., 2008; Cohen & Nirenberg, 2011; Stone et al., 2013; Zhou et al., 2010). As such, in the related literature ACP often appears to trigger challenging emotions for nurses that at times will impede their ability and desire to engage in ACP. Although not seen in the majority of nurse responses in this study, there were pockets of responses that lend to this position as elevated levels of uncertainty indicated in *undecided* responses by the nurses were present regarding level of confidence (22.7%), fear of blame (21.3%), emotional strength (18.5%), and concern for upsetting the patient (16.1%). This was in addition to notable levels of affirmation amongst the nurses in the sample for their answers to questions about concern for upsetting the patient (25.1%) and fear of being blamed for the patient's choices (17%).

Some study participants linked perceived personal inadequacies in relation to communication skills as contributing to their limited involvement in ACP, a finding evident in previous studies on ACP (Baughman et al., 2012; Ceccarelli et al., 2008). It can be speculated that individual nurses who doubt their ability to discuss and plan for future clinical care with patients and families in a way that exemplifies sound communication skills may then restrict or limit the degree, and perhaps the frequency, to which

they participate in ACP and its related activities. Furthermore, if nurses are apprehensive, fearful, or have negative emotions regarding ACP, one can speculate these emotions may also impede successful nursing engagement in ACP. These negative emotions can be barriers to success, leading nurses to take a more peripheral or supportive role in the ACP process rather than the leadership role afforded to them under the WRHA regional policy. This has further implications for patient care and effectively meeting the clinical care needs of various patient populations locally. It is known that planning for anticipatory clinical care with patients is a responsibility designated to health care team members providing direct clinical care to patients (WRHA, 2011). Thus, nurses removing or limiting themselves in this intervention inevitably increases the burden of responsibility on other members of the clinical care team, such as physicians. Furthermore, a perception of physician reluctance regarding involvement in ACP was a theme identified by nurses in their responses to the open-ended question. This perception is supported by other authors who have identified that nurses perceived a level of reluctance amongst physicians to engage patients and/or their families in ACP (Seymour et al., 2010; and Zhou et al., 2010). This presents a challenging scenario for accomplishing this necessary intervention in the clinical care setting and has the potential to compromise the quality of care delivered in local health care facilities.

Experiences

The minimal uptake of completing a HCD amongst medical-surgical nurses and those who are close to them echoes findings noted by various authors, such as Wilkinson et al. (2007) and Fagerlin and Schneider (2004), who reported low rates of AD completion in their literature reviews. Low rates of HCD completion noted in this study amongst nurses and their loved ones depicts a similar picture and may indicate that the HCD is not valued. These findings were similar to, if marginally better than, the findings of Yee et al. In that study, low numbers of nephrology nurses (8.2%) indicated that they had completed an advance medical directive (AMD), and 6.3% indicated that their family members had completed an AMD.

In this study, past professional experiences more so than past personal experiences impacted how nurses engaged in ACP with their patients. Past experiences influencing ACP practices of nurses was

also a theme identified in the literature (Black, 2007; Baughman et al., 2013; Baughman et al., 2014; Minto & Strickland, 2011). In the literature reviewed for this study, past personal experiences were identified more frequently as impacting nurses in ACP practices than were past professional experiences. In contrast, however, participants of this study placed more emphasis on their past professional experiences. Similar to nursing practices identified in the literature review, local nurses generally indicated limited levels of engagement in ACP. The highest percentage of nurses described themselves as only *occasionally* engaging in discussions of ACP with patients. Although no specific parameters or numerical frequencies were allocated for each category of response, it is clear that local nurses' frequency of ACP discussions with patients and families is comparable to the trend of limited and inconsistent practices of the wider nursing discipline evidenced in the literature review (Baughman et al., 2012, Baughman et al., 2013; Samara et al., 2013; Silvester et al., 2013; Zhou et al., 2010). Furthermore, 17% of nurses in this study identified that they *never* discussed ACP with patients and families, which is a disheartening result. However, considering almost half of the sample surveyed reported they had not received any form of ACP education or training in their undergraduate nursing curriculum, this finding becomes more understandable. It cannot be surprising that nurses are not consistently engaging in ACP with their patient populations when no formal education or training was provided in their formative years of their initial nursing educational programs.

Nurses more commonly experienced ACP education or training in their professional work environments than in nursing school, however, only to a moderate degree (65.6% and 54.5% respectively with $n = 209$), denoting room for improvement. Receiving professional education and training in ACP was much more common for nurses locally than for nurses in the Yee et al. study. Only 24.7% of nurses in the Singapore study reported receiving ACP training or instruction professionally, significantly lower than the 65.6% reported by nurses in Winnipeg. It would appear that more focus or effort might be placed into the professional development of nurses locally in ACP. Of note here is the previously mentioned study by Baron et al. (2015), an example of the benefits education in ACP can have for health care providers. Nursing care home staff in that study receiving ACP seminars covering foundational

content of the intervention demonstrated increased knowledge scores against those that had not received the education and instruction, notably measured at up to 14 months after the seminars took place.

When gauging the impact of patients' family members on ACP, there was distinct agreement by local nurses that family members had a positive impact on the ACP process, but a third of respondents were unsure how family members impacted ACP, and a minimal percentage actually believed they impacted the process negatively. The variety of responses to family members' influences in ACP correspond to the findings presented in the wider literature, however, more instances for families negatively impacting ACP were noted. Oncology nurses surveyed by Zhou et al. (2010) identified family members' fragile and sensitive emotional state related to an unwell patient acted as a barrier to ACP, and resistance to ACP discussions by family members was a theme also described by several other researchers (Baughman et al., 2012; Jeong et al., 2011; Stewart et al., 2009). Conversely, Stewart et al. (2011) described findings that families acted as "facilitators" to ACP as their personal knowledge of a patient and their preferences were seen to be helpful in future care planning discussions (p.333).

Results of this the study highlighted that the following were positive contributing factors for frequency of ACP discussions with patients: nurses with advanced clinical experience (>11 years), of older age (>30 years), working in a clinical setting that required nurse involvement in ACP, past professional experience with death and dying, and professional exposure to ACP education and training. The importance of this finding is that one can speculate that these conditions optimize nursing involvement in ACP. The variables age, experience as a nurse, and death/dying exposures cannot be extraneously influenced, but the remaining variables (e.g., clinical expectations of practice and education) can be, and thus become areas of focus for creating positive change in the clinical setting for nurses and ACP. As with associations, it cannot be said that these variables cause ACP discussions to occur. However, it can be said that these variables appear to encourage, contribute, or support higher levels of reported involvement in ACP discussions and as such should be areas of focus for change.

Implications for Practice, Education, and Research

Strong knowledge scores and positive attitudes for ACP are encouraging but do not necessarily translate into strong ACP practices with patients and families. Therefore, it becomes important to work towards positive change and improvement in the local state of ACP. The purpose of this study was to explore the knowledge, attitudes, and experiences of registered nurses working in the area of medical/surgical nursing in care facilities under the WRHA. The intention in carrying out this study was to gain insights and information to inform and support necessary change in institutional-based settings and formal ACP education initiatives, encompassing both clinical care settings and undergraduate nursing curricula and programs. In the following sections, I discuss various strategies and suggestions as to how that objective can be achieved through practice, education, and research.

Practice. As a number of organizations have identified a clear role for nursing in ACP, it becomes unacceptable to accept the fragmented involvement of nurses in ACP as status quo and not push for change and improvement. A collaborative and inclusive document titled “Advance Care Planning in Canada: National Framework” was used to provide rationale for the study and illustrate how findings from this research could be used and applied. The purpose of the national framework was to create an inclusive document comprised of foundational principles in ACP that can be used to implement and sustain successful ACP practices across the country (CHPCA, 2012). The framework details four focal areas to successful ACP (i.e., engagement, education, system infrastructure, and continuous quality improvement) with two areas (i.e., engagement and education) being of particular interest to this study. Within this framework, engagement calls for investment and enrollment of all applicable parties in ACP practices, including health care professionals (CHPCA, 2012). The practice of nurses in this study related to ACP was a previously poorly understood dynamic, now elucidated to some degree and in one region in Canada by this study. For this sample of nurses, confidence is lacking and engagement in the ACP process is inconsistent and intermittent at best. Thus, changes in the clinical practice setting that mitigate difficulties experienced by nurses and support consistent ACP practices for the nursing discipline need to occur.

Based on the findings of this study, an emphasis on strengthening the skill set of nurses in ACP (e.g., communication, confidence, emotional coping skills) must be prioritized. Institutional-based improvements need to be introduced that will strengthen and empower the nurses' proactive and productive roles in ACP. This might take the form of preceptor or mentorship programs that focus on the work and role of the nurse in ACP, allowing for clinical opportunities for nurses to witness advance care planning discussions occurring between health care professionals and patients and their families. Increased transparency of nursing expectations and duties related to ACP is needed. A tailored educational program that addresses strategies for improved communication skills, confidence, and emotional coping skills for nurses and an ACP awareness campaign that outlines policy-specific expectations of nursing clinical practice incorporated in hospital or unit-specific orientation programs would promote achievement of this objective. A more visible policy presence on all medical/surgical units, and ACP workshops and seminars that include confidence-building exercises and techniques, and discuss emotional coping skills and strategies related to emotional distress experienced by nursing, would be beneficial. All initiatives should be interdisciplinary in focus, involving all members of the clinical health care team in teaching and education initiatives for ACP. All levels of health care and each subset of nursing (i.e., staff nurse, clinical resource nurse, administrators) should be involved in the planning phase of any initiative so that input is dynamic and appropriately focused on the needs of the group.

Nursing managers are not likely expected to take part in ACP due to the nature of their administrative roles. They can, however, assist in cultivating and fostering a supportive work environment that promotes staff nursing involvement in ACP. They should outline clearly for their staff what the role, expectations, and standards are related to ACP within their respective clinical areas. Undoubtedly, clinical practices will shift based on the demands of each clinical setting, and administrative and managerial staff should communicate what is required and expected from nurses in that setting to fulfill ACP responsibilities, based on the regional ACP policy, and to best meet the needs of the patient population. Furthermore, the provision of cyclical, nursing-focused, institutional-based programs, such as the ones previously mentioned, should be implemented and maintained in clinical settings and health care

institutions. This will increase competence among nurses, promote standards of practice, and elevate professional accountability. ACP working groups within hospitals and medical/surgical units, comprised of nurses of all levels and other health care team members providing direct clinical care, could hold monthly and as needed meetings to discuss the status of ACP in their clinical environment. Difficulties with ACP could be shared and discussed openly, opportunities for change and improvement discussed, and collaborative trouble-shooting performed. This would promote a more supportive and enhanced collegial clinical practice environment and likely minimize the burden of ACP on one health care team member alone, reinforcing this intervention as more of a health care team responsibility.

The findings of this study have practice implications for the WRHA. Although there was evidence that the level of knowledge was strong amongst this population of nurses, other challenges like emotional conflict, lack of confidence in ability, and variable levels of engagement are present amongst this group. As the WRHA is charged with regulating and overseeing the expert delivery of quality care in the region, the findings of this study should be of value and interest to this body. The task of operationalizing improvement strategies to enhance the state of ACP in the region by supporting, informing, and empowering the local nurses rests, in part, with regional authorities. The WRHA has reach beyond the health care institutions alone and thus can act as a powerful agent for local change and improvement. Interestingly, a recent nursing initiative of the WRHA is focused on increasing awareness and understanding of ACP across the region (WRHA, n.d.). Findings from this study can provide valuable catalytic information for this campaign and should be applied to and implemented with future initiatives.

Lastly, a revision or reform of the current ACP policy might be valuable to address the identified ambiguity related to how levels of care are interpreted and applied. As a large percentage of the sample was aware that a policy on ACP exists, then perhaps providing case examples or a case scenario workbook within the policy would benefit and improve collegial understanding for the diverse circumstances in which ACP is used and applied. Policy revision to specifically articulate health care team members' designation for participation in ACP should also be considered. A clearly stated

identification that nurses can and should be involved in ACP would contribute to the expectation of ACP involvement in clinical practice for the discipline and, therefore, likely support greater reported frequency of ACP discussions in this population of nurses. With this, ACP policy review should be an expectation of employment, perhaps made mandatory in nursing orientation and continued on an ongoing, perhaps annual, basis.

Education. Again, the “Advance Care Planning in Canada: National Framework” was used to provide rationale for the study and illustrate how findings from this research could be used and applied. Engagement (previously described) and education were two of the four pillars of successful ACP highlighted for the purposes of this study. Education is vital to the success of ACP and the framework specifically calls for the dissemination of “ACP-related content and skills” to those positioned to lead, implement, and coordinate ACP practices (CHPCA, 2012, p. 30). Generally speaking, nurses’ overall knowledge and understanding of ACP are strong; thus, when nurses are actually involved in ACP they likely will be informed and operating from a strong knowledge base. However, knowing is not doing, and informing nurses on what ACP is, its purpose, and value is key. For this demographic of nurses, ongoing teaching and learning initiatives targeted at nurses at all levels of care should be encouraged. Reinforcing the knowledge of nurses related to ACP and further educating and clarifying misconceptions identified in the findings of this study are required.

More consistent ACP teaching and learning in foundational nursing education is important as findings identified exposure to ACP in nursing curriculum was lacking. Formalized education plans need to be implemented across all institutions and nursing education settings (e.g., university and institutions, bridging programs, international nursing programs, upgrading programs, etc.) and would be beneficial if incorporated into professional practice and continuing competency requirements. This widespread exposure has the potential to normalize the work of nurses in ACP and issues with confidence among nurses could potentially be mitigated by early and sufficient education. Presenting clinical information and scenarios to nursing students using the medium of role-playing and skit presentation, known as “forum theatre”, has been used with positive results for nursing students. This type of clinical education

is used to relay clinically specific information and experience to students, while encouraging their active participation in problem solving and trouble-shooting through the scenarios presented (Tuxbury, McCauley, & Lement, 2012). Implementing this forward form of instruction, particularly in undergraduate nursing curricula, could provide a renewed approach to formal ACP education and a truer to life introduction to the concept of planning for future clinical care in nursing institutions where such training has not occurred.

Nurses in this study expressed a need for more guidance and direction in ACP within the clinical setting. The feedback and findings from nurses in the attitudes section of the questionnaire can be used to inform the creation of targeted educational strategies that will address the challenges nurses face related to their work in ACP. These resources could take the form of “cheat sheets”, pocket card guides, reference cards with communication prompts and opening phrases for nurses to draw on in ACP discussions. These tools should be readily available, for example, on the nurses’ lanyard, and their use needs to be promoted and normalized within clinical settings. The implementation of the educational tools could be supported by annual and semi-annual workshops and seminars within the health care facility or can perhaps be an incorporated component into hospital orientations and reinforced more routinely by clinical nurse educators and team-initiated safety huddles on the units. The positive attitudes of nurses demonstrated in the findings of this study may very well be an asset to the implementation and execution of educational reform in ACP. Furthermore, the WRHA has various ACP-related resources for health care workers available online, but the availability of these resources needs to be skilfully conveyed to nurses and their use strongly encouraged throughout each clinical setting, if not made an obligatory aspect of employment. Addressing educational and knowledge-based barriers that impede the work of nurses locally in ACP will undoubtedly bring improvements to the intermittent level of engagement evident in this study.

Research. As previously stated, several authors, along with the nurses in this study, have advocated for continued research on the subject of ACP. Ongoing investigation into ACP in Canada is needed to support continued change and improvement to the current state of ACP in Canada (Dunbrack,

2006; Easson, 2006; Schuklenk et al., 2011). The research conducted through this study is informative and valuable, and contributes to this initiative. Information that helped inform as to the knowledge, attitudes, and experiences of medical/surgical nurses locally was solicited, adding to the current level of understanding on the subject, however, the need for additional research is clear. Nurses' confidence with ACP discussions warrants further study and investigation. Research that specifically investigates the relationship between confidence and the ACP practices of nurses would be valuable along with research that investigates the "how" and "why" of nurses' knowledge, opinions, and ACP practices. For example, a qualitative observational study of nurses' practices related to ACP would be of great value.

Another area that warrants research attention is the influence of nurses' work environments on ACP practices. Evaluating the clinical environment, for example, medical units, surgical units, and combined medical/surgical units, could provide insightful information as to site-specific barriers or challenges not identified by the scope of this study, noting the highest percent of nurses that 'never' discuss ACP with patients and families were employed on surgical units. Furthermore, utilizing both qualitative and quantitative research methods is best to facilitate diverse knowledge acquisition. Future research should incorporate all nursing clinical care providers and look to incorporate interdisciplinary health care team members to broaden understanding and incorporate knowledge and information from other individuals essential to the success of ACP.

Limitations

Clearly, both similarities and differences exist from the findings in this study and the findings of studies reported on in the literature review. Nurses in this study live within the city of Winnipeg in Manitoba, Canada, work within specific clinical areas (i.e., medical-surgical units), and are employed under the local health care authority. The findings from this group of nurses are being compared to international literature detailing the knowledge, attitudes, and experiences of nurses in ACP and these variables will undoubtedly differ across countries. It is not ideal to compare international data on nurses and ACP to that of regional data on nurses and ACP; however, research on this topic is limited and thus this comparison is necessary.

The sample size can be viewed as a limitation of this study. Comparable cross-sectional descriptive studies, using the same sampling technique for enrollment, contacting members registered with an established nursing association or organization and distributing the questionnaire via an online survey platform, achieved sample sizes of 19% to 27%, which corresponds to sample sizes of 266 to 378 participants respectively (Chapman et al., 2012; O'Mara et al., 2007). Use of an online statistical calculating program to compute appropriate sample sizes identified a recommended sample size of 302 participants from an identified population of 1,400 individuals using a 5% margin of error and 95% confidence interval (CheckMarket, 2015). Thus, an ideal response rate was not achieved for this study. This study's sample of 218 participants, representing 16% of the population, is comparable to local studies conducted by Dr. Marie Edwards and colleagues that achieved sample sizes of 14% to 22% in similarly constructed studies (see for example Edwards et al., 2013). Thus, the 16% sample size achieved can be considered reasonable but not ideal, as the population is likely under-represented. The results of the study are relevant and applicable but are not specifically generalizable to the larger nursing population.

Upon further consideration, the questionnaire itself was applicable to medical/surgical staff nurses but perhaps much less applicable to nurses working in an administrative or a managerial capacity in the medical/surgical clinical care environment. It can be speculated that unit managers and other administrative nursing staff likely would not have routine contact with patients and families, as staff nurses and clinical resource nurses do, and their involvement in ACP is not likely an aspect of their designated nursing roles. Therefore, the population of 1,400 medical/surgical registered nurses locally is accurate but likely too large a number when considering appropriateness of participant enrollment in the study, as the study was in fact attempting to solicit data from a smaller subset of the identified 1,400 member population.

Given that only individuals employed in a staff nurse or clinical resource nurse position, not unit managers or other nursing designations, completed the questionnaire, the study findings are focused on this demographic of nurses and the knowledge, attitudes, and experiences of non-respondents is unknown.

Although it can be speculated that some non-respondents were perhaps unable to participate because they have limited contact with patients and families in their nursing roles, this is only speculation and likely only applies to a small segment of non-respondents. Due to the sample size achieved for this study, the potential variety of knowledge, attitudes, and experiences of this nursing population related to ACP is potentially under-represented and as such valuable insights and opinions may not be accounted for. To preserve confidentiality and anonymity of the population, no demographic information is known about the 1,400 members of the population. However, any number of factors may have resulted in limited participation, including lack of interest in the research topic, unwillingness to complete the questionnaire, lack of access to a computer or the internet, or lack of software compatible with the online survey platform. As well, people may have been out of town or away on vacation during the time the questionnaire was distributed.

The study was distributed to participants through the CRNM and participants were solicited by registration information, specifically home addresses that were located within the city of Winnipeg. Under these circumstances there is potential for nurses that live outside of Winnipeg but work within the city to be excluded from receiving the questionnaire (K. Mitchell, personal communication, December 30, 2014). Another factor to consider is the medium of online delivery of links to studies. Incompatible survey platforms or junk mail filters that blocked the email or questionnaire may have limited access to the questionnaire for some (Balch, 2010). Furthermore, not owning a personal computer, not having ready access to a public computer (Rosenbaum & Lidz, 2007), and perhaps limited computer skills may be limitations experienced through use of online survey delivery. Also, the CRNM registry for medical/surgical nurses would have been accurate as of the 2014 nursing registration renewal deadline of December 1st. Additional registrations made after that deadline are not tracked in the same way and, therefore, cannot be accounted for (K. Mitchell, personal communication, March 3rd, 2015).

It is important to discuss that no assessments of validity and reliability, beyond face validity, were computed for the questionnaire used. Face validity alone, a measure of content validity, was deemed appropriate and sufficient for the purposes of this study. Through consultation with an expert statistician

at the University of Manitoba, other assessments of validity and reliability were deemed unnecessary. The study utilized a questionnaire with questions posed to gain insights and information on various topics (or variables) under study and was not a psychometric tool. If each question or subset of questions was measuring specific constructs or characteristic of the variables under study, for example, how the variable is defined amongst the population, then reliability and further validity would be warranted. But as the questionnaire was only surveying for the understanding, opinions, and practices of participants and not specifically measuring a scale or construct of the specified variables, further psychometrics were not warranted (B. Stoltz, personal communication, August 2014).

Lastly, it is mindful to consider the subjective nature to self-reporting one's attitudes and practices. Emotions are an individual and subjective experience and, therefore, may not be defined, considered, or experienced by different people in the same way. Further to this, it is reasonable to assume participants responded to each question truthfully and to the best of their ability, however, participants reporting bolstered responses to study questions cannot be ruled out.

Conclusion

ACP as an intervention is a means to discuss and determine preferred treatment for care. With Canadians living longer and coping with chronic disease and illness, and with advancements in medical technology continuing, Canadians in hospital are facing the implications of medical decision making for future care. Within the hospital setting, ACP is of critical importance to facilitate the process of open communication around clinical care, supporting informed medical decision making for all patients. The purpose of this study was to investigate the knowledge, attitudes, and experiences in ACP with registered nurses working on medical-surgical units in hospitals within the WRHA, and that objective was achieved with the sample obtained. Nurses in this study were knowledgeable about various aspects of ACP, and displayed at times diverse attitudes towards patient autonomy and how ACP may impact patient and families, diverse outlooks on ACP, and varied thoughts on potential barriers and benefits to ACP. The information gained from this study is valuable and contributes critically to the growing research in the

area of nursing and ACP. Through implementation of this research the potential to influence the discipline of nursing at both the institutional and professional practice level is sizable.

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Appendix A – Questionnaire

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Research Project Title: “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba, Canada”

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Contact Information: Faculty of Nursing, University of Manitoba Marie.Edwards@umanitoba.ca or 204-474-8218

Sponsor: Fort Garry Branch Royal Canadian Legion Poppy Trust Fund

This page of the questionnaire should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or you need further information, you should feel free to ask by contacting the researchers. Please take the time to read this carefully and to understand any accompanying information. Purpose: A patient-centered approach to clinical care incorporates the inclusion of the patient and family in clinical decision making in the form of advance care planning (ACP). ACP requires ongoing communication and dialogue between health care team members, patients and families in order to support informed decision-making regarding clinical care and treatment in hospital. The purpose of this research study is to explore knowledge of, attitudes toward and experiences with ACP in registered nurses working on medical and/or surgical hospital units in Winnipeg. It is anticipated that the information obtained from this inquiry will provide valuable insights and information that can support and strengthen institutional-based improvements to the ACP process as well as bolster formal ACP education initiatives both in undergraduate nursing programs and within hospital settings.

What you are asked to do: If you agree to take part in this study, you are asked to complete a 51-item questionnaire. The questionnaire asks you to provide your answers in a variety of styles like true/false or selecting your response from a range of strongly agree to strongly disagree with questions that inquire as to your understanding, opinions and experiences with ACP. The questionnaire takes approximately 20 minutes to complete. Participation in this study is voluntary. Benefits to participation are contributing to related literature on this subject and expanding the knowledge base for future guidelines, interventions, or policies in this area. If any past experiences with ACP have been negative, then reflection on those experiences may bring up similar feelings for you, however, it is not anticipated that any harm will result from participation in this study. If any distress should occur for you as a result of participation in this study please consider seeking the services of the Employee Assistance Program which offers free of charge counseling services to all WRHA employees. Phone: (204) 786-8880, Toll-free: 1-800-590-5553, TTY: (204) 775-0586.

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw you can click the link provided at the end of the questionnaire to do so. The draw is being managed by James Plohman, Research Coordinator with the Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the draw and he will contact the two people selected. Gift cards must be picked up at the Manitoba Centre for Nursing and Health Research in the College of Nursing at the University of Manitoba (Room 212). The email addresses will not be provided to me or my advisor to preserve your privacy.

Privacy and Confidentiality: No identifiers that directly link you to your responses will be collected through this research process (e.g., email or IP addresses), and Fluidsurveys is used as an anonymous online survey platform so you will remain anonymous. While my advisor, Marie Edwards, is currently on the Board of Directors of the College of Registered Nurses of Manitoba, she will not have access to membership data as a researcher. Information submitted will be stored on password-protected computers and only me, my advisor, Marie Edwards, my thesis committee (Dr. Susan McClement and Dr. Bruce Martin) and a statistician employed by the Faculty of Nursing, University of Manitoba will have access to the data. All data will be destroyed as confidential waste seven years after the completion of the study. You may exit the survey at any time if you wish not to proceed and can omit any questions you do not want to answer, with no consequences to you. For those interested a statement summarizing the findings of the research can be obtained by accessing my advisor's (Marie Edwards) page on the University of Manitoba Faculty of Nursing webpage no later than September 2015 (http://umanitoba.ca/faculties/nursing/academic_staff/edwards.html). Findings of the research will be detailed in the thesis work of the principal researcher (Ogechi Asagwara) upon completion of her master's degree and posted on the University of Manitoba's Mspace, which is an open access site, meaning free and unrestricted access to the public online. It is also anticipated the findings will be presented at conferences or seminars and submitted for publication.

The University of Manitoba may look at research records to see that the research is being done in a safe and proper way. Completion and submission of this questionnaire indicates your consent to participate. This research has been approved by the Education/Nursing Research Ethics Board. If you have any concerns or complaints about this project you may contact the researchers, Ogechi Asagwara (umasagwo@cc.umanitoba.ca) and Dr. Marie Edwards (Marie.Edwards@umanitoba.ca, 204-474-8218) or the Human Ethics Coordinator (HEC) Maggie Bowman at 204-474-7122 or Margaret.bowman@umanitoba.ca

Section 1: Demographic Information

Please indicate your responses to the following questions

1. Please indicate your position at work

- Staff Nurse
- Clinical Resource Nurse (CRN)
- Advance Practice Nurse
- Unit Manager
- Nurse Educator
- Other, please specify _____

2. Please indicate the type of practice facility you work in

- Tertiary Hospital
- Community Hospital
- Other, please specify _____

3. Please indicate the type of unit you currently work on

- Medical Unit
- Surgical Unit
- Med/Surg Unit
- Other, please specify _____

4. Please indicate your employment status

- Full-time
- Part-time
- Casual
- Other, please specify _____

5. Please indicate your years of practice in nursing

6. Please indicate your age

7. Please indicate your highest level of nursing education achieved

- Diploma
- Bachelor's Degree in Nursing
- Master's Degree in Nursing
- PhD in Nursing

8. Please indicate your highest level of education achieved outside of nursing

- Not Applicable
- Diploma
- Bachelor's Degree
- Master's Degree
- PhD

9. Do you have Canadian Nurses Association certification in any nursing specialty?

- No
- Yes, if so please specify _____

10. Please indicate your gender

- Male
- Female

Study Definitions:

Advance Care Planning (ACP): Advance care planning is a process of open communication and information sharing between the health care team, the patient, and his/her family. This process of communication is meant to allow a patient's wishes for future medical care and treatments to be shared, explored and supported in a manner that facilitates informed decision making by the patient. In some instances, this process can occur with family members when a patient is not competent to make decisions for himself/herself.

Health Care Directive (HCD): Health Care Directive is a legal document that allows an individual to outline his/her wishes for or against specified medical care and medical treatments. This document is meant to serve as a record for care/clinical management in hospital, to be used if the individual becomes incapacitated and unable to speak for himself/herself. A proxy (substitute decision maker) can be named in this document. This legal document can be created or modified at a time when the individual is competent to make decisions.

Section 2: Knowledge of Advance Care Planning

Please indicate your response to the following questions

1. Advance care planning (ACP) discussions can occur without the patient filling out a Health Care Directive (HCD)

- True
- False

2. ACP discussions do NOT take into account the patient's life values and preferences

- True
- False

3. ACP discussions can only be initiated by doctors

- True
- False

4. ACP discussions can be initiated by nurses

- True
- False

5. The WRHA ACP "Goals of Care" form related to ACP decision making is always an equivalent document to a HCD

- True
- False

6. Documenting ACP discussions is NOT important

- True
- False

7. It is important to hold ACP discussions early in the course of illness, especially for those with a life-limiting disease

- True
- False

8. Communication skills are essential for ACP discussions

- True
 False

9. My place of work has a policy on ACP

- True
 False

10. The agreed upon ACP status must be documented as a physician's order

- True
 False

11. I am well equipped with the clinical knowledge I need to discuss ACP with patients

- True
 False

12. I don't really understand what ACP is

- True
 False

Section 3: Attitudes Towards Advance Care Planning

Please indicate your level of agreement to the following statements

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
I support the use of ACP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I worry I will upset the patient if I try to discuss ACP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing ACP will make patients lose hope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have the emotional strength to support the patient through ACP discussions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have the communication skills to discuss ACP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Our patients are not ready for ACP discussions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
If I discuss ACP with the patient, the family may blame me for the patient's choices	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I don't have the time to discuss ACP	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

	Strongly Agree	Agree	Undecided	Disagree	Strongly Disagree
If I talk about death, the patient may choose it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Discussing ACP or a HCD is advocating euthanasia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ACP helps in the medical care of the patient when he/she is seriously ill	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ACP can decrease the burden of decision making on family members	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
ACP allows patients to have a sense of control over their lives	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident engaging in ACP discussions with patients and families	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I consider ACP discussions as part of my nursing role	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Section 4: Experiences with Advance Care Planning

Please indicate your response to the following statements

1. Have you completed a Health Care Directive (HCD) for yourself?

- Yes
- No

2. Have any of your family members completed a HCD?

- Yes
- No

3. Have you cared for a patient with a HCD?

- Yes
- No

4. How often do you discuss ACP with your patients

- Very Often
- Often
- Occasionally
- Never

If you do discuss ACP with your patients, who usually initiates the discussions?

- Patient
- Family
- Me
- Other, please specify _____

5. My past PERSONAL experiences with death and dying influence how I engage in ACP with patients

- Yes
- No

6. My past PROFESSIONAL experiences with death and dying influence how I engage in ACP with patients

- Yes
- No

7. Family members have a positive effect on ACP

- Strongly Agree
- Agree
- Undecided
- Disagree
- Strongly Disagree

Section 4: Experience with Advance Care Planning

Please indicate your response to the following questions

8. Did you have any exposure to ACP information or training in your basic/foundational nursing education?

- Yes
- No

9. Did you have any exposure to ACP information or training at any point in your professional nursing practice?

- Yes
- No

10. Are nurses in your practice setting expected to be involved in ACP discussions?

- Yes
- No

11. Do you have resources in your practice setting to support ACP with patients and families?

- Yes
- No

If yes, what are those resources?

12. Is there anything else you would like to say about ACP?

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw please click the link below. The draw is being managed by James Plohman, Research Coordinator with the Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the draw and he will contact the two people selected. Gift cards must be picked up at the Manitoba Centre for Nursing and Health Research in the College of Nursing at the University of Manitoba (Room 212). The email addresses will not be provided to me or my advisor to preserve your privacy. Please click the link below if you would like to be entered into the draw: <http://fluidsurveys.com/s/Survey-Draw-Entry/>

Appendix B: ENREB Approval Letter



**Research Ethics
and Compliance**
Office of the Vice-President (Research and International)

Human Ethics
208-194 Dafoe Road
Winnipeg, MB
Canada R3T 2N2
Phone +204-474-7122
Fax +204-269-7173

APPROVAL CERTIFICATE

December 18, 2014

TO: **Ogechi Asagwara** (Advisor M. Edwards)
Principal Investigator

FROM: **Lorna Guse, Chair** [Redacted]
Education/Nursing Research Ethics Board (ENREB)

Re: **Protocol #E2014:137**
**"Advance Care Planning: The Knowledge, Attitudes and Experiences of
Medical/Surgical Nurses in Winnipeg, Manitoba, Canada"**

Please be advised that your above-referenced protocol has received human ethics approval by the **Education/Nursing Research Ethics Board**, which is organized and operates according to the Tri-Council Policy Statement (2). **This approval is valid for one year only.**

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please note:

- If you have funds pending human ethics approval, please mail/e-mail/fax (261-0325) a copy of this Approval (identifying the related UM Project Number) to the Research Grants Officer in ORS in order to initiate fund setup. (How to find your UM Project Number: <http://umanitoba.ca/research/ors/mrt-faq.html#pr0>)
- if you have received multi-year funding for this research, responsibility lies with you to apply for and obtain Renewal Approval at the expiry of the initial one-year approval; otherwise the account will be locked.

The Research Quality Management Office may request to review research documentation from this project to demonstrate compliance with this approved protocol and the University of Manitoba *Ethics of Research Involving Humans*.

The Research Ethics Board requests a final report for your study (available at: http://umanitoba.ca/research/orec/ethics/human_ethics_REB_forms_guidelines.html) in order to be in compliance with Tri-Council Guidelines.

Appendix C: Letter to CRNM

Kristin Mitchell
Communications Manager
College of Registered Nurses of Manitoba
890 Pembina Hwy Winnipeg, Manitoba
R3M 2M8

Winnipeg, Manitoba, R3C 1N9
Email: umasagwo@umanitoba.ca

Dear: Ms. Mitchell:

This is a letter formally requesting the assistance of the College of Registered Nurses of Manitoba (CRNM) with a survey I am carrying out. The title of my research study is “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada.” I am the principal investigator for this study and am a graduate student in the **College** of Nursing at the University of Manitoba. Dr. Marie Edwards is my academic advisor. This study is funded by the Fort Garry Legion Poppy Trust Fund Grant.

If possible, I would like CRNM’s assistance in sending out an email message inviting people to participate in this survey. The population of interest is all registered nurses on the register with CRNM who self-identify as working on a medical or surgical unit in a Winnipeg hospital. A link to the survey, hosted at the FluidSurveys website, will be included in the email message. The first page of the survey outlines the purpose of the study, what is required of participants, and how privacy and confidentiality will be protected. We also request that at one, two and three weeks following the initial email distribution that a follow up email notice with a link to the survey be sent to these nurses to attempt to increase response rates.

It is anticipated that the information obtained from this study will provide valuable insights and information that can support and strengthen institutional-based improvements to the advance care planning (ACP) process as well as bolster formal ACP education initiatives both in undergraduate nursing programs and within hospital settings. If you have any questions about this request, please feel free to contact me or my advisor (Marie.Edwards@umanitoba.ca). This research has been approved by the Education/ Nursing Research Ethics Board at the University of Manitoba (**Human Ethics Coordinator, Maggie Bowman, 204-474-7122 or Margaret.bowman@umanitoba.ca**).

Thank you for your time and consideration of this request.

Sincerely,

Ogechi Asagwara

Ogechi Asagwara RN BN, MN Student

Appendix D: Email Recruitment Message One

Below you will find an invitation to participate in a survey about Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada. We are emailing you this information because we protect your personal information and do not permit outside parties to access our member database. If you have any questions, please do not hesitate to contact me [with contact information from the CRNM employee sending out the message].

Dear Registered Nurse,

Nurses registered with the CRNM who self-identify as working on a medical or surgical unit in a Winnipeg hospital are invited to participate in this study. The College of Registered Nurses of Manitoba (CRNM) is contacting you on behalf of me (Ogechi Asagwara), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by Dr. Marie Edwards. This study's purpose is to explore registered nurses' knowledge of, attitudes toward and experiences with advance care planning. Advance care planning is defined as a process of open communication and information sharing between patients, their families and the health care team. This process of communication is meant to allow a patient's wishes for future clinical care and medical treatment options to be discussed and a level of clinical care in hospital determined (ACP R, M, C). Funding for this study was obtained from the Fort Garry Legion Poppy Trust Fund Grant.

The questionnaire takes approximately 20 minutes to complete and will ask questions about the ACP process and your understanding, opinions and experiences related to ACP. It is anticipated that the information obtained from this inquiry will provide valuable insights and information that can support and strengthen the ACP process.

Your privacy and confidentiality will be protected and you will remain anonymous. Participation in this study is voluntary.

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw you can click the link provided at the end of the questionnaire to do so. The draw is being managed by James Plohman, Research Coordinator with the Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the draw and he will contact the two people selected. The email addresses will not be provided to me or my advisor to preserve your privacy.

If you are interested in completing this questionnaire please click the link below.

(INSERT LINK TO ONLINE SURVEY)

If you have any questions about this study, please contact me or my advisor at the addresses below. This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at 204-474-7122 or Margaret.bowman@umanitoba.ca.

Sincerely,

Ogechi Asagwara

Marie Edwards, RN, PhD

umasagwo@cc.umanitoba.ca

Marie.Edwards@umanitoba.ca, 204-474-8218

Appendix E: Follow-up Recruitment Email Messages

Week One



Below you will find an invitation to participate in a survey about “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada.” We are emailing you this information because we protect your personal information and do not permit outside parties to access our member database. If you have any questions, please do not hesitate to contact me [with contact information from the CRNM employee sending out the message].

Dear Registered Nurse,

Recently you received an email inviting you to take part in a study entitled Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada. If you have already completed the survey, thank you. If you have not, and you work on a medical or surgical unit in a Winnipeg hospital, you are invited to participate in this study. The College of Registered Nurses of Manitoba (CRNM) is contacting you on behalf of me (Ogechi Asagwara), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by Dr. Marie Edwards. This study’s purpose is to explore registered nurses’ knowledge of, attitudes toward and experiences with advance care planning. Advance care planning is defined as a process of open communication and information sharing between patients, their families and the health care team. This process of communication is meant to allow a patient’s wishes for future clinical care and medical treatment options to be discussed and a level of clinical care in hospital determined (ACP R, M, C). Funding for this study was obtained from the Fort Garry Legion Poppy Trust Fund Grant.

The questionnaire takes approximately 20 minutes to complete and will ask questions about the ACP process and your understanding, opinions and experiences related to ACP. It is anticipated that the information obtained from this inquiry will provide valuable insights and information that can support and strengthen the ACP process.

Your privacy and confidentiality will be protected and you will remain anonymous. Participation in this study is voluntary.

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw you can click the link provided at the end of the questionnaire to do so. The draw is being managed by James Plohman, Research Coordinator with the

Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the draw and he will contact the two people selected, gift cards must be picked up at the MCNHR. The email addresses will not be provided to me or my advisor to preserve your privacy.

If you have already completed this questionnaire, thank you for your participation. If you have not yet completed the questionnaire and are interested in doing so please click the link below.

(INSERT LINK TO ONLINE SURVEY)

If you have any questions about this study, please contact me or my advisor at the addresses below. This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at 204-474-7122 or Margaret.bowman@umanitoba.ca.

Sincerely,

Ogechi Asagwara

umasagwo@cc.umanitoba.ca

Marie Edwards, RN, PhD

Marie.Edwards@umanitoba.ca, 204-474-8218

**Follow-up Recruitment Email Message
Week Two**



UNIVERSITY
OF MANITOBA

Below you will find an invitation to participate in a survey about “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada.” We are emailing you this information because we protect your personal information and do not permit outside parties to access our member database. If you have any questions, please do not hesitate to contact me [with contact information from the CRNM employee sending out the message].

Dear Registered Nurse,

Two weeks ago, you received an email inviting you to take part in a study entitled Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada. If you have already completed the survey, thank you. If you have not, and you work on a medical or surgical unit in a Winnipeg hospital, you are invited to participate in this study. The College of Registered Nurses of Manitoba (CRNM) is contacting you on behalf of me (Ogechi Asagwara), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by Dr. Marie Edwards. This study’s purpose is to explore registered nurses’ knowledge of, attitudes toward and experiences with advance care planning. Advance care planning is defined as a process of open communication and information sharing between patients, their families and the health care team. This process of communication is meant to allow a patient’s wishes for future clinical care and medical treatment options to be discussed and a level of clinical care in hospital determined (ACP R, M, C). Funding for this study was obtained from the Fort Garry Legion Poppy Trust Fund Grant.

The questionnaire takes approximately 20 minutes to complete and will ask questions about the ACP process and your understanding, opinions and experiences related to ACP. It is anticipated that the information obtained from this inquiry will provide valuable insights and information that can support and strengthen the ACP process.

Your privacy and confidentiality will be protected and you will remain anonymous. Participation in this study is voluntary.

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw you can click the link provided at the end of the questionnaire to do so. The draw is being managed by James Plohman, Research Coordinator with the Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the

draw and he will contact the two people selected. The email addresses will not be provided to me or my advisor to preserve your privacy.

If you have already completed this questionnaire, thank you for your participation. If you have not yet completed the questionnaire and are interested in doing so please click the link below.

(INSERT LINK TO ONLINE SURVEY)

If you have any questions about this study, please contact me or my advisor at the addresses below. This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at 204-474-7122 or Margaret.bowman@umanitoba.ca.

Sincerely,

Ogechi Asagwara

umasagwo@cc.umanitoba.ca

Marie Edwards, RN, PhD

Marie.Edwards@umanitoba.ca, 204-474-8218

Follow-up Email Message: Week Three



UNIVERSITY
OF MANITOBA

Below you will find an invitation to participate in a survey about “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada.” We are emailing you this information because we protect your personal information and do not permit outside parties to access our member database. If you have any questions, please do not hesitate to contact me [with contact information from the CRNM employee sending out the message].

Dear Registered Nurse,

Three weeks ago, you received an email inviting you to take part in a study entitled Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada. If you have already completed the survey, thank you. If you have not, and you work on a medical or surgical unit in a Winnipeg hospital, you are invited to participate in this study. The College of Registered Nurses of Manitoba (CRNM) is contacting you on behalf of me (Ogechi Asagwara), a graduate student in the Master of Nursing Program at the University of Manitoba, advised by Dr. Marie Edwards. This study’s purpose is to explore registered nurses’ knowledge of, attitudes toward and experiences with advance care planning. Advance care planning is defined as a process of open communication and information sharing between patients, their families and the health care team. This process of communication is meant to allow a patient’s wishes for future clinical care and medical treatment options to be discussed and a level of clinical care in hospital determined (ACP R, M, C). Funding for this study was obtained from the Fort Garry Legion Poppy Trust Fund Grant.

The questionnaire takes approximately 20 minutes to complete and will ask questions about the ACP process and your understanding, opinions and experiences related to ACP. It is anticipated that the information obtained from this inquiry will provide valuable insights and information that can support and strengthen the ACP process.

Your privacy and confidentiality will be protected and you will remain anonymous. Participation in this study is voluntary.

A chance to win one of two \$50 gift cards to Unimore Healthware and Homecare Products is being offered to study participants, which can be used towards the purchase of items like uniforms and stethoscopes. If you wish to enter yourself in the draw you can click the link provided at the end of the questionnaire to do so. The draw is being managed by James Plohman of the Manitoba Centre for Nursing and Health Research. Only he will see the email addresses entered into the draw and he will

contact the two people selected. The email addresses will not be provided to me or my advisor to preserve your privacy.

If you have already completed this questionnaire, thank you for your participation. If you have not yet completed the questionnaire and are interested in doing so please click the link below.

(INSERT LINK TO ONLINE SURVEY)

The survey will close on X date (28 days after start of data collection).

If you have any questions about this study, please contact me or my advisor at the addresses below. This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns or complaints about this project you may contact any of the below-named persons or the Human Ethics Coordinator (HEC) at 204-474-7122 or Margaret.bowman@umanitoba.ca.

Sincerely,

Ogechi Asagwara

umasagwo@cc.umanitoba.ca

Marie Edwards, RN, PhD

Marie.Edwards@umanitoba.ca, 204-474-8218

Appendix F: Pledge of Confidentiality

Note: This form is adapted from one created by Dr. Roberta Woodgate (with permission).



College of Nursing
Helen Glass Centre for Nursing
Winnipeg, Manitoba
Canada R3T 2N2
Telephone: (204) 474-7452
Fax: (204) 474-7682

PLEDGE OF CONFIDENTIALITY

This form is intended to further ensure that the confidentiality of information and data associated with this study is upheld. You are asked to read the following statement and sign your name indicating that you agree to honour this pledge of confidentiality.

I hereby agree and pledge to keep confidential any information that I am privy to through the draw for gift certificates that pertains to the study “Advance Care Planning: The Knowledge, Attitudes and Experiences of Medical/Surgical Nurses in Winnipeg, Manitoba Canada”, carried out by graduate student Ogechi Asagwara (supervised by Marie Edwards).

This research has been approved by the Education/Nursing Research Ethics Board at the University of Manitoba. If you have any concerns about this project you may contact the Human Ethics Coordinator (HEC) at 204-474-7122 or Margaret.bowman@umanitoba.ca.

NAME:

SIGNATURE:

WITNESS:

DATE:

Appendix G: Correlations

		I support the use of ACP	I worry I will upset the patient if I try to discuss ACP	Discussing ACP will make patients lose hope	I don't have the emotional strength to support the patient through ACP discussions	I don't have the communication skills to discuss ACP	Our patients are not ready for ACP discussions	If I discuss ACP with the patient, the family may blame me for the patient's choices	I don't have the time to discuss ACP
I support the use of ACP	Pearson Correlation	1	-.173*	-.157*	-.189**	-.157*	-.262**	-.096	-.084
	Sig.(2-tailed)		.012	.022	.006	.022	.000	.166	.225
	N	213	211	211	211	213	213	211	210
I worry I will upset the patient if I try to discuss ACP	Pearson Correlation	-.173*	1	.417**	.464**	.407**	.235**	.208**	.249**
	Sig.(2-tailed)	.012		.000	.000	.000	.001	.003	.000
	N	211	211	210	210	211	211	209	208
Discussing ACP will make patients lose hope	Pearson Correlation	-.157*	.417*	1	.407**	.379**	.230**	.324**	.247**
	Sig.(2-tailed)	.022	.000		.000	.000	.001	.000	.000
	N	211	210	211	209	211	211	210	208
I don't have the emotional strength to support the patient through ACP discussions	Pearson Correlation	-.189**	.464**	.407**	1	.641**	.290**	.240**	.358**
	Sig.(2-tailed)	.006	.000	.000		.000	.000	.000	.000
	N	211	210	209	211	211	211	209	208
I don't have the communication skills to discuss ACP	Pearson Correlation	-.157*	.407**	.379**	.641**	1	.234**	.269**	.380**
	Sig.(2-tailed)	.022	.000	.000	.000		.001	.000	.000
	N	213	211	211	211	213	213	211	210
Our patients are not ready for ACP discussions	Pearson Correlation	-.262**	.235**	.230**	.290**	.234**	1	.295**	.126
	Sig.(2-tailed)	.000	.001	.001	.000	.001		.000	.069
	N	213	211	211	211	213	213	211	210
If I discuss ACP with the patient, the family may blame me for the patient's choices	Pearson Correlation	-.096	.208**	.324**	.240**	.269**	.295**	1	.376**
	Sig.(2-tailed)	.166	.003	.000	.000	.000	.000		.000
	N	211	209	210	209	211	211	211	208
I don't have the time to discuss ACP	Pearson Correlation	-.084	.249**	.247**	.358**	.380**	.126	.376**	1
	Sig.(2-tailed)	.225	.000	.000	.000	.000	.069	.000	
	N	210	208	208	208	210	210	208	210
If I talk about death, the patient may choose it	Pearson Correlation	-.089	.142*	.053	.192**	.168*	.255**	.249**	.140*
	Sig.(2-tailed)	.199	.041	.446	.005	.015	.000	.000	.044
	N	211	209	209	209	211	211	209	208

		If I talk about death the patient may choose it	Discussing ACP or a HCD is advocating euthanasia	ACP helps in the medical care of the patient when he/she is seriously ill	ACP can decrease the burden of decision making on family members	ACP allows patients to have a sense of control over their lives	Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	I feel confident engaging in ACP discussions with patients and families	I consider ACP discussions as part of my nursing role
I support the use of ACP	Pearson Correlation	-.089	-.194**	.130	.166*	.256**	-.244**	.289**	.124	.123
	Sig.(2-tailed)	.199	.005	.060	.016	.000	.000	.000	.073	.073
	N	211	210	210	211	210	212	211	211	212
I worry I will upset the patient if I try to discuss ACP	Pearson Correlation	.142*	.162*	.045	.084	.089	.039	-.037	-.307**	-.157*
	Sig.(2-tailed)	.041	.019	.515	.223	.200	.578	.598	.000	.022
	N	209	209	209	210	209	211	210	210	211
Discussing ACP will make patients lose hope	Pearson Correlation	.053	.292**	.014	.005	-.053	.165*	-.066	-.191**	-.108
	Sig.(2-tailed)	.446	.000	.841	.942	.450	.016	.339	.006	.119
	N	209	209	209	210	209	211	210	210	211
I don't have the emotional strength to support the patient through ACP discussions	Pearson Correlation	.192**	.319**	-.091	.037	-.056	.242**	-.111	-.519**	-.280**
	Sig.(2-tailed)	.005	.000	.192	.590	.421	.000	.111	.000	.000
	N	209	208	208	209	208	210	209	209	210
I don't have the communication skills to discuss ACP	Pearson Correlation	.168*	.261**	-.044	.032	-.096	.158*	-.090	-.551**	-.221**
	Sig.(2-tailed)	.015	.000	.527	.643	.166	.022	.194	.000	.001
	N	211	210	210	211	210	212	211	211	212
Our patients are not ready for ACP discussions	Pearson Correlation	.255**	.337**	-.201**	-.058	-.063	.180**	-.073	-.088	-.160*
	Sig.(2-tailed)	.000	.000	.003	.403	.367	.009	.289	.205	.020
	N	211	210	210	211	210	212	211	211	212
If I discuss ACP with the patient, the family may blame me for the patient's choices	Pearson Correlation	.249**	.170*	-.068	-.072	-.039	.109	-.026	-.123	-.079
	Sig.(2-tailed)	.000	.014	.327	.300	.574	.117	.709	.077	.252
	N	209	208	208	209	208	210	209	209	210
I don't have the time to discuss ACP	Pearson Correlation	.140*	.042	-.064	.102	.072	.077	-.089	-.319**	-.351**
	Sig.(2-tailed)	.044	.548	.357	.143	.304	.269	.202	.000	.000
	N	208	207	207	208	207	209	208	208	209
If I talk about death, the patient may choose it	Pearson Correlation	.1	.275**	-.084	-.070	-.074	.204**	-.051	-.147*	-.045
	Sig.(2-tailed)		.000	.226	.312	.291	.003	.462	.033	.520
	N	211	208	208	209	208	210	209	210	210

		I support the use of ACP	I worry I will upset the patient if I try to discuss ACP	Discussing ACP will make patients lose hope	I don't have the emotional strength to support the patient through ACP discussions	I don't have the communication skills to discuss ACP	Our patients are not ready for ACP discussions	If I discuss ACP with the patient, the family may blame me for the patient's choices	I don't have time to discuss ACP	If I talk about death, the patient may choose it
Discussing ACP or a HCD is advocating euthanasia	Pearson Correlation	-.194**	.162*	.292**	.319**	.261**	.337**	.170*	.042	.275**
	Sig.(2-tailed)	.005	.019	.000	.000	.000	.000	.014	.548	.000
	N	210	209	209	208	210	210	208	207	208
ACP helps in the medial care of the patient when he/she is seriously ill	Pearson Correlation	.130	.045	.014	-.091	-.044	-.201**	-.068	-.064	-.084
	Sig.(2-tailed)	.060	.515	.841	.192	.527	.003	.327	.357	.226
	N	210	209	209	208	210	210	208	207	208
ACP can decrease the burden of decision making on family members	Pearson Correlation	.166*	.084	.005	.037	.032	-.058	-.072	.102	-.070
	Sig.(2-tailed)	.016	.223	.942	.590	.643	.403	.300	.143	.312
	N	211	210	210	209	211	211	209	208	209
ACP allows patients to have a sense of control over their lives	Pearson Correlation	.256**	.089	-.053	-.056	-.096	-.063	-.039	.072	-.074
	Sig.(2-tailed)	.000	.200	.450	.421	.166	.367	.574	.304	.291
	N	210	209	209	208	210	210	208	207	208
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	Pearson Correlation	-.244**	.039	.165*	.242**	.158*	.180**	.109	.077	.204**
	Sig.(2-tailed)	.000	.578	.016	.000	.022	.009	.117	.269	.003
	N	212	211	211	210	212	212	210	209	210
It is important for patients to be able to have a choice in their future medical treatment should they lose the ability to make decisions	Pearson Correlation	.289**	-.037	-.066	-.111	-.090	-.073	-.026	-.089	-.051
	Sig.(2-tailed)	.000	.598	.339	.111	.194	.289	.709	.202	.462
	N	211	210	210	209	211	211	209	208	209
I feel confident ACP discussions with patients and families	Pearson Correlation	.124	-.307**	-.191**	-.519**	-.551**	-.088	-.123	-.319**	-.147*
	Sig.(2-tailed)	.073	.000	.006	.000	.000	.205	.077	.000	.033
	N	211	210	210	209	211	211	209	208	210
I consider ACP discussions as part of my nursing role	Pearson Correlation	.123	-.157*	-.108	-.280**	-.221**	-.160*	-.079	-.351**	-.045
	Sig.(2-tailed)	.073	.022	.119	.000	.001	.020	.252	.000	.520
	N	212	211	211	210	212	212	210	209	210

		Discussing ACP or a HCD is advocating euthanasia	ACP helps in the medical care of the patient when he/she is seriously ill	ACP can decrease the burden of decision making on family members	ACP allows patients to have a sense of control over their lives	Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	It is important for patients to be able to have a voice in their future medical treatment should they lose the ability to make decisions	I feel confident engaging in ACP discussions with patients and families	I consider ACP discussions as part of my nursing role
Discussing ACP or a HCD is advocating euthanasia	Pearson Correlation	1	-.084	-.063	-.136	.412**	-.084	-.056	-.002
	Sig.(2-tailed)		.226	.362	.051	.000	.224	.421	.973
	N	210	208	210	208	210	209	209	210
ACP helps in the medical care of the patient when he/she is seriously ill	Pearson Correlation	-.084	1	.397**	.326**	-.175*	.297**	.085	.197**
	Sig.(2-tailed)	.226		.000	.000	.011	.000	.223	.004
	N	208	210	209	208	210	209	209	210
ACP can decrease the burden of decision making on family members	Pearson Correlation	-.063	.397**	1	.559**	-.080	.202**	.080	.239**
	Sig.(2-tailed)	.362	.000		.000	.245	.003	.247	.000
	N	210	209	211	209	211	210	210	211
ACP allows patients to have a sense of control over their lives	Pearson Correlation	-.136	.326**	.559**	1	-.220**	.278**	.067	.229**
	Sig.(2-tailed)	.051	.000	.000		.001	.000	.334	.001
	N	208	208	209	210	210	209	209	210
Prolonging life is more important than honoring a patient's request to refuse life-sustaining treatment	Pearson Correlation	.412**	-.175*	-.080	-.220**	1	-.209**	-.055	-.061
	Sig.(2-tailed)	.000	.011	.245	.001		.002	.423	.377
	N	210	210	211	210	212	211	211	212
It is important for patients to be able to have a choice in their future medical treatment should they lose the ability to make decisions	Pearson Correlation	-.084	.297**	.202**	.278**	-.209**	1	.176*	.215**
	Sig.(2-tailed)	.224	.000	.003	.000	.002		.011	.002
	N	209	209	210	209	211	211	210	211
I feel confident ACP discussions with patients and families	Pearson Correlation	-.002	.085	.080	.067	-.055	.176*	1	.487**
	Sig.(2-tailed)	.973	.223	.247	.334	.423	.011		.000
	N	210	209	210	209	211	210	211	211
I consider ACP discussions as part of my nursing role	Pearson Correlation	-.002	.197**	.239**	.229**	-.061	.215**	.487**	1
	Sig.(2-tailed)	.973	.004	.000	.001	.377	.002	.000	
	N	210	210	211	210	212	211	211	212

* Correlation is significant at the 0.05, **Correlation is significant at the 0.01