

ADVANCE CARE PLANNING CONVERSATIONS:  
THE FAMILY PERSPECTIVE

by

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## Abstract

The course of endstage renal disease (ESRD) and receiving hemodialysis (HD) treatment is complex and filled with uncertainty. Part of this illness experience includes making end-of-life (EOL) care decisions. Many families are unprepared to make such decisions. Advance care planning (ACP) creates an excellent context for laying the groundwork for these emotionally charged conversations. Hemodialysis patients, their families and healthcare providers (HCPs) are in a unique position to begin the ACP process early in the illness trajectory, revisiting it when the patient's health status, prognosis and treatment modality changes.

To date, little research has focused directly on how families experience ACP conversations in the context of ESRD or HD. The purpose of this study was to explore family members' experiences of participating in a facilitated ACP conversation with the HD patient. This approach recognizes and privileges the family's role in the illness trajectory of ESRD and validates that they too are HCPs' clients.

Five families, consisting of the HD patient and one family member, who went through the ACP process were interviewed along with an ACP facilitator from the nephrology program. This focused ethnographic study applied the theoretical perspective of postmodernist critical theory to derive and analyze data from in-depth semi-structured interviews. Findings revealed a detailed description of the ACP process that included timing, readiness to acknowledge the potentiality of death, facing mortality, and finding meaning in the illness experience. As families started to deconstruct their experiences, they shared stories of communication breakdown, highlighting the complexities of their relationships with HCPs. Understanding the factors that potentially contribute to HD patients', their families' and the renal staff's discomfort with death were analyzed.

The study findings provide important direction for HCPs about how families make ACP decisions, how they perceive the ACP process, and what they identify as their EOL care needs and wishes. Failure to implement ACP as part of an EOL care program means that death will continue to be denied and clients' EOL care needs will remain un-addressed. In order for ACP to be effective on HD units, sustainable resources are essential for patients, their families and HCPs.

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## CHAPTER ONE

### Background to the Problem

Families<sup>1</sup> are an integral part of patient<sup>2</sup> care. As informal caregiver(s)<sup>3</sup>, family member(s) have numerous responsibilities both within the household and in the healthcare system when caring for their loved one. Bearing these responsibilities means families are significantly affected by the illness trajectory. The trajectory of a chronic illness represents the long process of disability and decline prior to death, resulting in difficulty for all parties involved to recognize when the patient is actually dying (Weissman, 2004). Its course is unique for every individual, leading not only the patient but also the family down an uncertain path filled with complex decision-making opportunities. “Each individual experiences his or her disease in a unique manner, reacts to interventions in a distinct way, and confronts disease-related stressors that are specific and particular to his or her life context” (Thorne, 2005, p.7S). How the family experiences the impact of the illness determines how effectively they will manage it (Knafl & Gilliss, 2002; Öhman & Söderberg, 2004; Strauss, Corbin, Fagerhaugh, Glaser, Maines, Suczek, & Wiener, 1984; White, Richter, Koeckeritz, Munch & Walter, 2004). The burden of care for families continues until the patient recovers from the illness. However, if that illness is chronic then no end is in sight.

The “revolving door syndrome” is used to describe the continuous circling of patients with a chronic illness through the hospital. They experience frequent acute illnesses in addition to an underlying chronic disease, or they experience an exacerbation of their chronic illness (Winzelberg, Patrick, Rhodes, & Deyo, 2005, p. 293). This cycle causes many families

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<sup>1</sup> For the purposes of this research study, family is defined as *who they say they are* and the patient is included in all references to family unless otherwise indicated.

<sup>2</sup> The word “patient” was chosen over the word “client” to represent the individual receiving care from either the family or healthcare providers.

<sup>3</sup> An informal caregiver is a family member; partner; friend; or neighbour who provides care for a critically ill loved one without pay. It may be provided at home or in another care setting where the critically ill person is receiving care. Informal caregivers are sometimes described as “loved ones” and/or are sometimes called *family caregivers* with the understanding that “family” can include anyone that the ill person or relatives consider to be close (Dunbrack, 2005).

emotional distress, never knowing when the end has arrived; they may experience a renewed hope as every hospital discharge marks (brief) health improvements.

One chronic illness exemplifying the “revolving door syndrome” is chronic kidney disease. Over time, it follows a downward trajectory resulting in endstage renal disease<sup>4</sup> (ESRD). The responsibilities of care increase with each reduction in kidney function, worsening co-morbidities and age. Dialysis<sup>5</sup> and kidney transplant<sup>6</sup> complications, and the problems caused by other co-morbidities require frequent hospitalizations over the course of the illness trajectory. Consequently, there is little respite for the family caregiver(s). The family’s life transforms with each change in life-sustaining treatment choices of dialysis and kidney transplant(s). Endstage renal disease patients and their families know that interruptions to treatments or the complexity of certain complications will be fatal (Swartz & Perry, 1999). Death is a constant companion lurking in the shadows of their subconscious (Calvin, 2004).

### The Healthcare Provider-Client Relationship

Families are dependent on healthcare providers (HCP) for support, assistance and direction throughout the trajectory of ESRD (Loftin & Beumer, 1998). They too have needs and concerns requiring HCPs’ attention. In fact, hemodialysis (HD) is said to be a “family focused journey” (White, Richter, Koeckeritz, Munch & Walter, 2004, p. 373). Therefore, families living

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<sup>4</sup> ESRD represents stage v of chronic kidney disease, when remaining kidney function is less than 15% (glomerular filtration rate < 15 cc/minute). If a life sustaining treatment (such as dialysis or transplant) is not sought soon the resulting body system complications caused by a build up of toxins, and fluid and electrolyte imbalances will eventually cause death (Candela & Parker, 2006; National Kidney Foundation, 2000b).

<sup>5</sup> There are two types of dialysis treatments: peritoneal dialysis and hemodialysis. This study focuses on hemodialysis treatments only. Hemodialysis is a process of cleaning ones blood of toxins and impurities, and rebalancing some electrolytes and fluid using a special machine. The standard routine is a 4-hour treatment 3 times weekly for the remainder of a person’s life. Typically, treatments take place in an outpatient clinic requiring healthcare professionals from a variety of disciplines to oversee various aspects of the treatment (Kidney Foundation of Canada, 2006; Thomas, 2002).

<sup>6</sup> Kidney transplant refers to a patient receiving a kidney from another person (the donor). The transplanted kidney replaces the work of the patient’s non-or minimally functioning native kidneys. The person must take anti-rejection drugs and other medications for the duration of the transplant. Its longevity spans from 0 to 20 plus years. This treatment is not a cure (Kidney Foundation of Canada, 2006; Thomas, 2002).

with ESRD essentially become clients<sup>7</sup> of HCPs as well. Furthermore, HCPs more fully understand family interrelationships and “family member functioning” (p. 35) when they see the family as a whole and observe their interactions both as a unit and individually (Wright & Leahey, 2005). Exploring and understanding the family’s perspective provides an additional opportunity to learn about the situatedness of the family within the illness experience and particularly within end-of-life<sup>8</sup> (EOL) care. Given that the meaning of death and dying is “rooted in a historical-social-spiritual context” (Burgess, Stephenson, Ratanakul & Suwonnakote, 1999, p. 204) everyone involved will need to recognize how their diverse cultural, ethnic, and religious backgrounds influence meaning and decision-making.

A key factor within this evolving HCP-client relationship is communication. The literature reveals a great deal about communication between families and HCPs, identifying its chequered history, persistent pitfalls and the need for improvement (Chambers-Evans, 2002; Dunbrack, 2005; Haley, Allen, Reynolds, Chen, Burton & Gallagher-Thompson, 2002; Levine & Zuckerman, 1999 & 2000; Thorne, 1993; Thorne, Nyhlin & Paterson, 2000). As the patient’s health deteriorates the need for an increased frequency in communication between family and HCPs occurs. Part of watching a loved one experience a downward trajectory of the illness is wondering not just when and how the patient will die but what kinds of EOL care decisions will have to be made along the way (Germino, 1998).

Many families are unprepared to make such decisions, especially when they have not spoken directly with the patient about EOL care wishes, values, and beliefs. If open dialogue does not exist with the patient and/or amongst family members, then the caregiver(s) bear this burden alone (Fried, Bradley, O’Leary & Byers, 2005). Conversely, it may be the patient who is open to communication about EOL issues but the family is closed. Members of the family and/or

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<sup>7</sup> The word “client” represents the family who also receives care from healthcare providers. The patient is often not included in this reference within the text.

<sup>8</sup> The term “end-of-life” (EOL) in this study and thesis is used in broad context. It is meant to include all decision-making in the last days, months, or even years of an individual’s life (Hammes & Briggs, 2004).

the patient may turn more frequently to HCPs for answers, direction and support. Unfortunately, all too often they encounter another closed door (Dunbrack, 2005; Levine & Zuckerman, 2000).

Healthcare providers often avoid talking about death for numerous reasons, including their personal discomfort with the topic and feeling unprepared to address it in their professional practice (Callahan 1995; Swartz & Perry, 1999). This situation is complicated by a lack of (consistent) program resources (such as receiving both funding and time to support EOL care training and education), along with a lack of available staff and patient teaching tools (Price, 2003; Popple, Cohen & Germain, 2003). The cumulative impact of these challenges that families experience imposes a position of silent bystander, wherein they often feel powerless and helpless in their caregiver role from both an unpredictable disease and an overburdened healthcare system. Additionally, each unresolved problem within the family potentially increases their physical and emotional distance from each other compounding their isolation (Robinson & Wright, 1995). One strategy called advance care planning (ACP) is purported to create a safe and supportive context for the patient, family and HCPs to begin engaging in EOL care conversations. However, as I will elaborate on below, the term ACP carries several meanings within the literature.

### What is Advance Care Planning?

The definition of ACP that I applied to this study is derived from the health region in which this study was conducted. The objectives of this health region's ACP program are based on Gundersen Lutheran Medical Foundation's *Respecting Choices* program® (2007) that has been implemented in numerous states across America, in parts of Australia (Silvester & Stickland, 2007) and more recently in the province of Alberta (Calgary Health Region, 2007). The program objectives resemble those from other ACP programs (Norlander & McSteen's, 2000) and are reflective of Kolarik, Arnold, Fischer and Tulsy's (2002) suggested ACP objectives.

Advance care planning is a comprehensive process of planning ahead for health care decisions that may have to be made by an appointed representative<sup>9</sup> or a (temporary) substitute decision maker<sup>10</sup> in the event of incapability of the individual ([Health Region A], 2007)<sup>11</sup>. It is a process rather than a final outcome that honours patients' values, beliefs and wishes. Patients and their family member(s) can address their mortality, find meaning in the illness experience, and start discussions about what to do when the patient's health deteriorates (Kolarik, Arnold, Fischer & Tulsy 2002; Larson & Tobin, 2000; Martin, Thiel, & Singer, 1999; Singer, Martin, Lavery, Thiel, Kelner, & Mendelsohn, 1998). Furthermore, ACP engages HCPs to participate in this dialogue, potentially strengthening their collective relationship(s). Quite often, as additional resources, many ACP programs provide trained facilitators<sup>12</sup> whose role it is to support and encourage open dialogue between all parties involved.

The advance care planning facilitator (ACPF) acts as a tool to address EOL care concerns from each involved person's perspective (Hammes & Briggs, 2004). In addition, ACP programs may also use an ACP workbook (non-legal document) or Advance Directive (legal document) as another tool and resource to guide ACP conversations. It is important to note that many terms are used across North America to describe the role of the patient appointed representative, such as healthcare proxy, substitute decision-maker and surrogate decision-maker. Throughout the literature review, I have kept the term used by the authors and in all other chapter discussions; the term substitute decision-maker (SDM) is used because most of the study participants had not

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<sup>9</sup> A Representative is chosen and appointed by a capable adult through a Representation Agreement. This person must also: be an adult, be capable, have been in touch with the incapable adult in the past year, have no known dispute with the adult, and be willing to abide by the duties of a temporary substitute decision maker ([Health Region A], 2007).

<sup>10</sup> Temporary Substitute Decision Maker (TSDM) is appointed by a health care provider after an adult has lost capability and a health care decision needs to be made; chosen from the following in order: spouse, either by marriage or common law relationship (even very short term) and including same sex relationships, adult child (children equally ranked) parent (parents equally ranked) brother or sister (siblings equally ranked) any other relative by birth or adoption ([Health Region A], 2007).

<sup>11</sup> I have removed the name of the health authority for reasons of confidentiality, inserting [Health Region A] into all citations and references made of this health region.

<sup>12</sup> Facilitator is defined as a person who, as part of a group, encourages discussion and other activity without directing it or controlling it actively (Barber, 2004, p. 531).

initiated the legal process for appointing a representative. In addition, depending on the province or state an Advance Directive<sup>13</sup> (AD) may refer to the legal document alone or incorporate the discussion(s) with the healthcare proxy. For the purposes of this study, advance directive refers to the legal document only, and I have made attempts to ensure this consistency throughout the literature review.

The literature documents the evolution of ACP, identifying its many challenges. The largest study to look at aspects of ACP, particularly the completion of an AD document, was called the *Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments* (SUPPORT) (SUPPORT Principal Investigators, 1995). It examined how people died in hospitals, exposing the extent to which aggressive life-prolonging measures were still being used in often medically futile situations and/or when unwanted by patients. The study enrolled approximately 9,000 seriously ill patients in five hospitals from 1989 to 1994 and occurred in two phases. It involved sampling patients, their surrogates, physicians and nurses in order to understand patient preferences, decision-making processes, and how these were communicated. The study findings showed that physicians were not aware of patients' treatment preferences, wishes were not honoured, and breakdowns in communication between patients, their families and physicians frequently occurred (Kennard, Speroff, Puopolo, Follen, Mallatratt, Phillips, Desbiens, Califf & Connors, 1996; Schroeder, 1999).

The outcomes of the SUPPORT study, though distressing, provided clear evidence of the need for improved communication. The study results marked the start of national and international initiatives aimed at improving the quality of care at the EOL. As part of this process, the concept of ACP emerged, which is considered by many to be a more comprehensive approach compared to focusing on the completion of AD alone. However, ACP is not without its

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<sup>13</sup> Advance Directive for health or personal care consists of instructions given by a capable person, often in written form, about their wishes for health care treatment and/or personal care in the event that they become incapable of giving informed consent. The advance directive may appoint a proxy who will assume responsibility for ensuring that the person's wishes are respected (Dunbrack, 2006, p. 25).

faults and challenges. Numerous studies report both positive and negative outcomes, strengths and weaknesses, as well as arguments for the use of ACP (Davison & Simpson, 2006; Kolarik, Arnold, Fischer, & Tulsy, 2002); all of which will be discussed in detail within the literature review in chapter 2. In general, the literature provides increasing evidence demonstrating ACP's effectiveness as an excellent tool for facilitating communication between the patient, family and HCPs. Implementing ACP as a standard of practice within nephrology is challenging given the multiple barriers identified in the literature. However, ACP is forging a pathway to find a place within hemodialysis units.

### The Complexities of Hemodialysis

Life on HD is challenging (Faber, 2000), and lengthening a person's lifespan does not necessarily equate with an improved quality of life (Rabetoy & Cohen, 2003). In fact, for some individuals it may increase the length of illness and dependency (Soltys, Brookins & Seney, 1998). A person can survive on HD from a month to several decades depending on the acuity and extent of their co-morbidities. However, for many patients, particularly the elderly, it becomes their last or only treatment option for a number of reasons, many of which contribute to their increased risk of death. It is not uncommon for some dialysis units, particularly those located within an acute care setting, to have upwards of 15 deaths monthly. For example, in a health region I am familiar with, one HD staff person stated that there were 12 patient deaths on the unit within 3 weeks (ACPF, personal communication, June 27, 2007).

The complexity of HD care and frequency of treatments spanning over time allow relationships among patients, between families and with HCPs to develop. Often these relationships become more like friendships and it is not uncommon to hear the HD unit being referred to as a "family" (Swartz & Perry, 1999). Consequently, experiencing the death of an HD patient can be more difficult than in other acute settings. Given the frequency of death and the often well-established relationships on the unit, patients, their families and HCPs are in a unique

position to engage in ACP conversations. However, exploring emotions, particularly those surrounding death, challenges everyone's spirituality, cultural, and personal beliefs, values and wishes. Therefore, ACP creates an excellent context for laying the groundwork for these emotionally charged conversations. Unfortunately, the multiple barriers surrounding talking about death within the context of chronic illness (Callahan, 1995; Hickman, 2002; Jezewski & Meeker, 2005) also plague many HD units.

### Problem Statement

Hemodialysis patients, their families and HCPs are in a unique position to begin the ACP process early in their illness trajectory, revisiting it when the patient's health status, prognosis and treatment modality changes. Such an approach enables everyone to understand how the family situates and contextualizes the illness experience thus creating an opportunity for a smooth transition into planning for EOL care.

Failure to implement ACP as part of an EOL care program, particularly within hemodialysis, means that death will continue to be denied and/or ignored, clients' EOL care needs will remain un-addressed, and communication breakdown will persist, further damaging relationships with clients. Families will continue to feel isolated in their caregiver role(s) and will remain confined to the position of silent bystander. Additionally, HCPs not only harm their clients but also themselves when their denial negatively impacts their moral voices, challenges the ethics of practice and contributes to burnout (Redman, Hill & Fry, 1997; Sherman, 2004). In order for ACP to thrive on hemodialysis units, sustainable support resources are essential for not only the patient and family but also HCPs. Yet to date, little research has focused directly on how families experience ACP conversations within the context of chronic illness let alone within ESRD or HD.

### Purpose of the Study

The purpose of this study is to explore, from family members' perspectives, the experience of participating in a facilitated ACP conversation with a loved one: the hemodialysis patient. This research approach recognizes the family's inherent role in the illness trajectory of ESRD and validates that they too are clients within the HD setting. Implications resulting from this research study will inform HCPs, such as myself, about how families make decisions about ACP within their individual and familial context, how they perceive the ACP process, and what they identify as their needs and wishes in planning for their loved one's eventual death.

### Research Question

The research question that I explored is: How do families of hemodialysis patients experience advance care planning conversations?

### Significance of the Study

Understanding families' ACP experiences informs HCPs of the resources necessary to support them through the ACP process. This study provides an opportunity for the potential accumulation of evidence contributing to the utility of ACP as a component of nephrology programs, particularly hemodialysis units, in providing optimal quality care. Despite the sizeable attention ACP has received, Kolarik, Arnold, Fischer and Tulsy, (2002) argue that consensus on the goals and objectives of an ACP program have not yet been reached. Therefore, study findings may highlight both effective and ineffective components of an ACP program. Lastly, this study will make a contribution to ACP, nephrology nursing and family nursing research. However, it is recognized that the study findings, due to challenges encountered in recruitment, time and limited resources provide a narrow scope for interpretation and application for change in practice. These issues are addressed within the methods in chapter 3. The small sample of participants is not necessarily representative of other individuals who to date have participated in

the hemodialysis unit's ACP conversations. Therefore, the interpretation of findings is situated within the limitations of this thesis project.

### Assumptions

The following assumptions underlie this study and were derived from my experience as a nephrology nurse and as a novice researcher. These assumptions shaped my thinking about certain aspects of families, communication and ACP within the hemodialysis setting. The relevant assumptions that I held during the study were as follows:

1. The definition of family applied in this study was: *family is who the patient says it is*. This definition was most relevant during the recruitment phase when interested individuals read the recruitment poster and study information letter. They must have understood this definition in order to determine their eligibility.
2. I assumed that given the chance, patients who have thought about stopping hemodialysis treatment wanted to talk about EOL care issues with either particular family member(s) and/or dialysis personnel. I believed that these individuals would be the ones most receptive to participating in ACP conversations.
3. The family members who were involved in the facilitated ACP conversations with the patient would want to reflect on this experience and share their perspectives with the researcher. It was these individuals that I assumed would most likely make up my study population.
4. I assumed that all staff on this HD unit was actively involved in the initial ACP project and since its inception; they have learnt how to integrate it into their practice. Consequently, they understand what ACP is about and its context within the greater picture of HD and ESRD. Therefore, study recruitment from this unit should be straightforward given that ACP was well established and everyone was aware of its existence.

5. It should not be difficult to determine the number of eligible study participants because I assume that the number of previously completed, current and remaining HD patients and (possibly) family ACP conversations have been routinely logged on this unit.
6. The concept of the HD unit being a “family” invokes an image of a supportive community. Given this impression of togetherness, I assumed that patients and their families shared their ACP experiences with each other. In addition, I was told that there is a strong positive patient response towards ACP on this HD unit. Therefore, these combined factors should contribute to a good study enrolment whereby patients are encouraging each other to become involved.

### Chapter Summary

Advance care planning is a comprehensive approach to addressing EOL care issues that promotes effective communication among patients, their families and HCPs. Endstage renal disease has a complex illness trajectory impacting significantly on the whole family. Family member(s) are commonly the primary informal caregiver who often bears a burden of silent bystander. They contend with an unpredictable disease, manage complex treatments, and navigate an overburdened healthcare system with generally, inconsistent support from HCPs. Patients receiving HD treatment need collaborative approaches to care and their families require dependable support, as they too are clients. Advance care planning is well situated within this illness experience, offering a set of tools and resources that will contribute to a successful partnership. Yet to date, little research has focused directly on how families experience ACP conversations within the context of chronic illness let alone within ESRD or HD.

In chapter 2, the literature review will highlight both research and literature on ACP as a component of EOL care within the context of ESRD. The family’s role in this illness experience is discussed at length, addressing the issues in becoming a SDM and how communication breakdown with HCPs potentially impacts the effectiveness of this role.

## **CHAPTER TWO**

### **Literature Review**

The purpose of this literature review is to evaluate current research findings on ACP research and the family's role within this process in order to provide a foundation on which to base my research study. In keeping with the methodology of ethnographic research, the literature review examines the current social and political context of EOL care in Canada and in nephrology. The notions of death, culture in its broadest sense and AD are examined, documenting their powerful influence on the quality of the HCP-client relationship. Decision-making and communication are key components of both the patient-family and HCP-client relationships that are essential to an effective ACP process.

#### End-Of-Life Care in Canada

The current social and political context of EOL care in Canada is at the forefront of the Canadian healthcare system. Dying from long-term chronic disease(s) has reached epidemic proportions and is expected to continue rising. Quality end-of-life care is the right of every Canadian. "How we die is important and worthy of our attention, because it is sometimes in our power to help people to die well" (Rabetoy & Cohen, 2003, p. 87). For every death an estimated five other people are affected and family members constitute at least one of these five other people (Subcommittee to update "Of Life and Death" of the Standing Senate Committee on Social Affairs, Science and Technology, 2000). In order to understand the individual's experience of death and dying, it is necessary to also understand him/her within the context of the family. "Any significant event or change in the family affects all members to varying degrees...[thus even a small change] can lead to a variety of reactions, with some family members changing more dramatically or quickly than others" (Wright & Leahey, 2005, p. 35). Therefore acknowledging the family as a whole, taking the time to understand member

interrelationships, what meaning they attribute to the illness experience, and learning their perceptions of EOL issues will assist HCPs in providing comprehensive client care.

Statistics show that over 220,000 Canadians die each year and 75% of these deaths occur in people over 65 years of age (Subcommittee, 2000). The emphasis of palliative<sup>14</sup> care resources within the country has focused on cancer patients. About one quarter of the total deaths in Canada are related to cancer, and patients with cancer account for more than 90% of those receiving palliative care (Subcommittee, 2000). However, more people are dying from multiple serious chronic diseases as opposed to acute illnesses. The World Health Organization (2006) reported that chronic diseases and living with multiple co-morbidities is reaching worldwide epidemic proportions. Approximately 35 out of the 58 million global deaths were due to chronic disease in 2005. In Canada alone, an estimated 89% of deaths in the same year were chronic disease related.

The World Health Organization (WHO) projects that over the next 10 years this percentage will increase by 15% (WHO, press release, 2006). Overall, as people live longer, the incidence of living with one or more chronic diseases increases due to advances in science and technology. These circumstances amplify the need for progressive approaches to addressing longer illness trajectories that involve a slower cognitive and/or physical decline towards death. Thus, the demand for more effective and compassionate care during the last years of life and not simply during the last few months or days of life is a necessity (Subcommittee, 2000). However, approaches to effectively addressing EOL issues are often fragmented, lacking a consistent treatment framework and receiving insufficient funding to support the growing demand for palliative care resources across Canada.

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<sup>14</sup> Palliative care is care aimed at relief of suffering and improving the quality of life for persons who are living with or dying from advanced illness or who are bereaved (Dunbrack, 2006, p. 29).

In the early 1990s the Canadian government appointed a committee called the Special Senate Committee on Euthanasia and Assisted Suicide to look into the issues of euthanasia and assisted suicide. After listening to the testimonials of Canadians over a 15 month period, it became evident that palliative EOL care in Canada was meagre and in need of reform (SSCEAS, 1995). Consequently, the Special Senate Committee released a report titled: *Of Life and Death* (1995) that made recommendations for improving public access, developing standards, and providing professional and public education on all aspects of palliative EOL care. In 1996, the Representation Agreement Act (RSBC, 1996) was enacted to acknowledge and promote patient autonomy. In June 2000, following a review of progress since 1995, the Standing Senate Committee on Social Affairs, Science and Technology released the report *Quality End-of-Life Care: The Right of Every Canadian* (Subcommittee, 2000) wherein it acknowledged that little work had been done on the previous recommendations. Therefore, it proposed a national strategy involving federal leadership and collaboration among key stakeholders from across the country.

In December 2000, the Quality End-of-Life Care Coalition was formed and published the report *A Blueprint for Action*. In June 2001, Health Canada's Secretariat on Palliative and End-of-Life Care was established. The Secretariat hosted a planning workshop, leading to the establishment of five community-working groups. From December 2002 until March 2007, the coalition worked to promote, develop and implement strategies to address palliative EOL care in Canada. One of the five community working groups was the Public Information and Awareness Working Group (PIAWG). This group achieved several outcomes, one being the development of the *Palliative and End-of-Life Care Public Information Awareness Raising Framework* (Acart Communications Inc., 2006). This framework involved both public and health care professionals' perceptions and feedback. The collective group identified numerous barriers that impeded providing care and accessing supportive resources. The two most pertinent barriers that

are relevant to this study are death prevailing as a ‘taboo’ topic and communication breakdown between HCPs and clients.

A second outcome from the PIAWG was the research done on assessing the needs of informal caregivers (family, friends and loved ones) in actual or anticipated palliative and EOL situations. The barriers that informal caregivers encounter involve both information needs and a number of gaps or challenges in the healthcare system. These issues and proposed strategies were summarized in the report titled: *The Information Needs of Informal Caregivers Involved in Providing Support to a Critically Ill Loved One* (Dunbrack, 2005). A third outcome from the PIAWG was to form a sub-group whose core focus was on the development of ACP. Over the course of several years, this sub-group held a forum in 2005 and another in 2006. The intent of these two sessions was to involve stakeholders and experts in the field to network, share information, and identify key priorities.

Two of these key priorities identified provide additional justification for this study. These two key priorities were a need for standardized terminology regarding ACP and better training of HCPs around the issue (Minister of Health Canada, 2007). These findings were congruent with those described in the report titled: *Advance care planning: The glossary project* (Dunbrack, 2006). This report summarized feedback from focus groups of health care professionals, legal professionals and consumers across the country. The participants from all three group-types commented on the complexity of commonly used concepts and terms of ACP. They suggested that more disease-specific programs and organizations should support the development of specific ACP guidelines and resources tailored to their clients’ needs. In addition, the need for more evidence based ACP research for evaluating its processes and measuring outcomes was also identified.

Over the past 12 years, significant achievements in advancing palliative and EOL care in Canada have taken place; however, more work is required as our healthcare system remains far

from perfect. As Canada forges ahead in its quest, so too has the United States with the implementation of various strategies at all system levels. The Patient Self-Determination Act in 1990 and the Advance Planning and Compassionate Care Act in 2002/2007 were two political proactive strategies aimed at improving patient autonomy.

Organizations such as the Last Acts committee (2002), the National Consensus Project for Quality Palliative Care (2004, May) and the Robert Wood Johnson Foundation (2007) promote excellence in EOL care issues through funding of research initiatives, education and the development of other public support resources. These North American initiatives are slowly improving the delivery of EOL care particularly as research delves into identifying barriers and effective ways to address these issues well in advance of imminent death (Curtis, Wenrich, Carline, Shannon, Ambrozy, & Ramsey, 2002; Martin, Thiel, & Singer, 1999; Rodney & Howlett, 2003). These studies' findings emphasize the diversity that exists in patients' EOL care needs among chronic illnesses. They also provide further evidence to the argument for disease specific EOL care approaches. Yet to date, only a limited amount of studies have examined EOL care and ACP needs within the renal patient population.

### End-Of-Life Care in Endstage Renal Disease

Chapter 1 introduced ACP as being well situated in the ESRD trajectory to address the HD patients', their families', and HCPs' EOL care needs. The following discussion provides the background for this argument. Chronic kidney disease affects an estimated 1.9 million Canadians (Kidney Foundation of Canada BC Branch, 2005). Hypertension and diabetes mellitus are themselves chronic diseases that account for approximately 50% of all new cases of kidney disease. In addition, they continue to exert systemic effects long after a person's kidneys have failed. The WHO projects that deaths related to diabetes will increase by 44% in Canada by 2015 (WHO, press release, 2006). In the Canadian Organ Replacement Registry 2006 Annual Report, the rate of incident ESRD renal replacement therapy patients such as those receiving HD and

peritoneal dialysis treatments rose from 112 per million populations in 1995 to 158 in 2004, a 41% increase. Age was a major contributing factor in long-term survival (three- or five-year survival). As age increases, long-term survival decreases. This decrease was marked by a reduction to 19.6% survival in those patients 75 years of age and older (at five years).

Many patients with ESRD continue to develop and live with additional co-morbidities that further compromise their quality of life, increase the frequency of hospitalizations and cause more uncertainty of their longevity (Weisbord, Carmody, Bruns, Rotondi, Cohen, Zeidel & Arnold, 2003). The issues of confronting declining health, experiencing a more rapid functional decline (particularly in the elderly) and the incidence of facing an earlier death when compared with a non-HD patient of the same age (CIHI, 2006; Scheafer & Rohrich, 1999; USRDS, 2007) are known truths that only recently are being brought to the forefront as important factors within the context of planning for EOL care. Research exploring aspects of EOL care within ESRD is growing (British Columbia Renal Agency Provincial End of Life Working Group, 2005; Cohen, Germain, Poppel, Woods, & Kjellstrand, 2000; End-Stage Renal Disease Peer Workgroup, 2003; Hines, Glover, Holley, Babrow, Badzek, & Moss, 1999; Phillips, Brennan, Schwartz, & Cohen, 2005; Poppel, Cohen, & Germain, 2003; Singer, Martin, & Kelner, 1999) and its findings are raising more questions, calling for an in-depth exploration of ACP, particularly from the patient's and family's perspective. Hines et al., (1999) argue the hemodialysis population in particular is an ideal group for studying ACP given the amount of time patients, their families and HCPs spend together throughout this illness trajectory.

#### End-Of-Life Care in Hemodialysis

In hemodialysis, patients have the option to discontinue dialysis treatment and as a result death is imminent often within several days to weeks. In the United States, an estimated 60,000 ESRD patients die annually and approximately 20% of these deaths are the result of a decision to stop dialysis (RPA/ASN, 2002). Siegler, Del Monte, Rosati, and von Gunten (2002) completed

an extensive review on the history of death within the context of dialysis. They commented how surprising it was that nephrologists (let alone all renal care providers) are not better prepared at managing EOL care issues or instituting palliative care approaches given the amount of death that occurs in HD. Similarly, in research focusing on renal nurses' perspectives, study findings showed that the initiation or discontinuation of dialysis was described as being the most common ethical conflict in their practice, frequently causing moral dilemmas and in some instances moral distress (Redman, et al., 1997). It is a very unfortunate fact that very few nephrology programs across North America (Braveman & Cohen, 2002; Bullard, 2004; Cohen, et al., 2000; ESRD Peer Workgroup, 2003; Poppel, et al., 2003), if not internationally (Gunda, Thomas & Smith, 2005; Johnson & Bonner, 2004), have implemented a consistent framework for managing issues associated with death and dying.

In the United States, three initiatives took place to assess the quality of care at the EOL for ESRD patients. As a first step in 1997, the Renal Physicians Association and the American Society of Nephrology (RPA/ASN) came together with several other national Nephrology boards to develop a position statement (RPA/ASN, 2002). In 2000, the RPA/ASN published clinical practice guidelines titled: *Shared Decision-Making in the appropriate Initiation of and Withdrawal from Dialysis* ((RPA/ASN, 2000). A few years later in 2003, the ESRD Workgroup was formed to ascertain EOL care issues in nephrology, compiling a report of recommendations titled *Completing the continuum of Nephrology care end-stage renal disease peer workgroup* (Moss, 2003). All three of these initiatives support the implementation of ACP as part of EOL care and confirm that nephrology programs, particularly hemodialysis units, provide an excellent setting for embarking on the ACP process.

In Canada, nephrology programs and hemodialysis units are starting to take independent measures to incorporate AD and/or ACP (Ballantine, 2004; DaCosta, 2004; Dunlap, 1997; Tigert, Chaloner, Scarr, & Webster, 2005). However, the findings from this literature review

indicate that a unified approach or standardized framework has not yet been established.

Recently, the National Kidney Foundation of Canada included in their *Living Well with Kidney Disease* patient manual (2006) a chapter on conservative care and a discussion on Living Wills<sup>15</sup> wherein patients are encouraged to share their EOL care wishes and explore the meaning of their disease with their families. Incorporating this information into the patient manual is a big national step forward for nephrology programs.

Initiatives in British Columbia include the Provincial Renal Agency (BC PRA) forming a Provincial End of Life working group in 2004. Its goals are to assist health authority renal programs to develop and implement EOL care resources that include ACP programs as a standard of practice within all of its nephrology programs (BC PRA, website, 2005). Around the same time in 2004, one health region in British Columbia took the initiative to implement a comprehensive palliative care program that promotes early ACP discussions within the illness trajectory (Tayler & Grant, 2004). As part of this program, a three-month renal pilot project ([Health Region A], 2004) took place within several of the region's HD units.

Hemodialysis patients (with the option of involving their families) were invited to engage in ACP discussions with trained facilitators, exploring the patient's and family's values, beliefs and wishes regarding EOL care issues. Patients then decided whether they wanted to complete a type of AD document that was referred to as an ACP workbook. It was not legally binding and they had the option of placing it on their hospital medical chart. Thirty-five patients on HD participated in the initial project of which 34% had previous ACP conversation(s), 37% involved a family member/spokesperson in the facilitated ACP conversation(s), while 86% directed their own ACP conversation with a family member or spokesperson following the facilitated

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<sup>15</sup> The term Living Will originated in the United States. It is widely recognized by the public. For the purposes of this study, it means an expression of wishes for treatment in the event of incapacity to give informed consent in the nature of an instructional directive: an advance directive (Dunbrack, 2006, p. 28).

conversation. The ACP workbook was completed by 71% of the participants and 86% had filed their advance care plan on their health care record ([Health Region A], 2004).

At the end of the three-month pilot project 4 participants had died, and in each case their EOL choices were honoured. Preliminary findings from this pilot project indicated ACP was a welcomed approach to addressing future health care choices even though for some participants it created anxiety. Since the project's completion, ACP discussions with a facilitator have continued and the program has expanded into the regional community HD units and within several other medical areas of the health region ([Health Region A], 2004).

The development of provincial and local initiatives creates mounting recognition for the value of ACP in nephrology. Nephrology departments should offer comprehensive ACP and palliative care programs in order to improve the quality of EOL care, especially for individuals who choose dialysis discontinuation. However, a documented barrier impeding this process is North American societies' and medicine's denial of death.

### Death

The author Farber (2000) wrote that a strong denial of death is prevalent in North American societies whether it is overt or subconscious. Most people understand that one day death will happen to everyone, though not in the near future or until the individual is ready for it. Morgan and Laungani (2002) stated "death and bereavement are fact but dying and grieving are processes in which we engage and we do this by how we have been taught" (p. 1). In our schooling and work environments, HCPs most often have not been taught how to understand or work through their emotions regarding death or dying. Rather, modern medicine has transformed the notion of death from being a natural part of life into the enemy (Farber, 2000).

Callahan (1995) explored the evolution of death becoming a 'taboo' topic within North America. He questioned whether medicine can overcome its censoring of talking about death and viewing it as "the ultimate enemy" (p. 230). He posited that if change were possible then HCPs

would be in a better position to develop attitudes and practices necessary to “help everyone die as good a death as humanly possible”. However, such an immense transformation cannot be achieved alone rather “it will require a shift in American culture itself” (p. 230). The family, HCP and “society’s death-denying stance” are macro level social barriers affecting patient’s choice to face death and in completing an AD (Jesewski & Meeker, 2005, pg. 323). Similar findings were documented in Dunbrack’s (2006) report.

Previous and personal experiences strongly affect how individuals think and feel about EOL care issues along with the families’ willingness to even address the topic (Dinwiddie, Pfetscher, Kitsen, McCarthy, & Danko, 2003). Calvin (2004) described the process of patients confronting death and facing mortality as being “mixed with uncertainty” and stressed the importance of HCPs seeking to understand the driving force behind their actions” (p. 565). Outcomes from the study by Schwartz, Merriman, Reed and Hammes, (2004) showed that patients within the context of EOL reflected more often on what it meant for them to ‘live well’, sharing their values rather than on the meaning of their medical care. In Steinhauser, Clipp, McNeilly, Christakis, McIntyre, and Tulsky’s (2000) study, participants acknowledged society’s tendency to deny death and as a result, demand that greater preparation be made for dying.

Health care professionals in particular demonstrate difficulty in addressing ACP discussions, and as one study reports this may be due to the fact that “a culture of death denial prevails in dialysis units among renal staff, patients and families” (Dinwiddie, et al., 2003, p. 3). Furthermore, HCPs’ actions in denying the presence of death and avoiding an associated conversation have earned them a comical term by hospice nurses as “the elephant in the room” (Griffie and Nelson-Marten, 2004, p. 49). This metaphor boldly highlights some HCPs’ extreme discomfort with death. Unfortunately, such behaviour significantly impacts the HCP-client relationship and negates patients’ and families’ attempts at coming to terms with the dying process and facing death within their illness experience.

The research literature confirms how nurses regularly encounter healthcare system barriers and are challenged by both their personal values and beliefs, and professional practice while working in EOL care with patients and their families. In the large study by Ferrell, Virani, Grant, Coyne and Uman (2000) a questionnaire geared at oncology nurses addressed the issues of EOL care dilemmas, barriers commonly encountered in practice, and their perceived effectiveness of EOL education. Family member avoidance of death was perceived as somewhat of a barrier 73% and a severe barrier 19% of the time. Patients' avoidance of death was rated as not being a barrier 22% and somewhat of a barrier 70% of the time. HCPs' personal discomfort with death was perceived to not be a barrier 27% and somewhat of a barrier 56% of the time. Lack of AD and EOL care knowledge by HCPs was thought of as being somewhat of a barrier 57% of the time.

In Sherman's (2004) study, nurses indicated that two thirds of the ethical conflicts encountered in practice remain unresolved. Oncology nurses describe experiencing increased levels of stress, anxiety and apprehension with death because in caring for patients and their families who are on a terminal illness trajectory often triggers their own past experiences of loss and vulnerabilities. Similar findings were noted in other studies (Jesewski, Meeker & Schrader, 2003; Jezewski, Meeker & Robillard, 2005) wherein many oncology and emergency nurses acknowledged the potential conflict between their personal and professional values regarding death and dying. They stressed the importance of facing their own mortality first, not conveying their biases that may influence patient decisions, and learning to place the patients values at the forefront of care. The regularity of these nurses working with issues of death and dying, frequently encountering ethical conflicts and feeling poorly trained or supported in addressing these stressors significantly contributes to practice burnout wherein the care they provide becomes compromised.

As a nephrology nurse, I find the results from these studies disconcerting because oncology nursing predominantly addresses issues of death, dying and palliative care. The study participants' ambivalence raises questions about what supportive resources are in place to assist them to address their practice dilemmas and overcome these identified barriers. These findings also lead me to question how well nephrology is prepared to manage similar issues when they are still struggling to acknowledge and accept death as a natural part of the HD trajectory.

As I have already argued in this thesis, a proactive strategy for addressing the multiple challenges associated with death and dying is ACP. Advance care planning programs provide a suitable framework and medium for initiating the delicate and overwhelmingly challenging process of confronting not only the patient's impending death but each family member's and HCP's own eventual death as well. Findings from Martin et al.'s (1999) study within the context of HIV/AIDS concluded that ACP was about strengthening relationships with loved one's by facilitating communication, helping everyone to face and cope with the prospect of the patient's death, and relieving both the burden of death and of substitute decision maker. Furthermore, Albinsson and Strang (2003) discussed the potential educational opportunities that an ACP program offers, such as learning about the dying process, its associated treatment options and possible comfort measures. If the meaning of death and dying is "rooted in a historical-social-spiritual context" (Burgess, Stephenson, Ratanakul, & Suwonnakote, 1999, p. 204) then everyone involved in the patient's EOL care will need to recognize how their diverse cultural backgrounds influence how they create meaning and make decisions. In particular, it is imperative that HCPs are informed of the ethnic population(s) they work with and understand their primary needs, especially within an ACP setting since it is a person's cultural and social background that shapes EOL care preferences (Crawley, Marshall, Lo & Koenig, 2002). In addition, HD unit culture and the culture of its HCPs remain primary influences in determining appropriate patient withdrawal from life support (Cohen et al., 2000).

## Key components in Advance Care Planning

The key components in ACP that are examined in detail include culture, advance directives, decision-making, the family as SDM, the role of ACPF, and communication. Culture influences how patients, families and HCPs make individual and collective decisions, and communicate with each other. An advance directive was the first strategy used to facilitate decision-making and conversations about EOL care issues. Making EOL care decisions is challenging, particularly when disagreement exists regarding who should be involved in the decision-making process. The family as SDM carries a great deal of responsibility and requires a lot of support from both the patient and HCPs that is often not received. The research literature demonstrates how the role of ACPF is pivotal to creating a positive ACP experience yet disagreement persists on the existence of this role and who should occupy it. Finally, the effectiveness of open and ongoing communication facilitates a strong HCP-client relationship that invariably impacts the quality of EOL care.

### The Influence of Culture

Advance care planning discussions not only provide a context for exploring individual and family perspectives regarding death and dying but also afford the opportunity for clarifying how individual, family and community culture influence decision-making and interactions within health care. Bates and Plog (1976) describe culture as the system of shared beliefs, values, customs, behaviours, and artefacts the members of society use to cope with their world and with one another that are transmitted from generation to generation through learning. Several research studies found that a clash of culture, religion and ethnicity often create misunderstanding, false assumptions and misinterpretations between all parties involved (Larson & Tobin, 2000; Kagawa-Singer & Blackhall, 2001; Mazanec & Tyler, 2003). Furthermore, the authors Crawley, et al., (2002) highlighted several additional issues in EOL care that vary considerably amongst cultural groups and are pivotal in the patient, family and HCP triad. These issues included

understanding the appropriateness of openly naming a disease or discussing death; the expression of pain; attitudes towards suffering; and the role of family members and HCPs in serious illness (p. 677).

Wright and Leahey (2005) explained that families were affected by the context within which they exist both individually and as a whole. Context included their spirituality and religion; ethnicity; race; social class; and environment. Spirituality and religion influenced family values, size, health care, and socialization practices (p.77). Ethnicity influenced family interaction (p. 72). Social class shaped educational attainment, income and occupation consequently affecting family interaction and health care practices (p. 75) and finally, numerous environmental factors influenced family functioning (p.78). Knowledge of how the patient and family define their individual and collective culture is necessary for HCPs because culture affects our understanding of the meaning they place on death, the rituals of coping and the dying process.

Healthcare providers must not only consider their patients' and families' cultural context but also how their own personal and professional culture influences their interactions. Stephenson (1999) and Rodney (Personal Communication, October 12, 2007) explained that HCPs are affected by not only the context within which they practice but also from their personal lives. The healthcare system and its subsequent systems levels all have their own organizational culture that dictates the delivery of care. Therefore, remaining ethnically and culturally sensitive means appreciating that everyone has their perspective and all of these viewpoints are legitimate "ways of constructing meaning around death and dying" (Burgess, et al., 1999, p. 204). It is imperative that HCPs seek to understand the context of each person's life and experiences, including their own by first understanding the cultural backgrounds (Krakauer, Crenner & Fox, 2002) and then learning about "the circumstances that make up the foreground" (Anderson, Reimer-Kirkham, Waxler-Morrison, Herbert, Murphy, & Richardson, 2005, p. 326).

Findings from Blackhall, Frank, Murphy, Michel, Palmer and Azen's (1999) study, recommended that physicians accept responsibility and do not view their role as "simply one of objectively offering options without giving an opinion" but rather offering an opinion that "clarifies the context within which s/he is discussing end-of life care" (p. 1787). This profound decision does not rest solely on the shoulders of the family. Even though in these studies it is the physician's role that is highlighted, I see the authors' argument extending to include all HCPs working with specific patient population groups such as with renal patients. Therefore, HCPs are reminded that culture and ethnicity have a strong influence on personal communication.

Consequently, when providing care, HCPs should learn about the patient and family's beliefs and attitudes regarding views on illness, dying, truthfulness, the significance of death, and concepts such as the afterlife and miracles. Gaining such information helps to create "an environment conducive to communication" (Griffie and Nelson-Marten, 2004, p. 49). Furthermore, HCPs should also acknowledge the existing discrepancies in power between clients and themselves. One power dynamic is the struggle patients experience in being dependent not only on a life-sustaining treatment but also on the HCPs who deliver, monitor and evaluate that treatment. Drought and Koenig (1996) found that AD documents in particular failed to address the existing power inequalities in the decision-making process.

### Advance Directives

A discussion about AD documents is not a focus of this study; however, given that ACP evolved from AD some commentary is necessary. As noted in chapter 1, AD for the purposes of this study refers to the legal document only. Numerous studies have demonstrated the utility of AD and identified several dangers.

Advance directive documents are useful when they are perceived as giving some decision-making control back to the patient, thereby respecting his/her wishes and honouring autonomy, particularly if the patient does not trust the medical providers and fears being over

treated (Drought & Koenig, 1996). Singer et al., (1999) clarify that “patients want a voice in their end-of-life care rather than specific control over each life-sustaining treatment decision”, and that having such discussions made them feel “less isolated in the face of death” (p. 167). Additional advantages of an AD include it assisting to reduce the decision-making stress and guilt of family members (Sawchuck & Ross-Kerr, 2000).

The AD document becomes a resource when there is disagreement among family members, conflict between the family and health care team, or when a non-traditional family member is the surrogate decision-maker (Tulsky, 2005). It is also a tool for assisting individuals in initiating EOL conversations (Tigert et al., 2005). However, several reasons exist for why ADs may not be completed or altogether avoided. A person’s current health status and age; a person’s personal past experience with death of friends and family; clearly understanding the document’s contents and the role of health care proxy (SDM); having personal needs and questions met; having a resource person to assist with the process (Jezewski & Meeker, 2005); feeling ambivalence and lacking readiness in acknowledging death and facing mortality (Drought & Koenig, 1996); being perceived as premature within a person’s illness trajectory (Moss, 2003) or simply procrastinating about addressing the entire EOL issue (Sawchuck & Ross-Kerr, 2000) were all reasons for its deterrence.

A study by Schwartz, Wheeler, Hammes, Basque, Edmunds, Reed, Ma, Li, Tabloski and Yanko (2002) provided additional evidence on the downside of receiving an AD document alone. The researchers found that 76% of the intervention group who engaged in ACP conversations with a facilitator along with receiving an AD were in complete agreement with their understanding of the patient’s EOL care wishes compared to 55% of the control group who only received the written AD information. A secondary outcome revealed that intervention patients became less willing to undergo life-sustaining treatments for a new serious medical

problem, more willing to undergo such treatments for an incurable progressive disease, and less willing to tolerate poor health states.

Similar findings were documented in Jezewski, Meeker, Sessanna, and Finnell's (2007) systematic literature review. They concluded that receiving education (a didactic intervention) without the ability to ask questions (a person-to-person interaction) did not significantly increase the AD completion rate. In fact, the didactic method's post intervention rates of AD completion ranged from 0% change to 34% increase, whereas the interactive method ranged from 23% to 71% increase. However, "the increases in completion rates were usually no higher than the predicted average completion rates for the general population" that being below 20% (p. 530). In Ferrell et al.'s (2000) study, the most common EOL care dilemma and barrier encountered in oncology nurses' practice was the use of an AD. Thirty seven percent of participants rated the use of an AD as being "very common" in their practice and 32% rated it as "somewhat common."

Lynn and Goldstein (2003) documented the dangers with an AD. One significant danger occurs when it does not follow the patient as s/he moves through the healthcare system, potentially resulting in inappropriate aggressive treatments thus having a detrimental impact on both the patient and family. The researchers argued that such events should be labelled as medical errors warranting further investigation and vigorous follow-up.

The overall messages arising from the literature on AD documents are as follows. A patient's treatment decisions are not stagnant, but rather fluctuate depending on the current health circumstances. Advance directives only capture a moment in time and do not account for the natural ebb and flow of the chronic illness trajectory. Repeated exposure to AD documents as a process, taking place over time facilitates improved comprehension. Advance directives cannot stand-alone, rather should be accompanied by a HCP who can provide ongoing guidance and support as the patient and family work through the process. The researchers posit that the role of

AD documents contributes to improving EOL care, so long as its limitations and potential dangers are recognized and understood. An AD should be completed and instigated prior to the occurrence of a health crisis rather than upon the respective hospital admission (Jezewski, et al., 2005; Jezewski et al., 2007; Lynn & Goldstein, 2003; Schwartz et al., 2002).

Lastly, HD units should offer, encourage and provide ample opportunity for every patient to consider completing an AD document, ACP workbook and/or appoint an SDM given the high mortality rate of ESRD and increasing number of deaths proceeded by dialysis termination. The development of a framework that also considers the complexity and diversity of AD decision-making is critical (Drought & Koenig, 1996).

### Decision-Making

Chapter 1 described how families living with ESRD must live within a strict regime of rules set out by not only the disease itself but the consuming HD treatment as well. They are bound to these strict regimes with many struggling to gain control over something that is uncontrollable. Families are often said to have a more complete and complex view of the patient and his/her experience with the illness yet are not often included in the decision-making with HCPs (Chambers-Evans, 2002; Levine & Zuckerman, 2000). They are frequently perceived as a nuisance hindering the delivery of care to the patient yet are required to carry the burden of care at a moments notice (Levine & Zuckerman, 2000). Healthcare providers hold the decision-making power, choosing what information to disclose and thus leaving the patient and family vulnerable, often feeling powerless within the process (Drought and Koenig, 1996).

Levine and Zuckerman (2000) completed an extensive literature review on the ‘hands on/hands off’ mixed messages that families endure regularly as caregivers. They found multiple paradoxes and a double standard between HCP and family decision-making. For instance, they noted how clinicians complained about disagreement in decisions and potential conflict among family members yet failed to acknowledge the privileges they provided themselves. They too

frequently experienced internal group disagreement, expressed decisional uncertainty and required time to reach a consensus. However, they did not allow such luxuries for the families. Rather, they presented themselves as a “united front”, “instigating an all-or-nothing standard” (p. 13) and “failing to subject their own underlying values to the same scrutiny as those of families” (p. 14). Levine and Zuckerman argued that working with families means, “developing an ethic of negotiation and accommodation” (p.14).

Strauss et al. (1984) stated: “None of all the various tasks that kin do is so intellectually and emotionally demanding, so difficult to pursue, so fateful in its outcome, and yet so little understood by [HCPs], as the work that goes into crucial decision-making” (p. 147). Therefore, acknowledging family based values is part of what it is to respect patient autonomy. Advance care planning also helps to respect the autonomy of family members (Doukas & Hardwig, 2003). Singer, et al. (1998) further concluded that ACP is a “social process” (p. 883) and is based on factors such as exercising autonomy and control. The literature demonstrates the multiple challenges in working with families from diverse ethnic and cultural backgrounds who do not perceive patient autonomy in the same light (Blackhall, Frank, Murphy, & Michel, 2001; Hern, Koenig, Moore, & Marshall, 1998; Crawley, Marshall, Lo, & Koenig, 2002). This perspective is shared by the researchers Drought and Koenig (2002), whose study involved completing an extensive review of current literature on ‘choice’ within EOL care decision-making. They concluded “there is little or no empirical evidence to support the autonomy paradigm of patient ‘choice’ in EOL decision-making: shared decision making is illusory” (p.114).

Health care providers must first explore how involved patients want their families to be in their care and decision-making, and then based on their direction, move along to establish the family members’ expectations as well (Blackhall et al., 2001; Hern et al., 1998). In particular, if patients decide that a family member(s) will act as an SDM then they must remain equally

informed of the patient's current and ongoing health status. Taking on this role is by no means a simple task, but rather a commitment extending the duration of the patient's lifespan. In the end, as it has been proven through much of North America's healthcare history that HCPs continue to hold the key in creating a positive or negative client health care experience. All of these issues are pivotal to communication and decision-making, are integral components of the HCP-client relationship, and are fundamental to ACP conversations.

An important component of the decision-making process within a terminal chronic illness is thinking ahead to EOL care. Part of EOL care is appointing an SDM who will be able to speak on behalf of the patient when incapacitated. The research literature provides some statistics on who is commonly chosen and why. In the study by Hines, et al. (1999) the focus was on ascertaining HD patients' preferences for involving physicians and family members in ACP. Their findings indicated that patients involved their surrogate and family members in their decision-making more often than their physicians or other HCPs.

Patients discussed specific treatment preferences with their physician 6% of the time and involving them only 2% in future discussions. Only 36% of the time were physicians included in conversations about desired treatment if patients became very ill, and 9% of the time did patients want physicians to lead conversations about their desired treatment. The researchers argued that their findings clearly demonstrated the need for reform within HD units wherein "a patient-centered, family-based model of care" is enacted and the physician's role in ACP is to encourage the process within the context of the family (p. 827). If the patient identifies that family involvement is part of his/her illness experience, particularly within HD, then HCPs must modify their approach to care by incorporating the family and perceiving the patient as integrated into this one unit.

## The Family as Substitute Decision-Maker

Several retrospective studies (Dunbrack, 2006; Woods, Berzoff, Cohen, Cait, Pekow, Germain, & Poppel, 1999) that interviewed families and SDMs after the patient's death provide confirmation on some of the issues identified in present day studies, thereby strengthening the argument for improved ACP strategies and effective communication. Study participants reported having a positive experience with AD, honouring the patient's wishes and reducing the patient's amount of suffering as contributing to positive bereavement and closure. Meeker and Jezewski (Meeker, 2004; Meeker & Jezewski, 2004; Meeker & Jezewski, 2005) completed extensive work on understanding the perspectives and needs of family members acting as SDM. Their findings identified the complex moral, emotional and cognitive challenges in being a family member and an SDM. Their findings revealed how surrogates often experienced long-term physical and psychological outcomes and preferred decision-making to be a group or consensual process involving additional family members rather than their individual decisions. Surrogate satisfaction was also significantly influenced by the quality communication with HCPs.

Surrogates had a great deal of advice to share with others new to this role. They emphasized starting discussions early, stressing the significance of getting to know their family member's EOL care wishes. They clarified that remaining sensitive and respectful of the other person's needs and feelings was integral. Surrogates encouraged individuals new to this role to have confidence in their capabilities, to trust their judgment and be strong advocates for both the patient and for themselves. The advice they shared with HCPs in how their role could be better supported included being brought into formal decision-making earlier in the course of the illness. HCPs should remain honest and kind; provide guidance and space; comprehensive information and supportive resources that facilitated independent decision-making. It was also important for HCPs to respect choices made without having expectations to influence them or be directly part

of the decision-making. These findings inform clinicians of the importance in understanding the needs and perspectives of the surrogate decision-makers.

The research literature has also documented circumstances when family members have struggled in their SDM role. Fagerlin, Ditto, Danks, Houts and Smucker (2001) discovered that some SDMs have difficulty in separating their own values and beliefs from the patients, thereby failing to honour patient autonomy or self-determination (Fried, Bradley & Towle, 2003). This occurred even after having a joint discussion about the patient's wishes regarding medical treatment at the EOL (Pruchno, Lemay, Field, & Levinsky, 2005). Fried et al.'s (2003) research also presented an alarming piece of evidence in which caregivers who were in disagreement with the patient were significantly more likely to under rate the state of severe physical or cognitive impairments as acceptable than what the patient found acceptable. Additional barriers to ACP included patients often overestimating the accuracy and capabilities of their proxies (Moss, 2003), or families remaining too optimistic for a more positive prognosis, frequently holding unreasonable expectations of what the physician could do (Larson & Tobin, 2000).

Caplan's (2000) study uncovered another disquieting finding that was referred to as "the proud caregiver syndrome" (p.3199). This syndrome occurs when the caregiver has devoted his/her entire life to the patient and is now unable to find meaning in life outside of this role. Such circumstance renders the caregiver incapable of choosing anything less than full aggressive treatment even when it conflicts with the patient's values and wishes (p. 3199). Though uncommon, the danger in this example demonstrates the existing pitfalls in the surrogate role.

On the other hand some researchers (Fagerlin et al., 2001) provide rationale for many of these negative study findings, questioning whether the reason for families' overestimation for a positive outcome was due to their reluctance in taking a risk on making an error of under treatment. Tulsky, (2005) also questioned the accuracy of how a hypothetical scenario compared to a real situation. Factors such as not knowing the extensiveness of the illness or the patient's

perceived quality of life and health, and not understanding the likely prognosis nor the options for care all influence making a decision.

One conclusion that Ditto, Danks, Smucker, Bookwala, Coppola, Dresser, Fagerlin, Gready, Houts, Lockhart, and Zyzanski (2001) drew was more research is needed in determining what constitutes an “acceptable” (p.428) level of SDM accuracy and how correctly this person can honour a patient’s wishes if s/he does not understand them. Fins’ (1999) perspective validates Ditto et al.’s (2001) argument. He proposed the use of an AD document over a SDM was sometimes more appropriate.

Based on findings from the SUPPORT study, Fins posited that the original study emphasized the “contractual dimensions of ACP at the expense of the covenantal relationship” thereby providing “a mistaken assessment of how patients and proxies negotiate the actual challenges of ACP” (p. 50). He argued that a contractual approach might be in order when the patient’s preferences are clear or when the appointed surrogate does not have a well-established relationship with the patient. Such circumstances would protect the patient from a proxy who may be “uninformed, ill-chosen, or even mischievous”(p. 47). However, when the proxy knows the patient intimately and is well aware of his/her expressed values, beliefs and wishes, then the proxy should be granted that respect and decision-making responsibility that was entrusted to him. Furthermore, Meeker and Jezewski (2005) question whether successful substitute judgment is possible given that it puts patient autonomy at risk when proxy decision makers choose differently than the patient.

The role of a SDM is particularly cumbersome and challenging as it involves a great deal of uncertainty in decision-making for which many are ill prepared. In order to be successful in this role effective communication between not only the clients and HCPs is necessary but also between the SDM and the patient. The research literature has discovered how differences in the needs and expectations between patient and SDM also contribute to communication breakdown.

Chambers-Evans (2002) argues that family, as surrogate decision makers are not the issue. Instead, the challenge lies in what are the most effective methods for involving family members in the decision-making process. She states, “while families struggle with the emotional burden of their role, clinicians struggle to translate complex information into comprehensible, meaningful and practical language” (p. 15). Chambers-Evans proposes that a reorientation of current models of the HCP-SDM relationship is necessary for the development of effective relationships, supportive communication pathways and shared decision-making. Healthcare providers have an equally important role to play in ACP whether it is as part decision-maker or facilitator of the process.

### The Role of Advance Care Planning Facilitator

A consensus on who is best suited for the ACPF role has not yet been reached. Based on the research, patients, their families and HCPs all describe several different professionals as being best suited for the role (Heffner & Barbiery, 2000; Kennard et al., 1996). Each professional discipline offers excellent attributes, strengths and opportunities. Research by Perkins (2000) and Quill (2000) discussed the valuable role that physicians play in being instigators of ACP, while Kovacs’ (2006) and Woods et al.’s (1999) work demonstrated how social workers are well positioned for this role. Research by Jezewski et al. (2003) presented an equally strong rationale for nurses owning this role. What is consistent throughout all of this research and discussion papers are the similar challenges each discipline faces and the call for necessary changes to current practice.

The issues and current barriers to implementing this role effectively included lack of time to engage in ACP conversations; lack of consensus on when to start them and who to include; program or fee-for-service funding issues; lack of educational and support resources to accompany these conversations; lack of professional training; overcoming personal comfort level with the subject matter; improving personal listening skills; honouring patient wishes even when

they may conflict with their own; and, finally, requiring clarification of role responsibilities. A different proposed approach is to view the ACPF as a collective role wherein it involved a shared team approach. Research that incorporates a patient-centered or family-centered type model of care argues for such an approach (Chambers-Evans, 2002; Doukas & Hardwig, 2003; Kovacs, 2006; Marchand, Fowler, Kokanovic, 2005; Schwartz & Perry, 1999). These practice models give the decision-making back to the patient and family who may rely more heavily on a particular discipline with whom they feel most comfortable. In addition, such a role contributes to fostering improved communication between HCPs and clients within the context of EOL care.

### Communication and its Breakdown

Communication about personal values, beliefs and wishes is of the utmost importance if a patient wants to be heard not only by his/her family but also by HCPs. Effective communication has tremendous potential to be instrumental in facilitating coping, self-care management, and an optimal quality of life, or, conversely in being toxic and damaging to those ideals. As discussed in chapter 1, often waiting until one's health deteriorates and death are imminent risks a person becoming incapacitated before having the opportunity to express his/her wishes. The author Quill (2000) argues that little is lost in initiating EOL discussions early and systematically in the illness trajectory whereas so much is lost when they are avoided. A perceived sense of "mutual understanding" (p. 428), comfort and a window into the illness experience are produced through conversations about EOL care. Similar findings were noted in Ditto et al.'s, (2001) and the SUPPORT Principal Investigators' (1995) studies.

Communication contributes to establishing a partnership wherein the responsibility shared among its members is "dynamic and responsive to changing needs and situations" (Levine & Zuckerman, 2000, p. 15). Davison and Simpson (2006) concluded that patients who questioned the relevance of early ACP conversations were not opposed to such conversations as often misinterpreted by HCPs, rather they did not understand the prognosis of their illness

trajectory enough to see its appropriate relevance. Having an understanding of how the patient perceives his/her illness experience and understanding what is and is not valued provides needed insight. Much of this process hinges on quality communication with all involved persons. The researchers Singer et al. (1999) believe that it is the patients' perspective that clinicians and health care organizations must understand to improve the quality of care they deliver particularly within the context of EOL issues. Other research findings found that patients often described HCPs as being too busy and ACP was a private matter to be discussed amongst family (Singer et al., 1998; Hines, et al., 1999; Lamont & Siegler, 2000). These perceptions were in part due to a lack of trust in their physicians or other HCPs, though some patients wanted to receive physician's advice about recommended options (Tulsky et al., 2005).

Findings from the studies by Fried et al. (2005) and Cherlin, Fried, Prigerson, Schulman-Green, Johnson-Hurzeler and Bradley (2005) provide evidence of how patient and caregiver issues impact quality communication. Cherlin et al. (2005) found that ineffective EOL care communication was due to several factors, such as the physician's lack of discussion about prognosis and treatment options, and what s/he thinks is being communicated. Factors impeding the family caregiver's understanding of prognosis is in part due to his/her lack of seeking clarification, potentially misinterpreting what is being said and possibly an unwillingness to hear the EOL care news. The study by Winzelberg, et al. (2005) obtained generalist physicians' perspectives on how they make decisions about their chronically ill frequently hospitalized patients, and how they communicated with the family members particularly about EOL care issues. The findings showed differences in treatment preferences; a breakdown in open dialogue that included exploring personal perspectives, assumptions and expectations; and expectations between physician and family that often resulted in conflict and negative physician emotions. Winzelberg et al. suggest that physicians consider how, "negotiating these differences openly may result in a mutually agreeable care plan" and facilitate improved communication (p. 297).

In the study by Fried et al. (2005), the researchers compared patients' and caregivers' communication concerns with each other, examining the relationship between these communication needs and caregiver burden. They determined that even though patients and caregivers share a desire for communication they often have different expectations and needs regarding the amount and quality of their communication. In two other studies by Fried et al. (2003 & 2006), communication breakdown between the patient and SDM showed that quite often patients do not want to hear about or understand the extent of the illness prognosis, even over time, which led them to not ask important questions or convey the information onto their families. These findings lead me to question whether family caregivers' dissatisfaction and/or their unmet informational needs force them to rely more heavily on HCPs, creating higher expectations of the quality of the communication. Unfortunately, as I indicated in chapter 1, all too often HCPs fail to meet family caregivers' increased needs for answers, direction and support thus worsening the breakdown in communication.

Communication breakdown between HCPs and their clients is an integral problem in the delivery of EOL care and ACP. This breakdown does not occur at the bedside in individual practice but at all systems levels, and the research literature documents the multi system barriers that plague healthcare. Thorne (2005) writes, "communication between chronically ill patients and their HCPs is a critical and imperative component of health service delivery and is a high priority in health system improvement" (p.5). The research literature is accruing evidence on how HCPs' behaviours and actions or sometimes lack thereof negatively impact the ACP process, let alone quality communication and decision-making. Thorne et al. (2000) describe HCPs as setting up "complex interactions that reinforce the existing dysfunction within health care relationships" (p. 308). They purport that clinicians who believe themselves to be untouched by these judgements are acting under false presumptions, failing to recognize "just how powerfully the systemic attitudinal culture, influences the everyday experience of their patients

with chronic illness” (p. 309). They continue by saying that from a patient/family perspective the “constructs of respect, trust and control within health care relationships are clearly of critical importance to quality of life with chronic illness” (p. 309).

Other documented barriers contributing to communication breakdown include HCPs’ personal values, beliefs and opinions interfering with professional ethics and conflicting with other’s perspectives; feeling poorly trained to initiate EOL care discussions; and a lack of departmental and hospital support resources necessary to carry the patient through the ACP process (BC PRA, 2005; Ministry of Health Services, 2002; Poppel, Cohen & Germain, 2003; Subcommittee, 2000). Davison & Simpson (2006) found that physician’s impression of disease prognosis directly influences the value placed on the timing of ACP discussions. Curtis, Patrick, Caldwell and Collier (2000) indicated that clinicians who did not perceive the patient’s illness as advanced or critical, or who observed that the patient did not seem ready to talk about EOL issues (without directly asking the patient) were significantly less likely to engage in EOL discussions. Therefore, introducing comprehensive EOL care programs into the healthcare system provides an environment conducive to addressing the aforementioned barriers.

In nephrology, initiating discussions about EOL care earlier on in the illness trajectory of ESRD provides time for the patient, family and HCPs to understand the patient’s wishes, to explore each person’s role and work towards achieving a well devised care plan. HCPs should facilitate a process of communication that remains sensitive to the individualized requirements of their clients, ascertaining the diversity of their needs and recognizing that they may differ significantly. Such an approach will decrease the incidence of communication breakdown, further demonstrating how ACP is an effective tool for engaging in this process.

#### Making a Case for Advance Care Planning

There is international consensus from HCPs in the value of having ACP conversations with patients and their families (Blank & Merrick, 2005; Gunda, Thomas & Smith, 2005; WHO,

2004). However, many issues and barriers must still be addressed in order to improve the quality of ACP and its effective delivery. Song (2004) noted several issues that have not sufficiently been addressed in current ACP research. This researcher concluded the importance for determining how and when EOL care discussions and decision-making should be delivered and how their impact would be judged. The review did not find any evidence of patients experiencing a negative impact from participating in EOL care discussions, which they note contradicts many HCPs' rationale for delaying or avoiding such conversations. Song noted that a number of studies ignored the importance of surrogate involvement and hence recommended that research on surrogate involvement in EOL discussions and its impact be further investigated.

A reason for HCPs' hesitation in encouraging ACP is their concern for it potentially taking away patients' hope (Davison & Simpson, 2006; Song, 2004; Steinhauser et al., 2000). On the contrary, there is sufficient evidence in the literature that refutes this assumption, indicating that hope is not lost by engaging in ACP conversations but rather transforms it. Davison and Simpson (2006) conducted a study on the relationship between hope and ACP. Their findings demonstrated that initiating ACP conversations early in the illness trajectory did not diminish patients' hope. Instead, it created opportunity to reshape it, invariably enhancing their trust in the patient-physician relationship and their sense of empowerment. Similar research findings were found in Steinhauser et al.'s (2000) study. Calvin (2004) reported that circumstances surrounding the EOL were "often steeped in uncertainty" (p. 562) and for some HD patients (Davison & Simpson, 2006) ACP was perceived as offering hope from which they drew strength. Furthermore, Martin et al. (1999) indicated that current research underestimates the effectiveness of ACP because it does not measure the psychosocial goals that are important to patients (p. 91).

The literature provides a variety of research evidence on nurses' perspectives regarding EOL care and ACP. Given these findings, I question whether the frequency of encountering

ethical conflicts, experiencing moral distress and burnout within specialty settings, such as HD units contribute to nurses keeping families at arms length and/or in disengaging in HCP-client relationships (Sherman, 2004). Little research is available on nephrology nurses perspectives and needs on ACP or EOL. The majority of the literature focuses in oncology and palliative care nurses. Interestingly, the nurses' perspectives on perceived barriers to practice and identified needs for improving practice are similar across all specialty areas.

In two studies involving oncology (Jezewski et al., 2003) and emergency (Jezewski et al., 2005) nurses, a needs assessment was conducted to determine what they needed to improve their ability to assist patients with ACP. The findings revealed four topics: time, education, support and the nurse's role. Time was necessary to engage in discussions with patients about ACP. Providing ongoing education on all aspects of ACP and learning how to facilitate such conversations with patients was imperative. Receiving institutional support from all levels, including having a mentor in the process, the availability of expert clinicians as a resource and promoting a team approach all contributed to creating a conducive environment. The fourth factor involved defining and clarifying the nurse's role and responsibilities in the process.

The research literature also documents the variability in how the qualities of ACP discussions are evaluated. Advance care planning conversations within current research varied in their length of time from 20-60 minutes and in frequency from 1-3 sessions per study. The methodologies were diverse, including one or more interventions such as answering a set of questions, filling out questionnaires to either semi-structured or open-ended interviews. Finally, the researchers Singer et al. (1999) surmised that even though the outcomes from their study were similar to "existing medically derived models and frameworks on quality end of life care" they raised the question of "whether existing measurement tools are successfully capturing the essence of the experience" (p. 166), calling for more extensive research into the content of ACP discussions.

Kolarik et al. (2002) stated that no consensus on the objectives of ACP, the contents of its conversation(s) and the associated documents, or on the process itself has been established. Therefore, they question how researchers and HCPs are able to determine whether they are asking the correct questions, using the best methods to collect this data or accurately interpreting the findings. Drought and Koenig (2002) stated, “researchers and policy makers should heed what [HCPs] have learned from empirical research on EOL care to develop more sensitive and supportive programs for care of the dying” (p. 114). Overall, the recommendations proposed by Song (2004), Kolarik et al. (2002), and Drought and Koenig (2002) provide strong support for the implementation of this study, as it may contribute further evidence that begins to address several of these issues.

### Chapter Summary

The purpose of this literature review was to evaluate current findings on ACP research and the family’s role within this process in order to provide a foundation on which to base my research study. In keeping with the methodology of ethnographic research, the review examined to some extent the current social and political context of EOL care and ACP at several healthcare system levels including Nephrology, which was the setting for this study. Several findings resulted from this literature review that included expecting patients and their SDMs to provide accurate reflective responses when presented with hypothetical life and death scenarios are unrealistic. This expectation is particularly improbable when patients and their SDMs are without context and when they do not or have not shared a close history, particularly when discussions regarding values, beliefs and wishes were not previously discussed. Imagining HCPs can successfully engage in ACP and EOL care conversations with little to no training, lacking additional system and educational resources, and without having an understanding of not only their professional but personal stance on death and dying is improbable. Rather, its success

hinges on the creation of supportive forums in which tools and resources along with the development of a system wide comprehensive EOL palliative care program is implemented.

An ineffective time for initiating EOL care dialogue is when the individual is critically ill and family stress is at its peak. Instead, the consensus in the literature suggests creating a process whereby a series of conversations occur over time at particular points, starting early and continuing throughout the illness trajectory and involving at least one if not all health care team members in varying capacities. Patient autonomy is not about informing the patient alone. On the contrary, it involves asking the patient how and how much s/he wants to be informed who will be involved and by whom are decisions to be made. Being a facilitator of ACP is not the sole responsibility of one HCP or one profession. Rather it is a collective decision by the team, patient and family that is based on their existing relationships, available resources and most appropriate personality fit.

Research demonstrates the numerous pitfalls and challenges of ACP. Therefore a consensus on its goals, content, process and team member responsibilities must be established in order to effectively integrate it into the diversity of health programs within the current health care system. The successful integration of ACP is not dependent on any one individual. Rather its sustainability requires a collective approach that is simultaneously being implemented from both the top level in healthcare system reform down to the bottom level in individual practice that will create its sustainability and success.

Families are but one player in the ACP process. The other team players are the patient and HCPs who at times behave more like adversaries than partners. Each member brings their individualized perspectives to the table, which includes past history and current context. Their set of needs and values about the process affect how they participate in ACP. The literature provides evidence to support each member's experiences and provides direction for improved collaborative actions suggesting new rules to apply to this evolving process.

## **CHAPTER THREE**

### **Methodology**

The purpose of this study is to explore the perspectives of five families' experiences of participating in a facilitated ACP conversation with a loved one: the hemodialysis patient. In chapter 1, a discussion on the background of this study provided evidence for the value of ACP in nephrology and HD practice. In chapter 2, the literature review highlighted ACP research findings and the family's role within this process. Chapter 3 examines the methodology applied in this study and the theoretical perspective followed throughout its implementation.

Qualitative research is well situated to address the challenges encountered in ACP. It permits an in-depth exploration of complexities and is ideal for inductively deriving understandings (Marshall & Rossman, 1999). The primary goal of qualitative research is to comprehend the "dynamic, holistic and individual aspect" (p. 16) of human experience in its entirety and within its own context (Polit & Beck, 2004). Ethnography is a qualitative research approach best suited to understand ACP from the family members' perspectives. Ethnographic research assists outsiders to appreciate the world through the participants' eyes and what they perceive as meaningful (Roper & Shapira, 2000). The theoretical perspective followed throughout the study was postmodernist critical theory. This point of view shed light on the barriers within the HD unit impacting ACP.

The data collection methods, research design, ethical considerations, data analysis, and rigor of the study are discussed at length in this chapter. A detailed examination of the factors, challenges and barriers encountered throughout study implementation are presented. The sample for this study included a total of five families and an ACPF from the nephrology program where the study occurred. The family participants were the HD patient and one family member. In order to protect participants' identities due to the small sample size, certain biographic

characteristics, details of the setting and the order of the participant interviews have been modified where it will not affect the interpretation of the data.

### Ethnographic Research

Ethnography originated in the field of cultural anthropology. Its researchers immersed themselves in remote, foreign or exotic cultures such as whole tribes, or small communities, studying these groups over long periods of time, and writing up their findings within books (Boyle, 1994). Over the years, ethnographic research has evolved to acquire cultural knowledge of a person's own society (Germain, 1986). It recognizes that human behaviour is contextual and through participant observation and interviewing captures this richness in detail. The researchers Drought and Koenig (1996) argued for the application of ethnographic methods in exploring EOL care research, indicating that it assists in understanding people's preferences, complex processes and the subtleties of how individuals negotiate them. Blackhall et al. (1999) also used an ethnographic approach in their mixed methods study. The researchers recommended that more studies apply a qualitative component when researching EOL issues, as it "helps to clarify and prevent [the] misunderstanding [of] data collected in other ways" (p. 1787). The findings from both of these studies provide a strong argument for the value of qualitative research and in particular applying an ethnographic approach.

Ethnographers believe that culture can be described and understood. Its purpose is "introductory and instructive" (Muecke, 1994, p. 190) being "neither wholly inductive nor wholly objective" (p.191). Ethnography is shaped by many factors such as "the historical circumstance, the ethnographer's subjectivity and conceptual stance, as well as by the particular people with whom the ethnographer works" (p.195). To date, this style of research has only been minimally used within nephrology and in understanding issues associated with death and dying. Aswanden (2003) conducted ethnography within the HD unit to uncover and understand the culture of dialysis units, enabling patients and HCPs to work towards better treatment outcomes.

Another ethnographic study looked at the role of humour in health care communication between HCPs and patients in a dialysis setting (Mallett & A'Hern, 1996).

The disciplines of nursing, social work and other health professions are increasingly adopting the ethnographic method. The style of ethnographic research they most frequently apply is called a mini or focused ethnography. The researcher selects a behaviour or belief and studies its meaning amongst a specific group of people, such as studying the value of ACP conversations with families in HD. Nowadays, researchers can spend less time in the field and their findings tend to be more problem focused and context specific. Muecke (1994) indicated, “focused ethnographies are used to develop nursing knowledge and practice” (p.198) and that a master’s degree thesis contributes significantly to the store of focused ethnographies in nursing. Therefore, findings from this master’s thesis study will contribute to the scope of knowledge on ACP and families within HD.

Mini ethnographies have been applied within the intensive care unit to explore HCPs’ and the surrogates’ decision-making regarding the cessation of life support (Seymour, 1999; Seymour, 2000). It was used to gain an understanding of generalist physicians’ experiences in EOL decision-making and communication with families of frequently hospitalized chronic illness patients (Winzelberg, et al., 2005). Farber, Egnew and Herman-Bertsch (2003) utilized it for defining clinicians’ roles in EOL and focused on various aspects of the patient’s experience in receiving a diagnosis of and living with cancer. In the context of chronic illness it was used in health promotion and to understand how families’ experience coronary disease (Preston, 1997). The, Hak, Koeter, and van der Wal (2000) applied an ethnographic approach to understand the role of false optimism in recovering from lung cancer. However, none of these studies directly addressed ACP conversations.

Kayser-Jones (2002) provided some insight into two aspects of EOL care. The researcher took a comprehensive look at understanding the process of providing EOL care to patients who

were dying in a nursing home and the experiences of their families. Several issues were explored, such as the quality of death with dignity, and the quality of communication between patients, their families and HCPs. The staff's lack of attention to cultural needs, cognitive status and their ineffective communication were findings that influenced the dying experience. Unfortunately, the study did not address the issue of ACP conversations. Thus, applying an ethnographic approach to study families' perspectives of ACP conversations in an HD unit is timely and appropriate. The family members' feedback will inform HD programs of whether ACP is an effective tool for addressing EOL care issues within nephrology.

For nurses, ethnographic research provides a means for linking "patients' experiences and nursing practice... in meaningful and sustainable ways" (Oliffe, 2005, p. 398). As I indicated in chapters 1 and 2, the relationships that develop between patients, their families and nurses within nephrology span a client's lifetime. The illness trajectory of ESRD and HD is lengthy, involving transitions and requiring enormous support that is often provided by nurses. The sustainability of ACP within the HD unit is dependent on the quality of the HCP-client relationship. In this study, the participants' histories and illness experiences were diverse, yet they consistently identified several issues as being pivotal factors confounding the HCP-client relationship. Therefore, applying an ethnographic approach highlighted the need for ongoing development of open continuous communication within the HCP-client relationship for facilitating a meaningful ACP experience.

### Theoretical Perspective

An important component of qualitative research is determining the theoretical perspective followed throughout data collection, analysis and drawing conclusions. I followed the theoretical perspective of postmodernist critical theory. Brown, Rodney, Pauly, Varcoe and Smye (2004) described the postmodern frame as "influencing how we view human relationships generally and in health care specifically" (p. 141). They continued by explaining that "social relations shape

and are shaped by individuals within them, and that relationships exist within a broader discursive context” (p. 141). Their argument then is reflective of the ongoing perspectives from North American society, its healthcare systems, in nephrology practice, and HD units in particular that death is a ‘taboo’<sup>16</sup> topic.

Postmodernists are skeptics who do not believe in there being a single truth (Johnson, 2000). “...Truth, beauty, and morality do not have an objective existence beyond how we think, write and talk about them...” (Johnson, 2000, p. 232). The larger worldview influences culture and society in general, as well as the values and practices of everyday life (Best & Kellner, 1997). Boyle (1994) described culture as “having multiple definitions, and the ethnographer’s theoretical orientation influences how s/he makes inferences from what people say and do” (p.160). Research practices are believed to be subjective creative processes dependent upon each researcher’s individual interpretations (Muecke, 1994). Thus, the researcher applying a postmodernist perspective must recognize that the data being collected and analyzed is from a snap shot of a situation at a point in time being viewed through one’s own lens (Rodney, personal communication, September 21, 2005).

In the context of family, a postmodernist perspective acknowledges the complexity and influence that multiple cultural and religious beliefs have on family structures and how family members explain their “illness narrative” (Wright, Leahey, 2005, p.30). Wright and Leahey (2005) explained that collaboration and consultation between nurses and families honour the knowledge and expertise of each person (p. 31). Taking a postmodernist critical theory perspective also sheds light on how pivotal communication between HCPs and clients is within the ACP process. The topics of patient autonomy and the need for family centered care surfaced indirectly in participant interviews. These issues are all identified as postmodernist critical theory concerns. Chesla (2005) reminded researchers working with families that like the persons

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<sup>16</sup> The term ‘taboo’ is defined as a prohibition or restriction imposed by social custom (Barber, 2004, p. 1581).

they study, they too can only see things from a perspective even though they live in layers of interpretation. This recognition is “both liberating and deeply disorientating” providing “a sharper vantage point on the limits and possibilities of science” (p. 382). By applying such a theoretical perspective, Brown, et al. (2004) further acknowledged that there are no easy answers in the aforementioned issues.

McCormick (2003) summarized critical theory as aiming:

To dig beneath the surface of social life to uncover the assumptions and masks that keep us from a full and true understanding of how the world works (p. 38). A major goal of critical theory is to reveal how surface reality often contradicts the underlying reality...what seems natural and inevitable is actually just one possible way for social reality to be arranged (p. 39).

Applying a postmodernist critical ethnographic perspective enabled me to more fully explore with families the complexity of their ACP conversations. As they considered their individual and collective experiences, they were able to share what meaning, value and impact the conversations had on them. Additionally, this exploration permitted me to identify some of the factors that constituted a positive versus negative ACP experience. The study participants shed light on the whole ACP process, identifying not only strengths but also barriers from a number of sources that, for one family in particular, contributed to a negative experience.

#### Data Collection Methods

The most common data collection methods in ethnographic research are participant observation, in-depth semi-structured interviews, examination of existing documents and fieldnotes. Several of these components provide a framework for cross-referencing findings from each data source. This approach then provides the researcher with a means for judging the validity of the data obtained and the truthfulness of the conclusions drawn (Roper & Shapira, 2000). Interlaced within these methods is how I situated myself within the research using

reflexivity. This approach provided me with a critical lens for identifying any potential biases, prejudices or misconceptions both prior to entering the field and during data collection that may potentially have influenced the research process. Under each data collection method, a detailed description and the challenges encountered while engaging in the research are discussed.

### Participant Observation

Participant observation is considered a central data collection strategy within ethnography. The researcher makes systematic observations and gains in-depth understandings of group members' experiences by becoming involved in their community life activities. Conducting participant observations on the HD unit, particularly observing the facilitator engage in ACP conversations presented a challenge. Roper and Shapira (2000) draw from Germain's (as cited in Roper and Shapira, 2000) ethnographic research to discuss seven aspects of participant observation that enables the researcher to achieve "subjective adequacy" (p. 13). The seven aspects are spending enough time in the setting; the location of the study; becoming involved in the social circumstances of the setting; understanding participants' language; experiencing "intimacy" (p. 15) through immersion in the culture; achieving consensus and accurate interpretation of the data; and lastly, being aware of bias. I applied these seven dimensions of participant observation to my study in order to evaluate its effectiveness.

The first dimension involves spending enough time in the field to learn about the people, their behaviours and events in order to be accepted as a member. My professional experience in nephrology nursing over the past 8 years provides me with a broad knowledge base for understanding the complexity of both living with ESRD and receiving HD treatment. I frequently observe how family members interact with each other. Unfortunately, I have not had the opportunity to participate in a renal family's ACP conversation(s) though I have had two ACP conversations with members of my own family. My professional and personal experiences have enabled me to learn a great deal about renal clients and to be accepted as a renal HCP.

Thus, I have a good understanding of interactions that occur between patients and their families, and HCPs and their clients.

The second aspect of participant observation is location, determining the most appropriate place based on the study's topic and research questions. The ACP process entails a series of conversations both informal and formal in nature. Currently, ACP conversations are almost all initiated by one of several ACPFs within the renal program who first approaches the HD patient. Subsequent conversations may not involve an ACPF and/or family member(s), and/or take place on the HD unit.

On the whole, spontaneous ACP conversations are not yet commonplace. If discussions do take place on the unit, they are perceived as private and transpire either directly at the patient's dialysis station while receiving treatment or at the personal residence. Advance care planning conversations can be highly emotional, serious and unpredictable. They tend to be sporadic and often unplanned. Part of the ACP conversation involves talking openly about death and dying and, as previously described in chapters 1 and 2, are still 'taboo' topics in most nephrology settings. Therefore, implementing participant observations of ACP conversations became a challenge and was perceived to be inappropriate by the gatekeepers. Moreover, the utility of observing an ACP conversation came into question since attending a current conversation did not provide time for the family to reflect on their experience, which was the primary intent of this study.

Another option for participant observation might have been to study family interactions on the HD unit, as this could have provided insight into the quality of their relationships with HCPs. Unfortunately, such interactions would most likely not be within the context of ACP or death. Observing family interactions on the unit would also be challenging for several reasons. Families do not consistently attend HD sessions and interactions with the patient and HCP vary depending on patient needs for that particular treatment session. The physical layout would also

limit observations to one area of the unit and the frequent turnover of actual dialysis sessions (2-3 times daily) would significantly limit any in-depth observations.

Additional challenges impeding participant observations on the HD unit involved the issues of patient readiness to address the subject and whether they perceived it to be good timing. Both of these issues are pivotal factors within ACP conversations. As a result of these challenges, the final decision was that participant observations for this master's thesis would be limited to the study participant interviews only.

In the third dimension of participant observation, the researcher is supposed to become involved in the social circumstances of the setting. One social circumstance that I believe would have contributed significantly to my participant observations, particularly observing how families interact with staff within the context of death, was by attending the HD unit's memory tea. The memory tea is a time for family members, peers and renal staff to commemorate the deaths of the unit's HD patients. A detailed discussion of this event is found in chapter 5. Unfortunately, I only learned about the memory tea towards the end of the study and at the time, I did not inquire about attending it. However, I am unsure whether my presence would have seemed intrusive and/or inappropriate. The challenge with discussions about death and ACP, as previously discussed in chapters 1 and 2, is in being able to ascertain a person's emotional response to them.

The fourth aspect in participant observation is language. The study enrollment criteria specified that all participants speak and read English. This criterion posed limitations on recruitment because a large percentage of clients on the HD unit had English as a second language. Roper and Shapira (2000) draw attention to another challenge in language. They assert that the researcher who routinely works within the study environment may be biased by a personal familiarity with the setting thus becoming insensitive to nuances and missing relevant communication patterns (Roper & Shapira, 2000, p. 15). This challenge presented as both a

strength and potential risk for me. Its strength was that clients and myself shared the same language of the disease process, its treatment options and common disease related events.

Our shared familiarity proved to be an advantage and comfort to participants who did not have to spend time explaining various technical terms and during the interviews, they indicated their appreciation of this. However, the risk in my having this knowledge was that it potentially prevented me from asking certain questions and/or taking for granted certain participant experiences. My thesis committee and hospital supervisor became my secondary critical lens throughout the study, as they were not experts in the field of nephrology. A secondary approach to this risk was in keeping a reflexive journal, which is discussed in detail later in this chapter under the heading of *Reflexivity*.

The fifth aspect of participant observation involves becoming “intimate” (Roper & Shapira, 2000, p.15) with the participants by immersing oneself in their world. I do not have a chronic illness and though my mother has type II diabetes, she remains independent and has not yet experienced any health complications. Therefore, I do not have “intimate” understandings of the illness experience nor as an informal caregiver. However, engaging my family in an ACP conversation and learning their perspectives, completing the ACP workbook, and finding meaning in death and facing my mortality were personal strategies I used for immersion. I shared some of these experiences with participants to create a stronger connection. I believe taking these approaches informed the participants of my commitment to understanding their experience and the high regard I placed on their perspectives.

One risk in the dimension of ‘intimacy’ is the potential restrictions applied by the members in the setting on what the researcher sees (Roper & Shapira, 2000, p. 15). Throughout the data collection period, I not only sensed this limitation with the study participants during the interviews but also by the gatekeepers in accessing certain information. Prior to embarking on this study, I was a stranger to this setting, a master’s student conducting a study for her thesis. It

is understandable that gatekeepers would be guarded. Being an experienced nephrology nurse and teaching at a reputable college created some trust in my knowledge and capability. However, as a researcher, I was a novice and this was a concern given the emotionally charged topic I wanted to explore. A detailed discussion of my experience with the gatekeepers and HD staff is explained in subsequent sections.

The sixth dimension of participant observation is seeking validation of the data and accuracy of its interpretation with participants. I approached this in several ways. Initially, I asked the same set of study questions to family participants, providing them an opportunity to engage in a family discussion about their perceived ACP experience(s). After the first three family interviews, findings from my analysis were integrated into the next new family interviews. The interviews with the ACPF occurred after the third and last family interview, which enabled me to further validate participant findings by comparing and contrasting their varied perspectives.

The seventh and final aspect in participant observation involves being aware of bias. The source of biases, according to Germain (as cited in Roper and Shapiro, 2000), and Roper and Shapira (2000) can come from the researcher's worldview that is brought into the study. Other sources could include the participants and the gatekeepers who may carry biases towards the researcher. These three facets of bias are discussed in further detail in subsequent sections.

#### In-depth Semi-Structured Interviews

The role of interviews as a method of data collection in ethnographic research is to validate observations made in the field, provide direction for future observations, and gather data about aspects of the participants themselves (such as their personal thoughts) which cannot actually be observed (Shapira & Roper, 2000). Formal interviews are systematic and questions occur after spending time in the field. Understanding the dynamics of the environment and interacting with participants enables "the questions to reflect the participant's worldviews and

not merely what [the researcher] believe[s]” (Roper & Shapira, 2000, p. 75). Informal interviews were not part of this study because participant observations were limited to the participant interviews and not in the field (the HD unit). Each of the five families enrolled participated in one family interview. Two separate interviews were conducted with one of the renal program’s ACPF. The duration of each interview was approximately 80 minutes.

The initial set of interview questions were developed ahead of time and were mainly open-ended. The types of questions were broad at first such as, “What was it like for you to participate in an ACP conversation with \_\_\_\_\_ (patient’s name)?” The questions became more focused over time such as, “What were some of your reactions to what s/he described as his/her wishes?” Since ethnographic research is considered “nonlinear” and “not fixed ahead of time there is flexibility in the types of questions asked, as new discoveries lead to new directions for cultural understanding” (Germain, 1986, p. 149). Another ‘nonlinear’ style of questioning used during the interviews was circular questions, which is well known in family nursing. This style “assists to reveal families’ understanding of problems...and seeks out relationships between members, events, ideas or beliefs” (Wright & Leahey, 2000, p. 160), such as “Could you start at the beginning and describe for me what was happening in your lives when you had your first ACP conversation?”

During participant interviews, I was not always provided with a detailed story of participants’ individual and collective experiences with death. Some participants remained more guarded than others. Their responses shed some light on their comfort level, informing me if I could pursue a particular topic in more detail. Quite often, the participants did not explain why their children were not involved in their ACP conversations or where their husband/children’s father was. Roper & Shapira (2000) pointed out the fine balance a researcher must maintain “between probing for deep feelings and beliefs, and being intrusive” (p. 75). Given the sensitivity of ACP as a topic, probing for deep feelings was done with the utmost respect to

client privacy. If there was any evidence of discomfort or reluctance in pursuing a particular line of questioning, I did not pursue it.

All formal interviews were tape-recorded and fieldnotes were taken with the participant's permission. Participants were encouraged to ask questions pertaining to the study. A comparison of within family responses and between family responses enabled me to search for common themes, negative cases, and contradictions. I often tried to clarify these observations in future interviews either with the next family or by seeking clarification from the ACPF. However, the issues of having a small sample size, being a novice interviewer, and having one negative case all contributed to the limitations of this study. They are discussed in detail later in this chapter under the heading of *Rigor*.

Roper and Shapira (2000) described two potential discrepancies during participant interviews. The first refers to participants who may restrict both access to and the type of information they divulge to the investigator. This restriction did occur with some study participants who chose not to share certain family histories as previously described. The second discrepancy refers to participants who may be reluctant to share their perspective in front of other family members within the context of a family interview, especially if it does not conform to family practices. This discrepancy was not overtly present during the study interviews but could still have taken place.

### Fieldnotes

Throughout the recruitment period, detailed fieldnotes were kept. No participant attrition occurred but notations were kept about the reasons why some families declined to participate in the study. After each interview, my observations, perceptions and interpretations of the participants, the environment during the interview along with both my interviewing and researcher skills were recorded. Documentation of my participant observations was limited during the interviews, as it seemed to affect the flow and felt disrespectful given the sensitive

nature of the topic. After each interview, I committed several hours to writing up my observations in a fieldnotes journal. I documented the “who, what, when, where, why and how” of each interview (Agar, 1980, p. 92) and all of my senses were on the alert. I focused on the following participant nonverbal cues as outlined in Roper and Shapira (2000): speed of speaking; presence or absence of eye contact; emotional outbursts of laughter or tears; changes in body position; and shifts in content. Participants’ emotions, tone of voice, and mood were also observed and noted. Additionally, the verbal and nonverbal cues in how participants interacted with each other and with me, the researcher, were documented.

I gave a copy of all interview transcripts to my thesis committee and we reviewed five of the seven together. Any challenging discrepancies or differing content that I found were also reviewed with the committee, such as trying to understand the meaning behind participants’ being so frank and matter of fact about death. Another example was participants’ tangential healthcare experiences that occurred throughout the illness trajectory, such as when Mark started describing one HD experience, which led him to share a different story, until he stated the following:

“Now we’re getting way away from your subject...but maybe it’s part of your subject in a way...well I mean, I have been around hospitals now for [a number] years with Jane...and I have seen things happening that I thought, good God, it doesn’t even make sense...” (3\_5\_1995-2062).<sup>17</sup>

During data analysis such tangents proved to be very informative, becoming what I came to understand as communication breakdown. I sought feedback from my committee members regarding my interviewing skills and appropriateness of both my questions and depth of probing. We discussed in detail the challenges I experienced as an interviewer and researcher. All thesis committee discussions were tape-recorded and integrated into the fieldnotes.

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<sup>17</sup> The numbers in brackets following each study participant comment, such as (5\_9\_2191-2195) is a numerical log of the statement within the respective participant interview.

The reflexive journal and memoing were two other components of my fieldnotes. The reflexive journal was my constant companion in documenting my experience as a researcher, especially with regard to separating myself from my familiarity as a renal HCP. All of the issues and concerns addressed were often further analyzed in this journal. I utilized memoing throughout data collection and analysis in which reflective remarks, ideas or insights I had about the data were logged (Roper & Shapira, 2000). Memos are a form of coding, requiring further testing since they are not objective. They assist us to “question our understanding of the data and provide direction for further exploration of our study and supporting literature” (p.102). Finally, all of my fieldnotes, the reflexive journal and my memos were strategies used to keep a detailed paper trail throughout the study. The purpose in keeping detailed documentation enables “others to substantiate my interpretations” (Roper & Shapira, 2000, p. 83). A detailed audit trail contributes to a study’s rigor.

#### Situating Myself as an Ethnographer

As a nephrology nurse, listening to personal narratives enables me to understand first hand many of the client’s inherent struggles with ESRD. Germain (2001) described two qualities an ethnographic researcher must possess that are an equal necessity in nephrology nursing. The first calls for the researcher to be authentic and identify with the community while still maintaining a professional distance. In nephrology, the nurse-client and nurse-family partnerships are long-term, often spanning several decades. Within the hemodialysis unit in particular, staff, patients and attending family members interact for a minimum of 12 hours each week. Thus, renal nurses quickly learn how to share aspects of their lives with their patients while still maintaining a professional distance. My nephrology experience creates ease for participants when disclosing their stories, given we share the same disease and care related terminology. I am also better able to attach meaning to their ESRD related events. The

experiences I have accumulated enable me to move between what ethnographers refer to as the 'emic' and 'etic' or insider (as a nephrology nurse) and outsider (as a researcher) perspectives.

The 'emic' perspective refers to the insider's view of the world. It occurs through participant observation and interacting with the participants thus enabling the researcher a deep understanding of the practices and beliefs of the group (McCormick, 1997; Roper & Shapira, 2000). Eight of my 11 years of nursing practice have focused on nephrology, specifically within hemodialysis, peritoneal dialysis and the chronic kidney disease clinics. I teach clients newly diagnosed with chronic kidney disease, clients starting HD treatment, and nurses specializing in nephrology. In particular, I frequently observe how family members interact with each other in the chronic disease clinic and HD unit. These experiences afford me an insider's perspective into the inherent health challenges and lifestyle changes experienced by families living with ESRD and receiving HD treatments. A second 'emic' perspective that has given me insight into the family's experience with ACP is my personal familiarity of going through the ACP process with my family and completing an ACP workbook.

The 'etic' perspective refers to the outsider's view of the world, the outsider being the researcher. Shapira and Roper (2000) described this view to be how the ethnographer observes events and then tries to make sense of them, by continually stepping in, participating in activities and being influenced not only by the experiences but also by the relationships encountered. Then, the researcher steps out to analyze the collected data and identify patterns of behaviours. Interpretations of observations are checked for accuracy using informal and formal interviews with participants. In this study, I compared the family members' observations and experiences with the ACPF's as a form of member checking. Another method used for assisting me to remain reflective in my 'etic' role was my thesis committee and hospital supervisor who do not have any nephrology experience. As previously described, they became a secondary critical lens through

which to identify any taken for granted participant statements; potential biases; assumptions; and missed or misguided interpretations.

The second quality of an ethnographic researcher involves building relationships with informants while keeping data confidential. Earning patients' trust and respecting confidentiality are a necessity when conducting ethnographic research, and are foundational requirements of the nursing profession as part of the *Nursing Code of Ethics* (CNA, 2002), and are part of the *Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans*<sup>18</sup> (1998). Other strengths I brought to the study were being comfortable in health care situations, knowing the language, being accustomed to working with patients from diverse ethnic backgrounds, and having well developed interviewing skills from completing numerous health assessments. These are all characteristics that Germain (2001) suggested as important qualities ethnographic researchers should possess. Roper and Shapira (2000) described various behaviours considered imperative within ethnographic research, such as maintaining a respectful attitude, remaining flexible and adaptable to participants' schedules. Throughout my previous descriptions of data collection methods the application of these behaviours are apparent.

Ethnographic researchers must also learn how to gain entry into the field. My position of being a nephrology nurse enabled me to gain both access into the field and trust from research participants. However, once access is gained, Roper & Shapira (2000) indicated, I was aware that I must step out of the role of nurse, adopting the position of researcher, which I did and found at times challenging to do. One challenge in particular that I encountered was a conflict in my role as researcher versus nephrology nurse. It took place when interviewing the ACPF wherein several of my responses included the collective "we". I referred to us as HD staff rather than keeping myself separated as the researcher. On several occasions, I found myself making

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<sup>18</sup> The full reference is as follows: the Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada Tri-Council Policy Statement on Ethical Conduct for Research Involving Humans, 1998.

similar statements within family interviews. It was a challenge to maintain this distinction of roles given how comfortable I am in my nephrology-nursing role and not in my researcher role, as I am a novice. My awareness of such challenges occurred through the application of reflexivity.

### Reflexivity

Roper and Shapira (2000) described reflexivity as a process that intentionally uses the self as an instrument within one's research. It includes contemplating "the reciprocal exchange between the ethnographer and study participants" (p. 116). Reflexivity requires that the researcher remain "completely aware of oneself, one's responses, and one's internal state in relation to a specific situation, and at the same time attempting to understand the patient and the situation" (p. 26). It enables the ethnographer to identify potential biases, prejudices or misconceptions both prior to entering the field and during data collection that may potentially have an influence on the research process. It also provides a means for maintaining rigor because it supplies readers with details of the study's activities; enabling them to decide for themselves whether the text is believable (Koch & Harrington, 1998).

My values, beliefs and knowledge make up my worldview that I bring to my research. Preconceptions will influence my data collection, interpretation of findings, and the description of those findings. At the outset of the study, I spent some time identifying both my professional and personal reasons for choosing the topic of ACP from the family's perspective. Wright and Leahey (2005) emphasized the importance in recognizing my own 'ethnic blind spots' and to consider how they may impact my perceptions (p. 73). This was of particular interest given the amount of research being done on the issue of patient autonomy and how it is situated within a person's ethnic and cultural context (Blackhall, et al., 2001; Blacksher, 1998). One of my 'worldviews' that can act as an 'ethnic blind spot' is how I view patient autonomy. I realize that for my personal self I believe in self-determination and being centre stage in all decision making.

However, I have learned over time and through developing this study that not all people view patient autonomy in the same light. Therefore, as described in the studies of Hern, et al. (1998), I have come to respect a new way of understanding patient autonomy within my professional practice. It encompasses not only the patient being centre stage in all decisions but also for the patient to chose his/her family as the primary decision makers. In both cases, patient autonomy is maintained and respected.

Midway through my study, my thesis committee referred me to the book titled *Emotions and Fieldwork* by Kleinman and Copp (1993), which made me question my initial depth of self-analysis. Thus, I regrouped my thoughts and spent more time reviewing my initial reflexive journal entries. Kleinman and Copp recommended that a set of key questions be answered prior to entering the field, such as: What images do I hold of the people and the place I am about to study and how do I feel about those images? How did I come to study this setting at this time? What kinds of setting activities or subgroups might I avoid or discount because of who I am or what I believe? Answering these questions brought further clarity to how I situated myself within ethnographic research. Throughout this study, the authors Kleinman and Copp (1993) provided me with a resource of critical questions to answer that enabled me to maintain a strong sense of self-analysis, particularly as I moved between the ‘emic’ and ‘etic’ viewpoints.

### Research Design

#### Preliminary Fieldwork

Preliminary fieldwork entailed becoming familiar with ACP given that it was not part of my current nursing practice. This occurred in three ways. The first was by attending a 2-day workshop on becoming an ACPF during the spring of 2006. The second element involved attending several local conferences on EOL care issues within the context of the provincial healthcare system. I spent time researching the current issues and published evidence on all aspects of ACP. Lastly, I accessed someone who was familiar with ACP at an operations level.

As part of our interaction, I received a report presented in a table format summarizing the findings from an ACP HD pilot project ([Health Region A], 2004). This report provided data on the outcomes of the pilot project but did not provide details of its inception or process. Knowing some of this information would have assisted me in learning more about how ACP came to be in the health region where the pilot project was conducted. It may have highlighted any challenges encountered, how staff was originally prepared for the project, and how it actually played out.

### My own Advance Care Planning Experiences

I attended a 2-day ACP workshop on becoming an ACPF, which was an insightful experience. As part of our homework, I broached the topic of ACP with my fiancé and was surprised to see his complete discomfort in discussing the topic. He was also not ready to share his own wishes at the time. The second part of the homework was to complete the ACP workbook, which I did and was shocked by the amount of emotion it stirred. Going through this process helped me to realize just how hard it is to face not only my mortality but also in talking to a loved one, especially if he is not ready to do so. My experience was not unique to the group as I found out the following day. In fact, many participants at the workshop indicated that their family members would not engage in such a conversation at all. I saw this experience as twofold. It foreshadowed the potential challenges I might encounter when broaching this topic within my professional practice with my renal clients. It also foretold of the difficulty I might have in recruiting HD families to share their ACP experiences for this study.

A second major contribution to exploring ACP from a personal perspective occurred when I engaged my whole immediate family in an ACP conversation about my wishes. This came about after first consulting the study participants. As part of each study interview, I had asked participants what advice they could give me if I were to approach my family about engaging in ACP. I then took their advice and broached the topic with my family and it proved to be effective. The outcome from this conversation was to assist me to overcome my own

personal and professional discomfort with the notion of death, facing mortality and talking about them within the context of ACP. Furthermore, these approaches assisted me in understanding the study participants' experiences, even though mine were not in the context of a chronic illness.

### Contacting the Gatekeepers and Gaining Access

The gatekeepers introduced me to their current program within their health region. They were interested in having a research study conducted on one aspect of their program and I was keen to implement my study. We shared a mutual goal of advancing research on ACP. I was introduced to a second set of gatekeepers who consisted of the current ACP regional team and the ACP renal team. Once initial introductions were completed, we sat down to negotiate the logistics of my study being implemented on one of their HD units.

Roper and Shapiro (2000) describe the first step when conducting ethnographic research as gaining entry into the area under study. The researcher must put aside any preconceived notions in order to gain a fresh perspective. In my study, gaining access was a challenging experience that took time and perseverance. The numerous gatekeepers supported me throughout the whole experience. Even with this ongoing support, I had not anticipated the multiple challenges I would encounter in learning how to navigate through a different healthcare system and renal program. I was a stranger who had to demonstrate her capabilities both as a renal nurse (theoretically only) and as a researcher. I had to learn how to argue for the significance of my study--that of wanting to understand the family's perspective. I also felt that I had to make a case for using a qualitative perspective with a small sample size. I had to gain skill at knowing what questions to ask and to whom. I quickly learned the parameters under which the study could unfold.

The challenges I encountered at the outset included none of the gatekeepers, my thesis committee or myself being familiar with the logistics of family research or the receptiveness of how the study would be received by HD patients and their families. Conducting research with

families within an outpatient clinic and seeking feedback on a sensitive topic such as ACP proved to be a double challenge. It was only after consulting an experienced researcher familiar in both areas that I learned just how difficult implementing this study was going to be, particularly regarding the recruitment of participants. This discussion is explored in detail in the following sections.

### Setting

The setting for this study was an approximately 25-bed, in-centre HD unit in a large urban tertiary hospital located in the province of British Columbia, Canada. The HD unit has approximately 150 patients who routinely dialyze. The renal program has several ACP facilitators, and the ACP program has been active on this HD unit for several years. Advance care planning conversations within this unit are varied. The ACPF seeks out several types of patients. The first group are those whose health status has changed, who may be approaching a critical health crisis and who have not yet been invited to engage in an ACP conversation. Otherwise, the ACPF approaches patients as time permits, introducing the topic and presenting an invitation to participate. The option for self-selection from either the patient or family member is open. However, I have since learned that few people initiate ACP conversations; rather they are initiated by the ACPF due to multiple factors that are discussed in detail in the following two chapters. Occasionally, other staff inform the ACPF about a particular patient and/or family who mentioned or had questions about ACP and the ACPF will follow up with them.

The ACPF also invites the family to join a conversation if they are present. Otherwise, patients are encouraged to take the information home, informing their family of the topic and the invitation. Quite often, patients and/or their families need time to consider the topic and its meaning before choosing to engage with the ACPF. Some ACP conversations take place during the patient's dialysis treatment, surrounded by family and the facilitator. Other times, the

facilitator conducts the conversations at the family's private residence. The timing and locale for these formal discussions are determined by the HD patient and/or family.

After speaking with the renal manager, I received permission to interview families during the dialysis treatment at their discretion. Out of the five families interviewed, only one took place on the unit during the patient's HD session. The remaining ones occurred at the patient's personal residence with their consent.

### Sampling

An adequate sample size in qualitative research is one that permits case oriented analysis and that results in a new and richly textured understanding of experience (Sandelowski, 1995, p. 183). Providing clear descriptive explanations of the processes and steps used in sampling enhances the credibility of qualitative findings (Canadian Institutes of Health Research, et al., 2005). Sampling within ethnographic research is determined by richness of the data collected and how well "the full context of the culture is portrayed" (Germain, 1993, p. 249). It is also determined by how well the research questions are answered, as opposed to having a specified number of participants through random or systematic sampling (Germain, 1993).

Sandelowski (1995) indicated that sample might refer to numbers of persons, interviews, observations conducted, or events sampled (p. 180). She stated that a sample size of 10 for homogeneous sampling may be considered adequate, so long as the limitations of the extent to which generalizations can be made are acknowledged, and that theoretical sampling of the intended product for that moment in time was achieved. Sample size for this study was set at 5 to 10 families, depending on the rate of enrolment. The size was deemed appropriate given it's the study's scope was a master's level. All decisions regarding sampling were made in consultation with my thesis committee members who were familiar with conducting both qualitative and ethnographic research.

The sample size of this study was 5 families, consisting of the HD patient and one chosen family member. The two members were interviewed once together. A detailed description of the study participants is outlined under the heading *Research Design, Introduction to Research Participants*. Additionally, an ACPF from the renal program was interviewed on two separate occasions, being used as a ‘key respondent’ (Roper & Shapira, 2000, p.77) in order to validate information obtained from other sources and provide feedback on hypotheses. This ACPF estimated having completed approximately 150 ACP conversations with HD clients since the ACP program’s inception on the unit.

Sampling within this study was purposive and involved deliberately selecting participants who appeared knowledgeable about the research topic and/or had experienced the topic first hand (Roper & Shapira, 2000). Roper & Shapira (2000) stated that by checking similarities and differences of the information provided and seeking out people with wide ranges of experiences, the researcher attains a more complete understanding of phenomena and concepts (p. 79). The study’s sample was derived from the tertiary hospital’s in-centre HD unit. I chose an in-centre HD unit over accessing one of several community based HD units because of its larger eligible patient population.

Participant eligibility included English-speaking, at least 19 years of age, and able to give informed consent. The HD patient was currently receiving HD treatment within the particular unit, had involved at least one family member in their ACP experience, and had completed the ACP process that included having filled out the specified ACP workbook. My thesis committee in consultation with the gatekeepers and the health region’s Research Ethics Board (REB) determined this particular criterion for selection. The gatekeepers determined that improved consistency in family experience would occur if all enrolled families had completed the ACP process as opposed to having some still engaged in the process. The selection of subjects who had already completed the ACP process also alluded to them being an excellent source of

information, and they had the potential for introducing a variety of unique perspectives, given that each family is uniquely diverse.

### Recruitment and Encountered Challenges

Recruitment occurred over an 11-month period, from September 2006 until July 2007. Two staff information sessions were held in which the study was discussed in detail and questions were answered. The staff indicated their support and interest in the study. In hindsight, however, I realize that personal disclosure would have helped me to connect with the nurses. I could have shared several of my professional experiences in which I encountered ethically distressing EOL care dilemmas that became the primary reason for pursuing this topic of study. In addition, I did not highlight the numerous ethically challenging decisions that nephrology nurses encounter in their daily practice (Starzomski, 2006). Lastly, I could have engaged the staff in a meaningful discussion, asking them to share their experiences, particularly with ACP on the unit or how they perceived their role in it.

Staff support was integral to study recruitment because patients were likely to be trustful of something the unit supported. However, some patients may feel pressured and obliged to participate for risk of receiving poorer care or may think they are disappointing a staff member (Roper & Shapira, 2000). Therefore, having the researcher and staff affirm that participation was voluntary and that the patient's current care would not be affected were two steps that addressed the risk of coercion. Given the risk of coercion and the risk of the staff being both a recruiter and primary caregiver, the REB laid down specific parameters for how participants could be recruited. Neither the renal staff nor myself were permitted to approach patients directly to hand out study information letters. Unfortunately, these parameters contributed further to the challenges encountered in recruitment.

The REB also determined that leaving these letters in patient charts would still require staff to hand them out thus was not supported. If patients had questions about the study, renal

staff was not supposed to answer but rather direct them to a study letter, containing my contact information. Unfortunately, I did not have a constant presence on the unit to facilitate ease in answering potential participant and staff questions that arose, which would have aided in promoting or ‘spreading the word about the study.’

Another recruitment strategy that was proposed to the gatekeepers and REB was to mail a study introductory letter to the family residence of those eligible families, but they both declined this option. My understanding is that they were concerned in receiving a negative reaction by families given the sensitivity of the topic and it being perceived as a private issue. Therefore, it was determined that posters and information letters would be left on the unit and interested participants would contact me. The posters introducing the study were prominently displayed within the HD unit (or so the gatekeepers, thesis committee and myself thought) in areas regularly accessed by patients. These areas included the ice machine, the wall behind the scale, in the patient washroom, and the wall in the waiting area. However, during the participant interviews, I learned how ineffective the use of posters for recruitment purposes on this HD unit was. Several participants indicated not having seen any posters or information letters regarding my study--nor any on ACP for that matter.

The recruitment of families, as I soon learned, proved to be a great challenge. Families do not regularly attend HD sessions with the patient. Therefore, I had to access them through the patient. Not all HD patients have participated in ACP, because it is not a requirement and those who did participate may not have involved a family member. Of those patients that had ACP conversations not all had completed the initial process and completed an ACP workbook. In several circumstances, the family member who was involved had since died, leaving the patient who was interested in joining the study not eligible. However, regardless of the above limitations to potential enrolment, the gatekeepers indicated that approximately 100 patients had gone

through ACP on the unit, many with their families. Therefore, it was felt that enrolment may be slow but not difficult, given I was looking to recruit 5-10 families.

After two months, I had not received any calls of interest. I spoke with staff on the unit and learned that few patients or families had approached them and those that had, expressed confusion over the purpose and intent of the study information letter. My understanding is that several patients misunderstood the information letter as being the study consent form. Additionally, as I learned through some participant interviews, many patients did not realize that in order to receive more information about the study they had to sign the information letter, dropping it off in the box that was left at the nursing station or contact me directly. This information was all explained within the information letter. Thus, I was confused in trying to understand where the breakdown in communication stood. Therefore, the question for me became whether it was the recruitment strategy that was ineffective or the study topic that was not of interest.

My hospital supervisor suggested contacting a nurse researcher experienced in working with families in the context of ACP (Robinson, n.d.). The researcher had recently conducted a study that required a similar sample population and had encountered many of the same challenges with recruiting families, particularly within an outpatient setting, and due to the sensitivity of the topic (Robinson, personal communication, 2006). Her experiences validated the recruitment challenges we were experiencing, and she had useful feedback to share. Armed with the nurse researcher's suggestions, we regrouped to revise recruitment strategies. A second approach used to understand the challenges encountered in recruitment was to look at the literature. Unfortunately, I could not locate information addressing the potential challenges in family recruitment, particularly within the context of EOL care.

Three additional factors were identified as contributing to slow recruitment. The first involved a clarification in the actual number of eligible participants on the HD unit. Originally,

the gatekeepers informed us that 100 HD patients had gone through the ACP process. The original large pool was retrospective to the inception of ACP on the unit and did not account for the large number of patient deaths, family member deaths who had participated in ACP with the patient, and transfers to community HD units. I later learned the following information during an interview with the unit's ACPF, who stated the following,

“I think part of the reason we haven't had a lot of people to participate with their families talking to you [in your study] is that a lot of them have died and that in a way, I think I chose a lot of people who needed some resolution in a short period of time. So, I started with them” (01\_ACPF\_382/389).

Consequently, the actual number of eligible families proved to be eight, of whom one HD patient died, another patient's renal function recovered and one family declined to participate. In speaking with the patient whose family declined, the reason was due to the daughters being “not ready to revisit the topic” (Anonymous HD patient, personal communication, 2007).

The second factor contributing to slow recruitment involved clarifying the meaning of family. The ACPF brought it to my attention that both staff and patients did not understand my original definition of family as being: *who they say they are*. Therefore, a more detailed definition specifically outlining who such members could be was developed. The new definition was as follows: *Family may include one or more person(s) who fit the following criteria: a significant other, immediate family member, relative, and/or close friend with whom you [the patient] spoke to about your advance care plan; possibly your values, beliefs and wishes surrounding end-of-life care; the person(s) with whom you shared your thoughts about death and dying; or the person you appointed who will speak for you when you are not able to speak for yourself*. This definition was developed in consultation with my thesis committee, hospital supervisor and the nurse researcher.

The third factor that at the time I did not realize potentially contributed to slow recruitment was learned through the participant interviews. Study participants described ACP

and death as being hidden almost not permitted topics of discussion on the unit, let alone within North American society in general. This discomfort, as previously discussed in the literature review is well documented, spanning several decades. Only when the ACPF specifically initiated ACP conversations with patients and their families were these topics openly discussed, but were limited to these specific interactions. The study participants described how both the staff's and other patients' discomfort with death and ACP contributed to communication breakdown between clients and HCPs. Even though ACP was active on the unit for several years and some participants had been receiving dialysis on this unit for several months, they indicated that they were not aware of its existence until the ACPF approached them.

The ongoing challenges I was encountering were presented to the REB, and after several revisions to recruitment, over the following months, a successful plan was developed. This approach was twofold. The first change entailed a medical staff person from the unit obtaining assent for 'permission to contact' from those HD patients meeting enrolment criteria. This approach enabled the medical staff person to clarify that the information letter was not the study consent form, and by obtaining verbal assent, any participant discomfort in signing a form was removed. The medical staff person provided those patients with a study information letter and upon receiving their permission, obtained their contact information. I could then approach them on the HD unit to discuss the study. If families agreed to enrol into the study, they booked a date, time and location for the interview. The consenting process occurred prior to interview commencement. Any attrition was documented in my fieldnotes.

The second revised recruitment strategy was receiving permission for me to be present on the unit to answer questions if someone approached me. However, I had to remain in the patient waiting area and could not approach patients once they were connected to the dialysis machine for their treatment. At first glance, this approach seemed like an effective strategy. It provided me with an opportunity to create more of a presence as a researcher on the unit. As the

recruitment wore on, I noticed several items in the study missing on the unit. I no longer could locate the study information binder I had left for staff to peruse. The study information letters went missing along with the small box for collecting the signed ‘consent to contact’ slips of paper. I learned that the nursing unit had been ‘tidied up’ and many binders and so forth had been relocated to an office, and it was assumed that these study items had gone along with them. Upon learning that I could create more of a presence for myself on the unit, I hoped that these issues could be addressed. Unfortunately, this revised recruitment strategy too had significant limitations and as a result, I abandoned this approach.

The window of opportunity for interacting with patients and their families was small, given that patients usually arrived less than 30 minutes prior to their HD session, when they collected their supplies and weighed themselves prior to going to their HD station. Once patients were on HD, they would most likely not inquire about my presence, as they would be preoccupied with their treatment. Conversely, at the end of treatment, patients reweigh themselves, often use the washroom and then leave the unit, frequently in a hurry to catch their transportation (often public transportation called Handidart), which runs on a tight schedule.

It is important for me to stress that the reflective discussions I share here are meant to draw attention to how death in HD, regardless of the particular unit, remains a shunned ‘taboo’ topic, and how participant recruitment in a study such as this therefore faces many emotional as well as practical barriers. Accounts from the literature review in chapter 2 highlight the multiple challenges and pitfalls inherent with the topics of death, EOL care and ACP. Death, as previously discussed in chapter 2, is complex and multifaceted. Not only does it involve our personal histories, experiences, beliefs and values but also those of every individual involved in it. Additionally, the anxiety that HCPs experience in anticipating a negative response from clients in broaching the topic, the perpetuated paternalistic approach to care, and HCPs’ lack of knowing how to articulate or talk openly about death all contribute to its complexity.

This discussion is not about criticizing the HD unit. On the contrary, all of my interactions with staff, including the gatekeepers and REB, were extremely positive and exceptionally supportive. Rather, it is about drawing attention to the need for comprehensive approaches at all systems' levels to address these inherent challenges head on. The renal team has already advanced provincial nephrology practice by introducing ACP into the unit and is now beginning to identify various barriers, implementing strategies to support future growth. It is my hope that the insights from this thesis will inform that growth.

### Introduction to Research Participants

The research participants were diverse, having a variety of personal and familial experiences. They held different positions in their families and varied in age. There were five families with two members who participated in the study, one being the HD patient. Each family participated in one family interview. An ACPF from the renal program also participated in two separate interviews. To maintain confidentiality of participants' identities, particularly because of the study's small sample size, some details and characteristics are purposefully vague and the order of the family interviews has been changed.

*Family One: Lucy and Joanne.* Lucy is in her 70s, lives alone, and is a mother of three. She is non-Caucasian and divorced. Lucy started HD 2 years ago and went through the ACP process with an ACPF in the past 6 months, completing the ACP workbook at that time. She had previously spoken with her family about her EOL care wishes but not in the context of HD, which in turn changed some of her previous wishes. Lucy has a complex health history with other pre-existing co-morbidities. She appointed her adopted daughter Joanne as her SDM. At this time, they do not feel it necessary to make this a legally binding process. Lucy indicated that all of her children were in agreement that Joanne would be her SDM if she were to become incapacitated.

Joanne is in her 30s, married with a toddler. She works full-time as does her husband, and she is the primary caregiver for Lucy, who she refers to as her mother.

*Family Two: Sue and Mabel.* Sue is in her 80s and married. Her husband is her primary caregiver in the household. Mabel is her daughter. She started HD 6 years ago and went through the ACP process with an ACPF approximately 3 years ago, completing the ACP workbook at that time. She had not previously spoken with her family about her EOL care wishes. She chose not to involve her husband in the study but rather her daughter. However, during the ACP process, Sue involved both her husband and daughter in the conversations. Sue's health is relatively stable, describing her kidney disease as her main health concern.

Mabel is in her 50s, married and is a homemaker who spends a lot of time supporting her mother through ESRD.

*Family Three: Jane and Mark.* Jane is in her 60s, married and has two adopted (adult) children. She has an extensive ESRD history with no other significant co-morbidities. This is her second time on HD and has been dialyzing now for approximately 2 years. She went through the ACP process approximately 2 years ago, completing the ACP workbook at that time. She did not have any prior EOL conversations with her family. Jane involved her husband in her ACP conversations but had not discussed her wishes with her adopted children or other family members at the time of this study.

Mark is in his 60s, has several chronic illnesses and is currently on disability. Both Jane and Mark are independent and physically capable of managing their own respective health issues.

*Family Four: Rebecca and Veronica.* Rebecca is in her 70s and has four children. The status of her husband/children's father was not shared. She lives with her granddaughter who provides supervision and minimal assistance in the home. Rebecca has been on HD

for less than 6 months and has an extensive health history with several co-morbidities. She went through the ACP process with the ACPF less than 6 months ago, completing the ACP workbook along with several other related documents at that time. She had previously spoken with her family about her EOL care wishes and since starting HD those wishes have been revised. She has involved all four children in the ACP process offered by the HD unit. Veronica is the most involved daughter in her care though all siblings keep in close regular contact with Rebecca.

Veronica is in her 40s, married with four young children and is a homemaker. She was the only sibling to participate in the study, mainly due to the “others having hectic family and work schedules.”

*Family Five: Susan and Walter.* Susan is in her 80s, married with two children. One child is deceased and the other is estranged. Her husband Walter is her primary caregiver. Susan is crippled with multiple health complications and is dependent on Walter for all of her care needs. This is her second time on HD and has been dialyzing now for approximately 6 months. She went through the ACP process within the past 6 months, completing the ACP workbook along with several other related documents at that time. Her husband has known of her EOL care wishes for many years and had previously completed DNR orders and other directive documentation during prior hospitalizations. They recently revised and reconfirmed her wishes through the ACP process offered by the HD unit.

Walter is in his 80s, independent and physically very strong. He manages the household responsibilities and all of his wife’s care. They choose not to access any community resources to assist with Susan’s care needs.

*The ACPF.* The facilitator has been a HCP for more than 20 years, a renal staff person for the past 10 years and an ACPF for over 3 years.

Implications of family member diversity. The members' who held similar positions across participant families such as husbands versus daughters described different sets of needs that were based on their position in the family. The contrasting perspectives from the individuals occupying a particular family member position highlighted additional individualized needs. The implications of the diversity of study participants are strengths of this study. Even though the study's sample size is small, the consistency of participants' collective responses creates a strong argument for ACP and effective communication. Chapters 4 and 5 provide explicit examples of the individual and collective needs of family members in both the ACP process and within the HCP-client relationship.

### Data Analysis

“Qualitative analysis is mainly about maximizing understanding of the one in all of its diversity; it is case-oriented, not variable-oriented” (Ragin & Becker, 1989 as cited in Sandelowski, 1995). Data analysis is an inductive process, beginning with what is learned from the data rather than from preconceived ideas (Roper & Shapira, 2000). The information that emerges from collected data “guides the kinds of questions that can be answered by the project” (p. 93). The procedures used for analyzing the data are derived from Roper & Shapira (2000) and included coding fieldnotes and interviews; sorting to identify patterns; generalizing constructs and theories; and memoing to note personal reflections and insights. “During this process, the researcher moves back and forth among the steps” (p. 93).

Data analysis started after the third family interview was completed. I approached data analysis with each interview transcript in the same way by first reading it through along with the fieldnotes to become familiar with its content. I then created a 3-column table. The first column included all of the participants' remarks about any aspect of their ACP experiences. The second column included initial interpretations and observations about their statements or my accompanying fieldnotes. I also noted if participants from other family interviews made similar

or different remarks about the same issue or topic. The third column included my feelings; a critical analysis of my performance as the interviewer; the quality of my questions; and how well I listened to participants' responses. I also included thoughts on the following: future questions or on modifying current ones for upcoming interviews, comments about how statements were linked to the literature, and on identifying gaps in existing research literature.

Roper and Shapiro (2000) explained that as data are gathered they are identified and classified, progressing to more "abstract generalizations" as "patterns of behaviour and rules of the cultural group" are discovered and explained (p. 93). In order "to gain these [meaningful] insights, conducting inductive analyses requires immersion in the material" (p. 93). Identifying potential groupings was easier after each interview was broken down into the table format. Some groupings were based on a particular question I had asked while others emerged on their own, such as "being matter of fact about death" and "facing mortality." These common groupings were then colour coded. The same approach was applied to the next 2-tabled interviews. Coding for descriptive labels occurs when all of the gathered data are "first grouped into meaningful segments and then organized to compare, contrast, and identify patterns that shed light on beliefs and practices of the people in [the] study" (p. 94). This first-level coding helped to condense and reduce the data.

The remaining interviews were categorized using the same table format and similarly coded. The descriptive codes were later combined to generate broader and more abstract categories. Roper and Shapiro (2000) indicated that changes over time in the coding process occur as ideas about what is read, heard and sensed evolves. Several patterns within the study data were consistently identified in each participant interview. The role each participant held in the family made a difference to their experience. The described experience of a husband versus an adult child differed from each other yet were similar for each grouping. A second pattern was how each family provided their history of the illness experience that was fraught with

communication breakdown, caregiver stress and being kept at arms length by HCPs.

Communication breakdown became an overarching theme throughout each family interview.

I searched for any outliers throughout the data analysis process. Roper & Shapira (2000) described outliers as cases, situations, events or settings that differ from the rest of the findings. They can be used to test the rest of the data, possibly strengthening the analysis and potentially offering information that contributes to a clearer understanding and explanation of the findings (p. 99). One family out of the five interviewed described their ACP experience as negative and this became the outlier. The family was able to illustrate the factors that contributed to their negative experience, highlighting the primary issue as being communication breakdown. Ironically, these factors were the same ones identified by the other families as positive in their ACP experience. Therefore, the difference in having a positive or negative ACP experience seemed to hinge on how the process occurred.

Once all of the data relating to the ACP experience were analyzed, I reviewed all of the interview transcripts, seeking the data that I had initially left out. Each family interview contained what I had labelled as tangents about previous experiences with HCPs. I spent a lot of time trying to understand the underlying message in these families' experiences within the healthcare system, and how they related to their ACP experiences in the HD unit. Families described how imperative communication was in facilitating a positive ACP experience. As I took a step back from the data, I saw several important "if-then" relationships.

Roper and Shapira (2000) described these "if-then" questions as testing hypotheses or hunches that are based on the researcher trying to make connections between information learned from the data (p. 98). The following statements reflect several "if-then" relationships. If families' previous experiences with HCPs were predominantly negative, fraught with communication breakdown, then the accompanying negative feelings are forefront as they enter into HD and particularly ACP. A second "if-then" relationship was that if families are said to be

an integral part of patient care and to the ACP process, then their voices must be heard and their needs valued as equally important in HD. A third “if-then” relationship was that if HD staff perpetuates death as a ‘taboo’ topic, then ACP on the HD unit will continue to be fragmented and side lined. These possible themes emerged that explained recurring relationships between participants and HCPs.

The next level of analysis was to develop constructs and theories emerging from the data. Constructs and theories are generalized. Their purpose is “to generalize findings about the cultural world of study, find linkages between the ‘emic’ meanings and worldview of study participants and [the researcher’s] ‘etic’ interpretations of those meanings, then construct theoretical understandings that take both of these perspectives into account” (Roper & Shapiro, p.100). An important construct emerging from the data was this seeming contradiction between initiating a progressive ACP program yet death remaining a ‘taboo’ topic. This HD unit has taken steps towards tackling a very difficult topic head on in what I see as being one of the greatest challenges in current HD care. On the other hand, the notion of death and the associated fear in anticipating a negative reaction seems to plague this HD unit’s staff, patients and families which consequently may be threatening the future growth of ACP within the program. The study participants’ accounts, which I present in the following two chapters puts a spot light on this seemingly contradictory situation.

### Rigor

Rigor is vital in qualitative research and the methods I used to maintain rigor included auditability, credibility, fittingness, and confirmability, which were derived from Sandelowski’s (1986) description of Guba and Lincoln’s approaches. Applying this approach matched this study’s methodology. In order to provide a suitable audit trail, as I indicated earlier in this chapter, I maintained a reflexive journal wherein I kept track of my decisions, reflections, insights and emerging analytic ideas. As part of my journal, I regularly engaged in self-analysis

throughout the entire study, enabling me to constantly question how my role and my critical lens potentially influenced the data.

After each interview, I immediately logged fieldnotes in order to maintain their accuracy, noting my initial impressions and observations. I used the advice from both Roper and Shapira (2000), and Kleinman and Copp (1993) for direction on maintaining accurate and appropriate fieldnotes that would provide a “decision trail” (Sandelowski, 1986, p. 33) for future researchers to follow. All of these strategies contributed to the credibility of the study.

The credibility of the study participants’ knowledge as resources of information is another important factor contributing to the study’s rigor. All of these families are experiencing ESRD and HD first hand. They have also gone through the ACP process and thus will be able to comment on both their individual and collective experiences and can provide constructive reflective feedback on its presence and effectiveness on the HD unit. I further enhanced my study’s credibility in this chapter by providing a description of my behaviour and experiences as a researcher in relation to those of the participants (Sandelowski, 1986, p. 30).

Strategies that I applied within this study to improve trustworthiness of the data included contrasting and comparing the perspectives and responses of the HD patient, family member and the ACPF as data sources. “Trustworthiness becomes a matter of persuasion whereby the scientist is viewed as having made those practices visible and therefore, auditable” described Sandelowski (1993, p. 2). Demonstrating the credibility of study participants’ knowledge and understanding of the subject matter contributes to the trustworthiness of the data collected.

Sandelowski (1993) further stated “researchers informally engage in member validation every time they seek clarification for or elaboration of meaning and intention from the people they interview or observe, or check out their evolving interpretations of the data they collect” (p. 4). As I indicated earlier, the data analysis process started after the first three participant interviews were completed and then continued as new interviews were finished, thus enabling

for some preliminary emerging findings to be clarified within the next new family interview or second ACPF interview. Nonetheless, this approach was limited given my novice skills in identifying patterns and themes emerging from the data set. It meant that I first had to complete three family interviews before I could start to see similarities and differences.

The small sample size in this study acted as a strength because it facilitated in-depth interviews with each family member and the ACPF. Time permitted for completing a detailed data analysis of each entire transcript. This approach contributed to the study's comprehensiveness thus yielding meaningful participant description that not only included a summary of participants' perspectives, observations and interpretations of their ACP experiences, but also their concerns regarding communication (breakdown) and how the issue of death is perceived on the unit.

The small number of families recruited prevented me from completing a more thorough application of member validation. However, I reviewed the interview transcripts multiple times over the course of data analysis and compared my novice ideas regarding interview content with my experienced thesis committee members, who either confirmed or challenged my interpretations. In addition, the majority of findings reflected those found in other studies on EOL care and ACP within the context of chronic illness. The similarities shared among these differing studies along with confirming the fit of the findings with my thesis committee all contributed to the criterion of fittingness where the findings can "fit" into contexts outside the study situation (Sandelowski, 1986, p. 32).

The diversity in study participants' characteristics provides additional strength in the accuracy of the study findings. Participant's position within the family, such as being a husband versus an adult child to the patient; their varied length of illness trajectory and its complexity; and the varied timing of their initial ACP conversations in relation to length of time since initiation of HD treatments and time passed before participating in this study all contributed to

their diversity. Even though such diversity among HD patients and their family members existed, they all identified numerous consistencies in their experiences and their unfailing messages to HD staff about their experiences. In addition, comparing ACP experiences from both within family members' and between families' perspectives were an effective approach for confirming emerging themes. Nonetheless, making any definitive conclusions of the findings would require a larger sample size. Comparing all of the family participants' responses to the ACPF's perspectives further contributed to the accuracy of the data.

In qualitative research, "validity does not rest on reliability," particularly within a "naturalist/interpretive paradigm" in which "reality is assumed to be multiple and constructed" (Sandelowski, 1993, p. 3). The personal recounts of the participants' ACP experiences will most likely never be told the same way twice because it is part of their past. Their personal recounts are constantly being impacted by new ones, which subsequently affect their perceptions of them each time they are told again. Each person's story will be told differently with each new listener.

The study participants' ACP conversations were from one moment in time of their illness trajectory. A researcher applying a postmodernist perspective must recognize that the data collected and analyzed is from a snap shot of a situation at a point in time being viewed through one's own lens (Rodney, personal communication, 2005). At the time of the participants' interview, they had spent both psychological and emotional time away from this topic. Experiencing this distance from the events being discussed has had the advantage of having time to reflect on the meaning and significance of their ACP experiences thereby becoming a strength in the study. It is quite possible that when these families engage again in ACP conversation(s) at a different point along the illness trajectory their experiences may be different. This occurrence would then create another perspective and set of observations that may complement their initial remarks captured within this study. Conversely, details and events may have been forgotten or distorted by the lapse of time, potentially contradicting initial perceptions, and consequently

weakening the reliability of their experiential accounts. This perspective poses limitations on the findings as fixed in time rendering the interpretation of findings as situated within the limitations of this thesis project. A detailed discussion on other study limitations is presented in chapter 6, under its respective heading.

A final factor contributing to the confirmability of the study findings refers to the accuracy of each person's story being confirmed by the other family member who was present during the interview. This person often clarified time lines of events and reminded the other of their initial reactions, which they themselves had often already forgotten or thought it to be different.

### Ethical Considerations

Prior to the study's commencement, approval was obtained from the health authority's REB, as well as from the nephrology department manager. Members of the health region's ACP team agreed to work with me, as a student researcher. They assisted me in acquiring access to the desired sample population and locale.

The topics of ACP and death are emotionally laden issues that may cause distress. Therefore the REB requested that participants be forewarned of this possibility within the consent form and that they be provided with two supportive resources that were handed out prior to starting the interview. One resource came from within the renal program and the other was an unrelated community resource.

Consent was obtained from each study participant in which their rights as a research participant were discussed and their involvement or lack thereof would not affect the care received on the HD unit. Participants were reminded that they could defer from answering particular study questions, and stop the interview at their discretion. They could also choose to not have their interview tape-recorded and that the recorder could be turned off at any time.

Participants were informed that their participation in the study was confidential and that strategies, such as allocating them an identification number, and not making references to their names would be implemented. However, as the study unfolded the small sample size and the way in which they were recruited invariably increased the risk of their identity being known. The medical staff person who initially approached the study participants and the ACPF are the two HD staff personnel who could potentially identify participants based on certain characteristics disclosed within the study. Therefore, I also changed the sequence of family interviews and removed several specific characteristics to assist in further protecting their identity. One added layer of safety is that both HCPs are bound by their professional code of ethics that includes regulations on maintaining patient confidentiality.

Other strategies for maintaining participant confidentiality included safeguarding the transcripts, audiotapes, and computer discs of the interviews. These materials are being kept in a locked cabinet. After the study is completed the audiocassettes will be demagnetized and computer hard drives will be erased. However, the typed transcripts and fieldnotes obtained in this study will be retained for 5 years by myself and may be used for educational purposes and to publish academic papers.

One participant displayed an emotional response during the interview. This response was not triggered by the research question(s) but rather when he described the daily suffering he watched his wife endure and how little control they had over it. His emotional reaction prompted his wife to shed a few tears as well. Once their emotions settled, they both indicated a readiness to continue with the interview.

Another ethical issue was that of my ethical self. I had to remain constantly aware of my professional conduct. I did not take offence or become defensive when participants made negative comments or criticisms towards renal HCPs or the healthcare system. I also kept my body language relaxed and open in order to convey a non-defensive manner.

Finally, the dissemination of study findings will be presented to the staff of the hemodialysis unit, their nephrology department and the ACP team if they so choose. All study participants were asked whether they wanted to receive a summary report of the findings. Several participants indicated their interest in this report which will be given to them.

### Chapter Summary

The method of this study was focused ethnographic research and the theoretical perspective I followed was postmodernist critical theory. Applying this point of view shed light on the barriers within the HD unit impacting ACP. It brought the topic of death and dying into the forefront of nursing practice. The topics of communication breakdown, patient autonomy and the need for family centered care were inductively derived from participant interviews.

The data collection methods I used in this study that are essential to ethnographic research were participant observation (limited to the participant interviews), in-depth semi-structured interviews, fieldnotes, and reflexivity. Participant observation as a data collection method is complex. Using the seven aspects of participant observations enabled me to present both the strengths and challenges encountered in implementing them within this study. These data collection methods provided me with a critical lens for identifying potential biases, prejudices or misconceptions both prior to entering the field, during data collection and during data analysis that may potentially have influenced the research process. Participant confidentiality was honoured and actions to maintain rigor throughout the study were undertaken.

The chapters that follow this one present the findings arising from this study. Chapter 4 discusses the ACP process, while chapter 5 engages the reader in a discussion on communication breakdown. Chapter 6, the final chapter, presents a summary of the study along with its conclusions and implications for practice, education and research.

## **CHAPTER FOUR**

### **The Advance Care Planning Process: Findings and Interpretation**

A detailed description of ACP unfolded as the participants' families recounted their experiences and shared their perspectives on going through the process. As families started to deconstruct their experiences, they began identifying the ACP process' most important components. Poignant stories of communication breakdown, a major theme, surfaced that exceeded well beyond the ACP process to engulf families' complete illness experience, highlighting the complexities of their relationships with HCPs along the continuum. Embedded within their descriptions of the ACP process and communication breakdown were many themes and subthemes that have been divided into the following two chapters for further analysis, linking the findings back to the existing literature detailed in chapter 2. This chapter, chapter 4, examines the ACP process in the context of HD while chapter 5 discusses the major theme of communication breakdown that was encountered along study participants' illness trajectory.

In this chapter, themes and subthemes of the ACP process are analyzed. Family members' initial reactions to ACP being introduced are discussed followed by an examination of the themes of timing, readiness and finding meaning in the experience. Two subthemes emerged from the theme of readiness. The first subtheme entailed each family member who was involved in the process first coming to terms with death and the second subtheme was about facing mortality. A few of the participants, after working through the first two subthemes, experienced anticipation over the other person's reactions whom they wanted to involve in the ACP process.

After study participants shared their experiences of ACP in detail, they were able to critically reflect on the overall process, sharing what individual and collective outcome(s) occurred, and imparting recommendations to other HD families new to ACP. Next, study participants provided feedback on how the process was facilitated, determining that the role of the ACPF significantly influenced their overall experience. Participants described the

facilitator's role as valuable and fundamental. Care was individualized and tailored to meet each family's unique needs. The use of the ACP workbook was perceived as a useful tool for guiding people through the process and helping them to initiate conversations. However, several participants explained the challenges they experienced in trying to fully comprehend the implications of the complex medical terminology. Thus many of the participants recommended that an ACPF be present to support clients in working through the workbook.

### The Patient and Family's Perspective

Advance care planning was described as an invaluable experience, offering "peace of mind" (1\_2\_12). As I indicated in chapter 3, the study participants came from diverse backgrounds. They differed in age, had varied socio-economic backgrounds, and held a range of positions within the family. Overall, study participants believed that every HD family should be provided with the opportunity and encouraged to go through the ACP process. In fact, their recommendations extended to all people regardless of age or quality of health. Interestingly, these same findings were documented in Dunbrack's (2006) report on ACP in which the diverse focus group members shared similar recommendations.

Study participants discussed in depth their challenges in the current healthcare system, recognizing that no system is perfect, especially when humans are involved (5\_9\_2191-2195). The reasons given by participants for enrolling in the study were emancipatory. Their participation was perceived as offering a way to speak out about these challenges, with participants hoping to influence change and improve it in some way. The family members wanted HCPs, particularly those in HD, to know that they wished to be more involved in the patient's care in the context of ACP and throughout the illness. It was also important for family members to explain to HCPs how they were (sometimes) equally affected by the illness trajectory.

Families emphasized the importance of being knowledgeable, as many felt ill equipped to handle aspects of the patient's illness trajectory. They described needing ongoing support in which they would be provided with regular updates of the patient's progress; had the implications of certain health events and/or treatment decisions explained; and had their questions answered. Families indicated that if this happened they could then feel better prepared for the future and equipped to support each other. Yet regardless of their personal experiences with ACP, all of the study participants believed that it facilitated a positive experience in working through future health crises and at the time of the patient's death.

Each family's experience was unique thus emphasizing the need for providing individualized care and flexibility in the process. Family members were often encouraged to confront their own mortality, sharing their ACP wishes with others and some were prompted to complete their own ACP workbook or other legal document(s), such as a living will. Advance care planning brought talking about the patient's mortality into the open where it became a "non-issue" and could be revisited anytime in the future. For Jane, ACP created an outlet for grieving the loss of fellow HD patients. It also provided Jane and Mark with a process for grieving the loss of other close friends.

Many study participants also described how going through this process improved their relationship with the HD patient, bringing them closer together. They expressed having a renewed appreciation of the remaining time left as a family. Joanne explained,

"It's to enjoy what we got now. Like, we can waste our time. We can dwell on things and be sad...so what's the point in being sad all the time, we'd be missing out on the things that we can enjoy...Here we're thinking tomorrow all the time wasting that time...Let's just enjoy what we got and not waste what we got on things that are frivolous"  
(4\_7\_2009-2032).

Advance care planning provided many families with opportunities for positive experiences. Four participant families expressed their appreciation for the ACPF role, having the time to come to terms with the inherent ACP content, and to work through the process with their families. They

were also grateful for the ACPF's sensitivity, the ongoing support and follow-up, along with opportunities to openly share perspectives. However, in the case of the fifth participant family, Rebecca and Veronica, their ACP experience was perceived as negative.

Rebecca and Veronica explained that they felt a rapport had not been well established with the ACPF prior to engaging in the process. They described their overall experience as rushed and unsupported, without the opportunity to meet with the ACPF as a family, and insufficient time to work through the process together. Rebecca was new to the HD unit and was acutely ill (with uremic syndrome<sup>19</sup>) at the time of her initial ACP conversation(s) with an ACPF. She had trouble recalling everything that transpired during her initial few months on dialysis, describing this time as being in a daze or fog. Veronica shared her perceptions:

“It was all rushed, so...it didn't even hop in my mind to say, 'I want to go with you too.'...But otherwise I didn't feel like I had an opportunity to talk to the [ACPF] about it because I felt it was all really rushed, I was like, cause when we first got [the ACP paperwork], I said okay, well we'll do it next time, well, Mum kept saying, “no I've got to bring it in, they keep hounding me, I've got to bring it in” and I'm like... I just felt it was really rushed, you know I know it's important information and that, so it never really occurred to me to say oh I want to speak to the [ACPF], or somebody about this...” (5\_9\_1481-1563).

I was surprised by this family's story, because it differed greatly from the other families' descriptions of their ACP experiences. However, this family still affirmed that ACP was an important communication tool and a necessary component in HD programs. They suggested that they wished to be included in more discussions about the patient's progress and they desired the opportunity to share their needs as a family.

The study participants held a variety of positions within the family such as being a husband or a daughter. The expressed role responsibility and needs of these family members varied both individually and collectively. For example, the husbands' (Mark and Walter) involvement in the care of their wives differed from each other. Mark was not directly involved

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<sup>19</sup> Uremic Syndrome is the term used to describe the multiple complications and associated signs and symptoms occurring due to the build-up (inability to excrete) of nitrogenous and other wastes in the blood as kidney function declines (Candela & Parker, 2006; Chikotas & Oman, 2006).

in Jane's care, as she was independent, whereas Walter was Susan's primary caregiver, and she was physically dependent on him. Walter expected to be involved in all decisions and interactions with HCPs. Both of these families hinted at having a turbulent past with their children and/or extended families. Walter and Susan were estranged from their daughter, and Jane had chosen not to involve her adopted children in her initial discussions with Mark.

The other three families included adult children (Joanne, Mabel and Veronica) who described themselves as being the most involved sibling with the patient, frequently assisting their mother with aspects of activities of daily living. The adult children all had families of their own and expressed that they were experiencing additional challenges, managing their own lives while providing care to the patient. In describing their needs, they consistently had similar requests in how they wanted to be involved in their parent's care.

Several study participants first described what it was like to witness their loved one's declining health, and/or in being the SDM. They explained how ACP provided them an opportunity to share these challenges with each other in the family, thus making their experiences less isolating. Family members also received further clarification of their roles from the HD patient. Mabel recounted her emotional struggle in watching her mother experience a downward trajectory of the illness:

"I mean subconsciously I've thought about it. Obviously, because my mum is on dialysis you know but to face it that was the worst that's the hardest thing. But it's the illness, what she has and the dialysis that makes it so horrific, because we know it's going to happen eventually and that's what's so scary"(1\_2\_537-556).

"...But when I think back of how it was then...I get goose bumps and I get all choked up because it was terrifying...to face your parent like I say...to face my mum like she will be dying. I never think of that, and now...I'm much better. We all are, I think, in the family..." (1\_2\_854-883).

Advance care planning offered Mabel context for exploring her anxieties and a foundation for working through them. She described the enormous emotional distress she experienced in being a silent bystander, witnessing her mother's rapid declining health, and succumbing to ESRD and

life on HD. Mabel's experience resonates with the discussion previously presented in chapter 1. Witnessing a loved one's downward illness trajectory can be emotionally challenging, particularly when open dialogue does not exist with the patient and/or amongst family members, thus leaving the caregiver(s) to bear this burden alone. Several other study participants also described feeling powerless and isolated in carrying this burden.

Robinson and Wright's (1995) research on family nursing support the importance of bringing families together as an effective strategy for overcoming their sense of isolation and for promoting new and different dialogue. Furthermore, they caution that unresolved family issues overtime tend to "elicit both physical and emotional distance" (p. 334) amongst its members. This experience is reflected in Mabel's story as she described alienating herself from her husband and mother. Additionally, she described how the stress she experienced was consuming in that it began affecting her health. When she was finally able to engage her mother in a conversation about her anxieties, she claimed that both her health and her relationships improved. Other participants did not share the same extreme emotional experience Mabel described.

The dominant message that adult children participants expressed was an appreciation for having their parent make an advance care plan in which the burden of decision-making was no longer completely theirs. The distress adult children can experience in being the SDM is captured in Mabel's following statement:

"That's why I think this is so important because I wouldn't wish it on anyone to be just thrown into [a health crisis] that is much harder. That's what I realized and after feeling as bad as I did how it alleviated all that pain and anxiety, it just, diminished, you know, it's gone." (5\_7\_1425-1461).

Mabel's account resonated with the ACPF's observations when conducting ACP conversations with families, stating:

“It’s ideal if I can meet with them together. It’s like amazing cause you see the lights going on. The relief on the family member’s face as they hear. Gee, I don’t have to answer that question. My mother just answered it for me” (1\_ACPF\_898-910).

Statements such as these provide an argument for the utility of extending the invitation to engage in ACP beyond the patient to include the family.

Sue and Mabel recounted a conversation they had with another HD patient on the unit, in which the patient had declined to participate in an ACP conversation, stating that it was not necessary, because her son would take care of it. According to Sue and Mabel, this patient had never spoken with her son about her expectations or assumptions regarding this topic. Both Sue and Mabel expressed concern for the implications of making such assumptions and questioned whether the son really knew what to do or if he was in fact experiencing a similar distress to what Mabel had gone through. I agree with their concerns given the evidence previously described in the literature review, listening to families’ feedback in this study, and the ACPF’s experiences with patient and family interactions.

All of the participant families expressed how having the ACP opportunity ahead of time, before a health crisis, would reduce the risk of conflict at the bedside. They appreciated having time to explore their individual and collective perspectives finding meaning in the illness experience. The study participants explained how people could not predict how they would react or handle an unexpected situation. People do not know what else will be happening in their lives or their family’s that will impact how each person copes at the time of the crisis. Furthermore, having the opportunity to come together and discuss ACP would provide an opportunity to clarify misconceptions, ensure that everyone understands what the patient wants, from who and why. As a result, uncertainty would lessen and future opportunities for seeking clarification would be available. Joanne explained:

“If there’s an argument. I think, thank goodness this wasn’t the crisis. We’re arguing now? And you brought up this subject? Imagine if there was a crisis...how would it be then? Our emotion would be twice as high to get an idea...Yeah we’ll just have a practice

run...Let's see how everybody gets along. Whether or not they can say for themselves so they might say yeah, whatever, you're just saying that...but when they're alive and they hear it all for themselves...and I think sometimes you don't need to give the answer now. Come back in a month. Come back in two months" (4\_7\_2160-2232).

Lucy added:

"...With a problem you have suddenly to face it. Everybody has a different thought by thought, yeah but if you talk before they can say, hey, this is what my sister wants and you know [the] answer...you see, you have them all together...and they cannot say, I have a different idea. Come now and say to you what do you think...you see the togetherness is very important especially when everybody is a different person" (4\_8\_2187-2251).

The participants' remarks are well supported by the research literature.

Chambers-Evans (2002) stated, "what is not covered in law, clinical practice, or social upbringing is how one actually goes about fulfilling the role of surrogate decision-maker" (p. 18). Surrogates need time to explore the patient's expectations of them. Chambers-Evans further stated that "they feel torn between a need to hold onto their loved one and the desire to end the suffering" thus creating fear and indecision in making a wrong-decision (p. 22). Meeker (2004) shared similar findings from her research on the experiences of family SDMs in which they felt moral, emotional and cognitive challenges in their role. Singer et al. (1998) reported that part of the patient's purpose in engaging in ACP and completing an AD was to relieve some of the decision-making burden placed on loved one's shoulders. The studies by Nolan and Bruder (1997), and Singer et al. (1999) noted similar findings. Once study participants shared their perspectives on their ACP experience(s) overall, they were able to start breaking them down, identifying essential components of the process and the first component focused on participants' initial reactions to ACP.

### Initial Reactions

As the initial discussion of my findings has begun to show, ACP is a process occurring over time and involving, what I perceive to be called, 'stages of readiness' in moving forward for both the patient and involved family member(s). At first, study participants had to consider what

ACP was and their initial reactions varied considerably. They had to question whether this was the right timing in their lives and whether they were ready to engage in it. For many participant families, the HD patient was the first person approached by the facilitator to engage in an ACP conversation. Only in one family was this different. The daughter, Mabel who attended HD regularly with her mother, Sue, was approached first.

Study participants shared their initial reactions of being introduced to ACP. These reactions were diverse and often depended upon whether they were previously aware of its existence. Rebecca, Susan and Walter's responses resonated with Veronica who felt that the topic had not "come out of the blue" (3\_6\_11) and was "not bothered" (3\_6\_3), as her family and mother in particular, were already open to it. Even though ACP was not new for these families, they described having learned something from going through the more formalized process.

Lucy and Joanne described their initial reactions in learning about ACP within the context of HD as "eye-opening" (4\_7\_45). They had not realized how having ESRD and being on HD impacted Lucy's morbidity and mortality. For the other two families being diagnosed with kidney disease, starting HD was their initial context for ACP. Mabel said, "it really hit me" (1\_2\_1) while Jane, said she felt both "surprised yet confused" (2\_3\_1). Jane further described feeling quite disconcerted as if she "were signing her death warrant" (2\_3\_1), explaining that nobody had ever spoken of ACP to her before. Several study participants, along with the ACPF, also described how many people misunderstood what constituted ACP, often perceiving it to mean, "making funeral arrangements" (1\_ACPF\_265).

The ACPF described how other HD patients, when first broached about ACP, responded by looking at the ACPF "blankly" (1\_ACPF\_231). When this occurred, the facilitator would provide patients with the example of "it's kind of like making a living will," finding this

expression caused “people to nod in understanding” (1\_ACPF\_231-2). The ACPF shared the following statement:

“...There are moments when you can tell a person is just not ready. Not very often in that last while but I’ve talked to [over 100 people], so that you know, there aren’t very many that have been totally blocked to me” (1\_ACPF\_331).

I asked the ACPF if there were any physical cues that accompanied patients’ and families’ reactions. The facilitator explained that reading a person’s body language became a challenge when working with individuals with limited English or English as a second language, and learning of the many verbal and nonverbal communication differences. The ACPF recounted:

“[An ACPF from another ethnicity] can read the subtleties of the body. It’s not all [differences in] language. Sometimes [s/he] teaches me constantly about how things you might even avoid or the way you might word something” (1\_ACPF\_433-439).

Attention to nonverbal communication is documented in the literature as being a central issue in HCP-client interactions, and accurately interpreting cultural customs was an important component of assessing readiness (Coward & Sidhu, 2000; Crawley et al., 2002). The ACPF’s description creates a strong case for being able to access facilitators from diverse ethnocultural backgrounds because it helps all facilitators to better understand cultural safety<sup>20</sup>.

### Timing

The issue of timing was integral throughout all stages of the ACP process. Study participants were asked whether they visualized a right time for introducing ACP into their illness trajectory. They concurred that it took place within the context of assessing people’s readiness to engage in such a conversation, on how and when to start the conversation, and that time was needed to work through the process both individually and collectively. Sue explained,

“I think it’s not the right timing nothing. It is just how do the people start to think...oh we have to think what we do” (1\_1\_1097-1105).

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<sup>20</sup> Andersen, Perry, Blue, Browne, Henderson, Khan, Reimer Kirkham, Lynam, Semeniuk, and Smye (2003) explain how cultural safety is about HCPs acknowledging the imbalance of power, “inequitable social relationships” (p. 199), and respecting the cultural identities, needs and rights of their clients. Furthermore, it asks HCPs to “reflect on their own personal and cultural history and the values and beliefs they bring in their interaction with patients, rather than an uncritical imposition of their own understandings and beliefs on patients and their families” (p. 198).

Sue's statement explains that the issue is not about when is the right time to introduce ACP into the illness experience but rather the challenge lies in how to get started and how to engage others in the process. Time was considered pivotal in both creating and sustaining a meaningful experience. The pivotal moments in time included: a person's readiness in being introduced to ACP; a willingness to consider the meaning of death and facing mortality; finding meaning in the illness experience; creating time to share individual perspectives as a family; and having conversation(s) about planning ahead. Participants also mentioned needing time in the future to potentially revisit ACP if the circumstances of the illness or life changed. The following participant experiences reflect these critical moments in time.

The adult children participants indicated that both patient and family should be approached and offered the opportunity to discuss ACP, because each member had a different set of needs. Families highlighted the importance of having a HCP initiate the process. They therefore expressed appreciation for the role of the ACPF in taking the lead to introduce the subject, especially if they were unsure of how to do it themselves. The ACPF shared a similar perspective explaining:

“The timing is wonderful at times because I see the change in a patient and a family member might be there...”(1\_ACPF\_194).

If family member(s) were present when the HD patient dialyzed, such as in the case of Sue and Mabel, the ACPF could broach the topic either individually or with everyone together. If one person is not ready, then the facilitator could still initiate ACP with the other. In the case of Mabel and Sue, Mabel was the first person to engage in an ACP conversation with the facilitator but it took Sue much longer. Mabel explained:

“For my mum it took a long time for her to be able to decide to talk about [her ACP wishes] but eventually she did. The ACPF and I, we had quite a few conversations, like can you get your mum to talk about it, you know” (1\_2\_683).

The ACPF was able to address Mabel's ACP needs even though Sue, at the time was not ready to discuss ACP. At the same time, Mabel and the ACPF partnered and together encouraged Sue to begin exploring ACP.

Another important component of timing that study participants stressed was the importance of introducing ACP early in the illness trajectory at a time when the HD patient was relatively healthy or in a stable condition. Veronica reflected on her family's ACP experience and stated:

“Good timing, well, I suppose it is, because then you're back home and you're settled a little bit and you're in the routine of going back and forth [to HD], so it's not all everything at once”(5\_9\_1856-1890).

Taking the time to plan ahead meant that family members had time to consider their roles within a serious health crisis, and reflect on how they might handle these stressful situations, seeking meaningful clarification. Moreover, as previously discussed in this chapter and in chapter 2, the literature suggests this time as providing the HD patient with an opportunity to see how family members might react and behave during a health crisis. This would be informative when choosing a SDM (Davison & Simpson, 2006; Nolan & Bruder, 1997).

Not only is timing of the process important, but allowing time to review the ACP workbook with family and offer the services of an ACPF to meet with the family as well. Unfortunately, for Rebecca and Veronica's family, who described their ACP experience as negative, they would have benefited from having more time to work through ACP, and in particular its documentation. This outcome may have been prevented had the ACPF and family been able to meet prior to engaging in ACP, thus establishing an initial rapport.

### Readiness

The issue of readiness was pivotal to embarking on the ACP process for all participants. Throughout the process, study participants described encountering several challenges--both individually and collectively--as they explored the meaning of life, death and their place within

it. These challenges included being matter of fact about death, talking out loud about death, facing mortality and anticipating fear in the other person's response. After completing an extensive literature search, I was unable to locate information to support the study's findings about the notion of readiness within the context of ACP.

The first step of readiness occurred when the patient and/or family member(s) first considered ACP. As previously discussed, three out of the five participant families had engaged in ACP-like conversations prior to initiating HD. The other two participant families were first introduced to ACP in the unit. The ACPF described how to assess for verbal and physical cues that indicated patients and family readiness.

After first broaching the topic, the ACPF waited for the person's response, which provided "a lot to work with" (1\_ACPF\_820), describing that they may have "some little way of saying that they've got that handled" (2\_ACPF\_254). Physical responses included making and breaking eye contact or sometimes putting their hands up as if indicating, "that is enough for now" (2\_ACPF\_257). The ACPF explained how a person's readiness fluctuated throughout the ACP process. A patient who was comfortable before may have become uncomfortable when the ACPF checked in to see how the process was coming along. The ACPF explained:

"I've had good contact with [this patient] before. Now, he's putting up some sort of block, I'm trying to analyze what he's, there's definitely the eye contact. He focuses on the paperwork...I was trying to introduce talk, I want to talk to his wife, bring her into it. He's perhaps trying to handle things himself, protect her maybe that could be it...Um, he kind of diverted his conversation a bit away from what I was trying to talk about. Something that was meaningful but it was not on the topic. Some people will do that. They'll...kind of give me little miniature intensions maybe or little lectures..." (2\_ACPF\_263-275).

The ACPF's experiences reflect how patients' and their families' readiness changes throughout the process and must continuously be assessed prior to moving forward. However, readiness is not limited to the families' experiences but rather includes both the ACPF's and renal staff's

readiness as well. They too have to self-reflect on their readiness both personally and professionally to engage in conversations with others about death and mortality.

Being Matter of Fact about Death. One pivotal factor in determining a person's readiness was the ability to talk about death. I struggled to understand what participants meant in being so frank about death. Mark said, "You're born and you die" (2\_4\_124), while Sue said, "We all have to die...nobody knows it, you the first or I or we both together" (1\_1\_337-357). I felt perplexed in trying to understand their meaning. Over time, I began to realize their message to mean that human beings are mortal but people make a conscious choice in whether or not they chose to face their mortality or not. Advance care planning is meant to provide an opportunity to face mortality and come to terms with it by finding meaning in the illness experience. Common participant statements included Mabel saying, "If death happens right away, it's much easier then when you see your mother in this condition" (1\_2\_49), or Walter saying, "But you have to live with it; it's the body you've got...If it is your time to go, let go" (3\_5\_891/1061). Mark explained, "I guess a lot of people just aren't comfortable talking about it, you know...you're going to die at some point and hope that you're comfortable when you go" (2\_2\_169-175). All of these statements provide some insight into the challenges and perspectives of the study participants as they faced the issue of death.

A person's readiness in talking about death was also well summarized by the ACPF, who stated:

"Some patients misinterpret what is ACP and they exclaim the following: 'yes, I made all of my funeral plans.' That's very common...it does at least tell me that they're able to talk about something like death...Although they get a little nervous when you're talking about when they're actually alive...some people well...once they're dead 'hey that's ok...anything you want but ooh you mean I might be dying before that? ... I'm dying cause that's the scary part.' It's amazing for people to be so matter-of-fact about the dead part..." (01\_ACPF\_270-294).

According to several study participants and the ACPF, understanding what constitutes ACP was often misunderstood. This finding is congruent with the feedback from the participant focus

groups in Dunbrack's (2006) report. It is an interesting observation; making plans for after one's death is easier than thinking of dying and what that entails. I did not locate any research literature describing such an observation. Many participants also talked about believing in a higher being or an afterlife as giving them strength in facing death. It seemed to provide them with hope and guidance when thinking about the future. It also seemed to permit the future, regardless of how it turned out, to be bearable.

Talking out loud about death. Once participants explored their personal feelings about death, they had to then talk about it out loud. This proved to be another challenge that was well described by Sue, who felt it was one thing to be aware of her own feelings about death but quite another when having to speak about them with others. She explained:

“I never think so much over you know, I always choose to go away from [the subject] but then when [the ACPF] comes, so then we do all together...then you say a couple of times these words and it's easy” (1\_1\_730/738/846).

Having ESRD and being on HD brought the notion of death closer, making some individuals, such as Sue, feel quite uncomfortable. It would appear that what Sue and others expressed was that talking out loud about death transforms a person's inward thoughts outward, into reality where they cannot be retracted. Pollin and Golant (1994) provided a helpful explanation for the experience of facing death and mortality that I felt resonated with several of the participants' personal experiences. The researchers explained that a person's fear of death is not about overcoming or conquering it, but rather making peace with it. What is more, “facing this fear of death may contribute to an enhanced appreciation of life and for what previously was taken for granted” (p. 234). Findings from Jezewski and Meeker's (2005), and Martin et al.'s (1999) research studies found similar participant statements and experiences regarding death within the contexts of completing an AD and ACP. Therefore, study participants' initial steps in readiness with ACP involved first identifying what death meant to them in the context of their current life then sharing these thoughts with another person.

Facing Mortality. The third pivotal factor in determining readiness is the ability to face mortality. Hemodialysis patients had to face their mortality while family members had to face the patient's mortality. What struck me about the study participants was that despite their matter of fact statements about death, several struggled with facing their mortality; a deeply difficult task. Mabel summarized this phenomenon as "facing your mortality that's all it is and that's what hits you" (1\_2\_1264). Study participants spoke of experiencing an array of emotions in facing mortality, ranging from discomfort to complete distress. Regardless of the emotions experienced however, they consistently agreed that it must be done. Walter explained, "If you haven't thought of it, it's time you start" (3\_5\_1250) and Sue said, "Sure it's hard but has to be done. Now we know what we want" (1\_1\_1898). The participants concurred. They recognized how difficult of a task it was to face mortality and experience the associated emotional turmoil. They also acknowledged how many of them often chose to avoid it, fearful of its implications. In other words they avoided acknowledging what they already knew subconsciously to be the inevitable truth.

Over time, and often with the aid of the ACPF, many participants realized the benefits of bringing the topic out into the open where it could be openly discussed. They expressed that it was better to work through the process "now" rather than during a time of crisis. Several participants indicated that families who do not talk about the patient dying and the circumstances under which it may occur are more likely to fight and experience greater conflict when the time comes to make these decisions. Jane and Mark's experiences, in particular, described how the deaths of other HD patients brought the reality of a person's mortality in living with ESRD to the forefront. Jane needed an outlet to work through her emotions and Mark, at the time, did not know how to help her. Mark explained:

"She [Jane] kept on telling me that people were dying at the hospital and it's really starting to bug her because she figures she's going to drop off the face of the earth" (2\_4\_1733-1740).

Jane's perspective, on the other hand, was:

“Well nobody really wants to think about death and we don't like to think about it either but it's part of something that we have to face every day [in the HD unit]” (2\_3\_1283/1287).

In the end, ACP and speaking with the ACPF created the outlet Jane needed for coming to terms with mortality in HD. Pollin and Golant (1994) have recommendations for addressing a person's fear of death and mortality in the context of chronic illness, which again echoes the study participants' advice. They suggested that people should talk openly and frequently about death until they do not fear it anymore. “In fearing death, what people are actually afraid of is the end of living by not being able to complete one's life plans and the process of dying. It is the fear of losing control, enduring suffering and/or debilitation” (p. 237).

Anticipating Fear in the other Person's Response. After facing mortality, several of the participants then had to assess their readiness in speaking with others about it. Sue and Mabel described their struggle in coming to terms with their individual thoughts and then worrying about speaking with each other about them. The ACPF provided numerous anecdotal accounts of similar situations, indicating that this next decision of speaking with others often created communication barriers amongst family members. The anticipation itself became the barrier.

Jane shared her struggles in sharing her ACP wishes with her siblings. She said:

“I haven't had a chance to [speak with] my family member[s] because I haven't figured out a way to do it yet, the way to approach my sister and my brother on it. That's the hardest part” (2\_3\_244-249).

The issue of readiness within ACP involved several 'stages' in which not only the individual but also the family members had to address the issues of death and facing mortality. Study participants described how after they worked through this initial process, they found personal meaning in their illness experience.

## Finding meaning

Engaging in ACP conversations provided an opportunity for some study participants to complete a sort of life review. For others, it highlighted their hopes and unaccomplished life goals. Mabel, recounted her perspective and explained:

“That’s when I found out about life, especially my mother that it [kidney disease] came so early in her life, it was just so horrendous for me because that’s when it showed your mortality” (1\_2\_42-53).

Families must witness their loved one’s gradual deterioration in health from ESRD. Living with HD validates awareness of mortality and the potentiality of death. It confirms the reality of this person living with a terminal disease, requiring permanent life sustaining treatment. Walter’s observation reflected this perspective:

“...And you look at some of the cases there [in the HD unit] and then sometimes you’d say...really cruel to keep all those people alive...I sometimes think that is all our society, with all the advances that we are getting, we’re also God damn cruel. When I have looked around...I have seen cases there that I thought you’re better off to be free” (3\_5\_1767-1803).

Participants expressed their fear of the unknown in how the patient might die and the challenges of this experience. Walter further explained his experiences in witnessing his wife’s health deteriorate. He stated:

“And the thing is...and I’ve said that to [Susan] too in a sense, you are like a bird locked in a cage and she struggles and goes...has a lot of pain...but the day will come that the door will be opened and she can fly out and be out of her misery...I’ve seen her suffer so God damn much and I thought sometimes kid, I hope it’s over for you. You have no quality of life left. That’s something and...good God she has done so much good to so many people...” (3\_5\_897-945).

Susan and Walter maintained a positive perspective on life even though they lived with adversity daily, never knowing what to expect from tomorrow. They expressed how they had each other and that seemed to be all that mattered. I learned from them that they had been married for 50 years and considered themselves to be very close.

The participant Lucy also shared her perspectives on finding meaning in completing a sort of life review. She explained:

“So now after my dialysis, after the depression and so on, I said, ‘why?’ Yeah, why I going to take it that way anymore that is passed. I am now and...that’s why I’m now a happy girl because I want my kids to see that I’m a happy mum. That’s why I changed” (4\_8\_3589-3606).

Finding meaning in the illness experience and in facing mortality were integral parts of readiness in the ACP process. Once study participants achieved this personal readiness they expressed that they could move forward and broach the topic with loved one(s). For some this step came easily whereas for others, it became another large step to achieve.

### Facilitating the Advance Care Planning Process

Two methods were used to facilitate ACP on the HD unit. They were the ACPF and the ACP workbook. Study participants identified both pros and cons to each process.

#### The Role of the Facilitator

Many of the study participants commented on characteristics of the ACPF such as having a gentle manner, being approachable and supportive as they worked through the ACP process. They described the ACPF’s role as taking a certain kind of person who had a “non-threatening” (1\_2\_4) approach, was “easy to talk to” (1\_2\_4) and compassionate. It was equally important for the ACPF to be flexible, open-minded and non-judgemental. Families indicated that it was not only about who did the talking but how it was said. Walter stated:

“It comes down to training but don’t forget personality has one hell of a lot to do with it” (3\_5\_2414).

The ACPF needed to balance persistence with gentle nurturing without being aggressive or overwhelming. Some participants described needing encouragement to address their fears, while others needed the assistance in starting the process. Families described how easy it was for them to get caught up in their individual lives, pushing ACP to the background if it were not for the ACPF who offered gentle reminders. They often needed someone else to monitor the patient’s

health and ACP progress. The ACPF also kept the related paperwork organized and updated, ensuring it was completed correctly and filed appropriately.

Another important ACPF characteristic was to be assertive without being overly confident. Participants stated that they appreciated this facilitator's approach to ACP. Joanne recalled how she appreciated the ACPF's assertiveness and explained:

“This is how it is and [the ACPF] really made sure we got the point. Don't walk away, like if you're kind of like, ok I kind of don't get it. Like what do you mean? Like she wanted to make sure we understood 100%” (4\_7\_3095).

Four out of the five participant families stressed the importance and appreciation for this ACPF who they described as having taken the time to ensure as best as possible that they understood the facts and were clear about potential HD related health outcomes. 1

Timing and having time are key components of ACP where the facilitator must be knowledgeable in knowing when to broach the topic and in providing time to work through the process. Study participants expressed that they appreciated the amount of time the ACPF spent with them. However, the feedback from Rebecca and Veronica who had a poor experience with the ACPF was a threefold issue about lack of time. First, the family felt that the ACPF had not spent sufficient time with them upfront. Second, they felt that there was a lack of time to thoroughly go through the entire process and third, they thought that not enough time was spent following-up. On the other hand, Rebecca and Veronica agreed that it was the right time to be broached about the topic. A more detailed discussion of this family's experience is presented in the following chapter on communication breakdown.

One more key characteristic of an ACPF is the need to be available, to act on the moment when patient status or something else within the family changes, opening up the opportunity for new discussion given the current circumstances. This also meant that the ACPF needed to be available at most times of the day during the week including weekends, as family members often visit during evenings and weekend HD runs when they are not at work. Not only did the ACPF

meet with patients and their families during a variety of times and days of the week, but when requested, the ACPF would make a house call if the patient requested it.

The description of an ACPF that the study participants provide resonates with findings from the literature review. Several studies emphasized the utility of an ACPF to initiate and support the process, demystify terminology and clarify concepts thereby providing additional education to its consumers (Dunbrack, 2006; Jezewski & Meeker, 2005). In fact, the issues and current barriers to implementing this role that were described by HCPs in chapter 2 are the exact characteristics that study participants indicated were essential in making this an effective role. Thus, nephrology programs will need to acknowledge the amount of time, flexibility, training, and support resources necessary to ensure the success of the ACPF position.

Another valuable feature of the facilitator role that the study ACPF pointed out is how it demonstrates to HD families the amount of caring about patients occurring on the unit. The ACPF felt that this role helped family members feel more involved and informed of patient's well being on the unit. It also takes skill for the ACPF to recognize and work closely with families whose perspectives differ from other members in the family and often from HCPs. The facilitator role creates an opportunity to start addressing some of the potential conflict that could otherwise erupt at the bedside during a time of crisis. This role also provides a good starting point for addressing the issue of communication breakdown. For example, rather than first waiting for Sue to reach a state of readiness, the ACPF also approached Mabel about engaging in an ACP conversation. By doing so, Mabel described how having these conversations upfront most likely prevented a family conflict from occurring. She explained,

“This way we don't have to argue. We know our places and we know her wishes so there's no more arguments, which is very good” (1\_1\_1391-1395).

Study participants did not discuss the issue of whom, meaning which profession, was best suited for the ACPF role. In hindsight, I am surprised that they all seemed to accept the

current person in this role without further commentary, because it is a topic of interest in the literature. The ACPF argued that nurses tend to spend the most time at the bedside, thereby providing countless opportunities to connect and assess the patient's status. Furthermore, the added time spent with a patient and family up front potentially enables a stronger relationship to develop, making it easier to initiate an ACP conversation. In this way, including ACP simply becomes part of continuity of care in the illness trajectory. Jezewski et al.'s (2003) research also found that many of their oncology nurse participants saw assisting patients with ADs as a nursing role, and a role that nurses should take seriously. On the other hand, Perkins (2000) considered the physician as best suited for initiating ACP but in doing so called for a necessary change in their practice. Overall, the literature provides good arguments for not only nurses taking on this role but other HCPs as well.

My position on this debate is to argue for a team approach in which the patient and family could decide for themselves based on their comfort level with whom they wanted to speak with the most frequently. Each profession offers specific attributes that may address particular family needs. Additionally, as Walter previously indicated, individual personality and a person's perspectives on ACP are more likely to dictate how ACP fits within their personal and professional practice than position alone. Upon further reflection, the ACPF also concluded that ACP should be a team approach shared by all.

### The Role of the Workbook

The ACP workbook was the second method used to facilitate ACP in the HD unit. Overall, participants saw it as a good resource and valuable tool. However, study participants highlighted the challenges they foresaw and, for some actually experienced, in comprehending the necessary yet complex medical terminology. Participants stated that the workbook was "sensible" (3\_5\_5) and "makes you talk about [ACP]" (1\_2\_5). It provided context and direction for discussing ACP along with a method for instigating the conversation. The ACPF also

appreciated having the workbook, as it provided something tangible that could be shown to patients when broaching the topic. The two families (Lucy and Joanne; Sue and Mabel) who went through the workbook with the ACPF had fewer concerns with comprehending the medical terminology. They explained how having the ACPF present provided many occasions for clarifying any potential misunderstandings of the medical terminology along with the opportunity for receiving additional examples to support their interpretations.

A few participants concurred with Mabel's description of the workbook as a "legal paper" or "like reading a brief" (1\_2\_6). The complexity of the medical terminology presented a challenge for several participants. Jane explained:

"Its just things like about the feeding tube that was kind of disturbing...you know. I think that was about all that was very disturbing for me to talk about...there was a couple of questions here...I don't understand them...I had no idea what they were talking about and they forget that the patients don't all know these big medical words. And that somebody like myself that hasn't had much education...can't understand better" (2\_3\_2210-2260).

Her partner Walter conquered by saying:

"It gets misinterpreted... talk like you're talking to someone that doesn't have the form, doesn't have the university or the college [schooling]...a lot of people won't ask questions, which is silly" (2\_4\_2265-2290).

As the participants explained, some people will not ask questions or seek clarification. Such characteristics pose potential risks for misinterpreting the medical terms. The study participants' challenges are well represented in the literature (Dunbrack, 2006; Drought & Koenig, 1996; Phipps, True, & Murray, 2003) and by the ACPF who also agreed with their voiced concerns. In particular, the facilitator described the notion of cardiopulmonary resuscitation (CPR) as being most challenging, frequently having to "go over the education part" and its expected outcomes, adding "you can only word it so well in the document" (2\_ACPF\_417). In Jezewski et al.'s (2007) systematic literature review, the researchers concluded that there was sufficient evidence in the literature to prove how indispensable the inclusion of a person-to-person component was within all interventions involving the completion of any AD type document.

It is important to note that I did not complete an analysis of the ACP workbook, as this exceeded the scope of the study. Rather, I choose to focus on the participants' experiences in completing it. The workbook itself did not inform me of the process and how families arrived at their answers or provide any contextual history. It did not explain the beginning or middle of participants' stories at that point in time, rather it only told me a bit about the ending. What I appreciated most were the stories that families shared about what it was like to fill in the document, read through it, and now reflect on their experiences. This information was more valuable than explaining why they chose a particular answer for each question.

The ACPF indicated how feedback received from HD patients and families were taken into account since the inception of the ACP workbook on the unit, which has undergone several revisions. I am told that the study participants did not all receive the same workbook version, given that they went through the ACP process at different points in time. A few participants indicated that they had completed one or several of the revised workbook versions but not necessarily the most current one. The ACPF informed me that a new clause was recently added into the current version that was in reference to CPR and the inclusion of a medical opinion. I question whether there are potentially unforeseen implications for clients who do not all receive the same workbook content, particularly when they are from marginalized communities.

As I have indicated above, several participants expressed that a person had to be (well) educated in order to comprehend the implications of certain medical terms. In particular, Mabel expressed concern for individuals who are non-English speaking or have English as a second language. The ACPF further explained that often such families rely on one or two members who do speak English and may be educated. However, a new risk is introduced when a non-medical professional is being used as an interpreter. The person(s) may either change or choose to withhold certain information (Barnes, Davis, Moran, Portillo & Koenig, 1998). The ACPF described:

“Gee wiz, we’ve got all of this technology that they don’t even know exists. They don’t know what we are talking about by what a ventilator is and ICU treatment is. I think they want to be sure they have the most treatment or the treatment that is available to everyone else too. They want to be sure they have it too. There are people who you can see who are probably a bit nervous about that. [They might be thinking] ‘Just because we are old and from another country don’t not offer us care.’ So, there’s more education needed to bring them up to speed and their families at times. But in general they are like everyone else. They are generally open to the conversations. It is not so much culture by ethnicity it’s culture of their own family their own way of doing things is different. Everyone is different.” (2\_ACPF\_308).

For some patients, particularly those new to the Canadian healthcare system but also those from marginalized communities, there is a threefold struggle. Their first two struggles involve not only being challenged in comprehending the necessary medical terminology, but also potentially having insufficient education to grasp their meaning. Furthermore, they may be illiterate. Their third struggle is in trying to comprehend a difficult document written in a foreign language with the added complexity of being within a foreign healthcare system. Similar findings were noted in the study by Phipps et al. (2003), where several ethnic groups were involved in ACP and found the complexity of the language and terminology in the AD document challenging, given English was a second language for many.

The ACPF shared additional experiences, such as having come across errors with misinterpretation, finding the workbook incorrectly filled out, and finding out that someone else had filled it in for the patient. The ACPF explained:

“People, they don’t always read the whole thing...say they’ve chosen, “I want to have life support no matter what.” And yet the way I have come to know the patient, it doesn’t seem consistent with the way they view life. So then, [what] I have done [is] I will go back and read [it through with them verbatim]. They seem to jump in and select an answer without having read the introduction” (Int.02\_ACPF\_427-434).

The ACPF explained that given the number of discrepancies s/he has encountered while working with renal clients, it is now his/her practice to routinely review the completed ACP workbook in its entirety with the patient. The facilitator questions any inconsistencies, and clarifies whether it was the patient who independently filled out the workbook. In addition, the facilitator considers

the presence of a family an “added bonus,” as any misconceptions they may have can also be addressed. An added benefit in the ACPF having been involved in the process from the beginning with a patient and their family is the ability to question any contradictions encountered between patients’ initial preferences and the contents of their completed workbook. The ACPF explained:

“... We’ll have to change the whole document because that might have meant that everybody thought...the whole family needs to know. Sometimes it is scary because we could, I could still be missing something. I can only try and in fact that we are all on the same [page] that hopefully the patient, the family and I all understand the same thing” (2\_APCF\_452).

Another finding regarding the use of an AD document was from Jezewski et al.’s (2007) systematic literature review. The researchers found that none of the 25 studies reviewed had measured participants’ understanding of the AD document they had completed. Given these findings, the researchers cautioned investigators not to assume that completion of an AD document confirmed that the person filling it out had full understanding of its meaning or its implications. Therefore, the researchers recommended the incorporation of evaluating these two factors as being essential components within future studies measuring AD completion rates. The findings from the study participants, the ACPF and the literature drive home the message that consistent implementation and follow up is imperative with each patient--and hopefully family--completing an ACP workbook.

A third concern with the ACP workbook that a few study participants raised was in questioning the workbook’s intent. They questioned whether it was a method for HCPs to shift responsibility with decision-making and for protection against legal action. Walter shared his concerns and stated:

“All those pages don’t mean bugger all to me but it’s just to cover whoever has to make the decision that I am in the end responsible for it.” (3\_5\_2662).

The participants raise a valuable concern that is also identified in the literature by Drought and Koenig (1996). Within this HD unit, I am told that the workbook is used as a tool for conversing about ACP. It is not a legal document, but is, rather, a resource to the family and HCPs that outlines treatment preferences based on the patient's beliefs, values and wishes.

The intent here is to again draw attention to the concerns raised by study participants and to put forth the question of whether other HD families share similar concerns. It is important to note that in all study participant cases, the HD patients completed and submitted their ACP workbooks.

#### Family Advice and their Advance Care Planning Outcomes

Study participants were asked what advice they could provide about going through ACP to both my own family and families new to HD and ACP. They were also asked what going through the process had done for them. Regardless of the study participants' diversity, they consistently had similar statements. Their recommendations were to not assume what the other person's wishes are, or that everyone involved is of the same understanding. They told me that it is imperative that this exploration of perspectives and opinions be discussed up front well in advance of a health crisis. Conversations should happen when everyone is healthy, calm and can think clearly. The families' spoke from experience when they described how emotionally distressing it was to make critical decisions during a time of crisis and as Mabel stated, "I wouldn't wish it on anyone to be just thrown into it that is much harder" (1\_1\_1429). These findings resonated with the conclusions drawn from the researchers Meeker (2004), and Meeker and Jezewski (2004, 2005) in which family surrogates identified the complex moral, emotional and cognitive challenges associated with this role. Substitute decision makers encouraged individuals new to this role to have confidence in their capabilities, to trust their judgment and be strong advocates for both the patient and for themselves.

The participant families recognized the difficulty and challenges in speaking with a younger person who may still have numerous unaccomplished goals and dreams. They also expressed that they understood how easy it was to get caught up in daily life, putting the conversations and documents aside and thereby leaving them for a time of health crisis. Families told me that they wanted to be kept informed of the patient's progress and prognosis but understood that patient autonomy must still be valued. Many family members felt they were outsiders. As my earlier analysis indicates, families will also need the continued guidance from HCPs in learning more about the medical prognosis, including how having ESRD and being on dialysis potentially impacts other serious health events.

### Chapter Summary

Advance care planning was described as a valuable experience and resource. It is a process occurring over time, involving 'stages of readiness' in moving forward for not only the patient and family member(s), but also the ACPF and renal staff. Participants emphasized the importance of being knowledgeable, as many felt ill equipped to handle aspects of the patient's illness trajectory. Families described needing ongoing support throughout the process. They wanted to be provided with regular updates of the patient's progress, have the implications of certain health events and/or treatment decisions explained, and have their questions answered. They could then feel better equipped to make future SDM decisions and be prepared to support each other. The diversity of initial reactions and responses to the ACP process requires that the ACPF remain attuned to the individual's subtleties being expressed.

The issue of timing was intertwined throughout the ACP process. It took time to work through the individual then collective experiences. Each person had to overcome personal adversity in order to think about death and facing mortality. Readiness was pivotal to embarking on the ACP process for everyone. Over time, and often with the aid of the ACPF, many participants realized the benefits of bringing the topic out into the open. They concurred that it

was better to work through the process earlier in the illness trajectory when the patient's health was relatively stable rather than during a time of crisis. A final step in readiness was the anticipation in speaking with others about their ACP wishes, which often created communication barriers among family members. The anticipation itself became the barrier.

Study participants provided a detailed discussion on the role of an ACPF, including important characteristics and job responsibilities. Families described how easy it was for them to get caught up in their individual lives, pushing ACP to the background if it were not for the ACPF. The facilitator also pointed out a valuable feature of the role that was in how it demonstrated to HD families the amount of caring about patients going on in the unit.

The ACP workbook was the second method used to facilitate ACP in the HD unit. It provided context and direction for discussing ACP as well as a method for instigating the conversation. However, study participants highlighted the challenges they foresaw and/or experienced in comprehending the complex medical terminology. Thus it is important to acknowledge the valuable role of an ACPF within this process and the required knowledge, skill and ability needed to work with patients and their families in all aspects of ACP.

The study participants, in describing their experience with the ACP process, provided both constructive and analytical feedback that informs HCPs of the ACP program's effectiveness and highlights opportunities for improvement. In the following chapter, a detailed discussion on how families experience communication breakdown in the ACP process and throughout their illness trajectory is explored. This discussion highlights the complexities of their relationships with HCPs and identifies the persistent factors that continue to shadow death on the unit. Modifications to current strategies for incorporating ACP and the acknowledgment of death as regular components of the HD trajectory are needed in order to provide continued effective support to patients, their families and staff.

## CHAPTER FIVE

### **Communication Breakdown: Findings and Interpretation**

Chapter 4 provided a detailed analysis of the ACP process from the participant families' and ACPF's perspectives. The themes of timing, readiness and finding meaning in the ACP experience were analyzed along with several subthemes. Feedback on the ACPF role and ACP workbook were also discussed. Chapter 5 introduces the major theme and findings related to communication breakdown, which due to its complexity, is presented separately.

#### The Patient and Family's Perspective

Participant families described communication breakdown as exceeding the boundaries of ACP to involve their complete illness experience and often centred on HCPs' poor decision-making. The participant families' accounts shed light on the inadequacies of an overstretched healthcare system filled with unrealistic expectations and unreliability. Embedded in all of the participants' stories was a message of how destructive a lack of communication is to their confidence in HCPs and trust in the HCP-client relationship. The complexity of each individual's needs, expectations and understanding regarding what gets communicated, how it is said and how it is heard either facilitates or hinders communication. The issue of ACP was only one event along a continuum of experiences in which families emphasized the need for absolute interaction.

Communication breakdown primarily occurred during three timeframes in the family's illness trajectory. The first period encapsulated families' interactions with HCPs prior to ESRD and when the patient's other co-morbidities became the focus. The next segment occurred when the family entered into the renal program and more specifically within the HD unit. The third time that a breakdown in communication took place was in the context of the ACP process.

## Experiences prior to Endstage Renal Disease

An emerging theme from every family interview involved stories of communication breakdown, with the first phase occurring prior to entering into the renal program. The participants' accounts of their interactions with HCPs were diverse, yet all led to the same message of miscommunication. Families described feeling 'kept in the dark' by not being provided with explanations for the long delays in waiting to receive a procedure, often feeling ignored or forgotten about, and the disorganization of discharge planning. As a result, the participant families experienced emotional distress.

Long waits caused frustration and anger. Participants felt uninformed by HCPs who they perceived did not provide them with clear communication and explanations for delays in treatments. Jane described the daylong wait for a procedure where she remained on a stretcher without being offered any food or water while her husband Mark paced the waiting room without receiving any communication of her status. Jane explained:

“So it's...we understand what happened the first [time] cause there was a lot of emergencies that came in that had to get taken right away and yeah but it was, it was just a long frustrating day and nobody was saying much of anything and they weren't saying nothing to him [Mark] ...it's crazy...the nursing staff should be more open to let people know what the delays are or whatever to make it easier for the patients. (2\_3\_1877-1912).

Similar experience occurred with all participants and though they expressed having understood that delays happen, they requested two things. The first was to be provided with an explanation for the delay(s), and the second was that they were not left feeling ignored or forgotten about in often uncomfortable circumstances. In two participant situations however, the circumstances worsened.

Walter recounted a particularly frustrating episode in which his wife Susan was supposed to receive daily physiotherapy during her 3-week hospital admission, which he stated occurred only once. Walter indicated they were not provided with an explanation and experienced great challenges with Susan's lack of mobility when she was discharged home. Similarly, Joanne

shared her experience of Lucy “almost dying” due to a breakdown in communication between two hospitals’ medical teams caring for her mother. She explained:

“[Lucy] sat up on the ward dying. She has no communication or nothing, her Creatinine is 900 and I said, you’ve got to get my mum out of here to the other hospital...and when we got to the other hospital they said, “she just made it.”...So it’s too bad they didn’t [move her] right away. Like if you know, you don’t have that kind of resources...what’s the point of keeping someone there. And they told us the day before her Creatinine was at 700” (4\_7\_459-469).

Shortly after arriving at the new hospital, Lucy went into a coma, was transferred to the intensive care unit and underwent emergency dialysis. Joanne expressed deep disappointment in the medical teams’ poor decision-making, and recounted how it had almost cost her mother’s life. Unfortunately, the family described how their negative experience did not end here but rather continued through to Lucy’s hospital discharge. Joanne explained how the planning had started out well but when it came time to implement it, it fell apart, leaving the family to pick up the pieces. She explained:

“...The hospitals are funny too. They call me up and they’re like come get your mum [but she was not supposed to be discharged for several more months until her assisted living came up]...and [be] out of here by 5 [to]day...She can’t climb stairs, right. So, we just made up a bedroom in our, we took our dining room out [she stayed with us for 3 months until her assisted living came through]...” (4\_7\_809-845).

Families indicated that they were often left scrambling to put a makeshift plan together without adequate time, resources or supportive guidance to do so.

The participants’ stories demonstrate how HCPs often overlook not only the patient’s needs but also the families’. The following example further demonstrates the disorganization, poor decision-making and miscommunication that occurred among a medical team, particularly during implementation of discharge planning. Veronica explained:

“[Mum] was in the hospital for three and a half weeks right...all of a sudden we were phoned up one day and they said she’s being released, you know this afternoon...we haven’t talked to anybody we still have to talk as a family...we had an appointment going...but then that Social Worker went on vacation [after] saying, “oh no everything will be arranged like as in home care support”...and then all of a sudden I get from the nurse, a phone call, “no, no she won’t be released until we know what’s going on” cause I said, “I

can't just send her home" Yeah, and I have four children and my brothers and sister, sure they can take a few days off... and I needed to know what kind of support I needed to arrange...I mean it all fell into place... and of course you don't want to say [to your mum]...I don't want [you] to come home because she wanted to come home at that point, but she still needed a lot of help...as far the nurses went and their notes, she was doing everything on her own but she wasn't [I was the one combing her hair and brushing her teeth everyday]...so, the one day they say, we're going to discharge her this afternoon, I'm going 'AHHHHH'...and the next day 'no, [she's] not allowed to be discharged because [her] [blood]sugars too high' it's like, huh...how do I understand this! Anyways, well because there's so many people that you have to deal with, that's what I find with the system, and they don't really know what the other [is doing] they are so specified, and that's good to a certain extent but I found, like even this was in the hospital..." (5\_9\_988-1319).

These stories reflect the challenges in the healthcare system that families unknowingly must face. The participants' unfortunate experiences have left permanent impressions of mistrust and broken faith in the system.

Levine and Zuckerman (2000) summarized the impact that hospitals have on patients and their families, stating that they are forced to "conform to an often baffling and seemingly irrational system that seems intent on separating [them] rather than sustaining their relationships" (p. 12). The literature further documents the challenges that family caregivers encounter in having to care for the patient at home and how it is an expectation within our healthcare system. Peter (2004) described the burdens families endure particularly during the transition from hospital to home as the "Hamburger Helper" (p. 254) of nursing. Family member(s) are being forced to take on many of the responsibilities that normally were held by professional caregivers.

The boundaries of family members' role are blurring. They are rapidly becoming both the informal and now formal caregivers in which they are often 'being taken advantage of' by the healthcare system. The expected emotional and physical workload of this role has profound implications on family caregiver well being. Family member(s) are "left socially isolated and without adequate resources to provide care" (Peter, 2004, p. 255). Navaie-Waliser, Feldman, Gould, Levine, Kuerbis and Donelan (2002) discussed the inherent risks and dangers to both caregiver and recipient when HCPs rely on informal caregivers without considering their ability

to provide care. Furthermore, Levine and Zuckerman (2000) presented the paradox of the healthcare system that “distrusts and devalues families [but cannot] exist without them” (p. 9). Some healthcare organizations acknowledge how ill equipped and untrained family members are to manage patient care upon discharge from hospital but in the grander scheme of things, do little to prevent this from occurring (Selecky, Eliasson, Hall, Schneider, Varkey, ACCP Ethics Committee & McCaffree, 2005). Unfortunately, these problematic findings continue to occur right through to providing EOL care, death and bereavement (Dunbrack, 2005).

### Experiences with Endstage Renal Disease: Having a Chronic Illness

Once patients are diagnosed with ESRD, and particularly when they initiate dialysis, they often find themselves in a ‘catch 22’. The outside world either perceives them as appearing healthier than they actually feel or assume they are sicker because of dialysis. Joanne explained,

“...And then we had a hard time getting in here [the assisted living building]. They told her she couldn’t get in until she got to her own apartment. Oh yeah, it was horrible... and you know why she’s high risk, cause she was on dialysis. High risk but she’s been doing so much better...they made it sound like my mum was so decrepit, on dialysis...she’s half better than a lot of these [other residents] independence wise.” (4\_8\_872-943).

The literature documents (Fitzgerald-Miller, 1992; Knafel & Gilliss, 2002; Strauss, et al., 1984) the challenges patients continuously encounter in living with a chronic illness. The following account highlights the struggle of one study participant. Lucy explained that her children chastise her for appearing better than she feels when attending doctors’ appointments. Lucy said,

“That’s important to me that when they see me, they don’t say, ‘oh, I’m so sorry to see you like this.’ No. I don’t want people to do that to me because there is nothing to be sorry, my life is ok. Maybe I don’t look good that is why I try...I have 24 hours pain but they don’t have to know, really” (4\_7\_1706-1751).

Lucy’s choice to maintain her ‘healthy’ and ‘normal’ appearance creates prejudice in others who may doubt the extent to which her illness affects her. She is stigmatized by her chronic disease and must continually decide whether to disclose or conceal it (Joachim & Acorn, 2000). She indicates that regardless of her decision, she suffers the consequences because she is never

wholly accepted. Her relationship with her assisted living building manager exemplifies this point. Lucy described how she finds herself in constant conflict with this manager who cannot decide if she is too sick or too independent to be requiring assisted living.

Thorne (1993) commented on this double standard, indicating that outsiders often assume patients with “invisible differences” (such as chronic pain and the associated fatigue post HD treatment) exaggerate the effects of the illness, because “they do not conform to the expected image of an ill person” (p. 71). Families too experience the brunt of these assumptions because they remain ‘the fallback person’ when the extent of the patient’s illness is not believed. Joanne explained,

“I asked [the building manager], where do you want her to go, extended care? Like I don’t know what to do...or by herself...back into the community? I told the social workers before I had a nervous breakdown...I had responsibility of the baby and shopping. I had so much that’s going on. This is finally a little bit of a break. I told you it’s not for my mum, it’s for me...I can’t do it. I can’t run it anymore. My brain has lost it...” (4\_7\_1266-1302).

Families must remain strong advocates for not only themselves but for the patient as well.

Otherwise, they can be taken advantage of by an overburdened healthcare system. As Levine and Zuckerman (2000) pointed out, “the family is the primary buffer between them and the healthcare system” (p.11). The experiences of families in being the patient’s ‘buffer’ occurred throughout their interactions with HCPs, including the renal staff. Upon entering the renal program, families described finding themselves in a new environment through which they had to once again navigate.

Experiences in the Hemodialysis Unit. The renal program offered more structure and supportive resources to both the patient and family. Unfortunately, regardless of this improvement in support, families indicated that they could not let down their guard. They had to learn how to fit into this new environment. Not only did they have to learn to navigate the system, advocating for the patient, such as in the case of Walter and Susan, but they also had to manage the burden of care while coping with their own lives and health, such as in the case of

Joanne and Lucy. These perspectives are supported by the literature (Ohman & Soderberg, 2004; White et al., 2004).

Chronic kidney disease added an additional level of complexity to the patient's health. As ESRD approached, families became silent witnesses to their loved one's deterioration, often feeling helpless. As Mabel recounted:

“...Like I felt I was so alone and so did my husband. You know, thank god for computers you can just go in and research but it still doesn't tell you how you cope with it...and that's what was missing in my life” (1\_2\_2118-2168).

Dialysis was received with mixed emotions. For some patients, it offered a bit of a new beginning in which they began to feel better, regaining some of their independence, while others continued to experience complications and set backs. For the families, dialysis meant another upheaval in their daily routine and a new schedule-juggling act. They now had to arrange for thrice weekly transportation to the HD unit. The adult children explained how they often had to balance their own family's schedule along with their parent's. Amongst all of the chaos, families described feeling burdened with the responsibility of communication with HCPs being left up to them. They soon learned that most interactions within the HD unit occurred between the patient and staff rather than communication with the family as a whole. However, families described how hard it was at times to rely on the patient for information, to inform them of pending treatments, HCP rationales, or other HD related activities due to their often-compromised cognition from a multitude of factors such as uremia and anemia. Joanne shared her frustration:

“Communicate. [The staff] have to do something. They just assume that my mum understands. The whole thing they just said to her in 20 seconds flat. So we understand a little bit [but not the whole story]. I sometimes phone the renal nurse at the clinic or something like that and then she'll say a little bit of what's happening” (3\_7\_2648-2684).

“...And when I phone up. 'Yeah she's fine bye' and here [my mum] is on the corner falling over, sick as can be because she just had a crash [blood pressure dropped rapidly] but they see it so much, I understand that they see so many people crash. 'Oh yeah they, they'll bounce back, don't worry by tomorrow,' right but for the family member, oh...” (3\_7\_2620-2638)

Thorne (2003), in particular, demonstrated how HCPs' actions and attitudes play a large part in determining the degree of distress that patients and families will have in the course of their chronic illness experience. The ACPF shared her perspective in understanding the family's experience:

“...This is it, the family is going through in my opinion more than the patient cause the patient has often at least there's sort of a set path. You follow a treatment or you don't but the family is facing all kinds of changes at the end. They have to support the patient and each other and [this is] a lot of work for them” (1\_ACPF\_\_1130-1146).

The ACPF's observations reflect the study participants' views, as they often described feeling left out of the communication pathway. These observations affirm for renal staff the importance of checking in with the family, especially the families that are not able to come to HD, to find out how they are managing at home. Mabel, who attended HD regularly with her mother, still experienced a sense of isolation. She explained:

“...Because I suffered a lot, especially when [mum] was diagnosed...I was terrified you know... I think what could have helped if I would have a doctor or an experienced person that I could discuss this with, what's my role now, what should I do, you know, how should I approach this. I didn't know. I learned a lot in here (referring to the HD unit) (1\_2\_1999-2036).

Walter and Susan's story contrasts with the other families' experiences because of how Walter purposely places himself at the centre of his wife's care. During their interview, Walter explained how he kept the lines of communication with HCPs open. He kept a 'vigilant' schedule in which he checked in continuously with the multiple specialty health services involved in his wife Susan's complex care. He did not attend dialysis with her regularly, but expected that all decisions concerning her were made with his involvement, to which his wife agreed. He felt this was the only effective approach to ensuring his wife received consistent care with minimal confusion and distress. Unfortunately, the other study participants explained that they did not have the same amount of time to devote to overseeing the patient's care, in particular, the adult children who had families of their own. As a result, miscommunication often

resulted where conflicting stories and/or miss scheduled treatment appointments caused a great deal of additional stress and frustration for these families.

A reoccurring subtheme was the notion that “knowledge is power.” Participants expressed their frustration in not receiving the whole story about a situation unless they were present at the time the information was presented. Several participants indicated that they had a university education that helped provide them with some essential tools to comprehend aspects of the disease, understand complex terminology, particularly within the ACP workbook, and to know how to navigate the system. Regardless of this education, it did not address their need for knowledge of the disease, treatment options or the illness trajectory.

Mabel stated: “Yes, and I felt like an idiot because I didn’t know what’s happening. Knowledge is power right” (1\_2\_2758-2766).

Mark indicated: “Well it started to upset me because I didn’t get the full picture until she’s...we sat down and talked about it and if you don’t, you know, if you don’t have the information that you’re supposed to get I can’t make decent decisions. Knowledge is power you know...people just have to be a little more open” (2\_4\_1775-1807).

Walter explained: “...The business and my education too, you think a little further than your nose you know and that I have always in my head, what has to be done when it has to be done” (3\_5\_1282-1292).

If families felt more knowledgeable about the experience and felt better supported, they might feel more at ease, having a stronger peace of mind. Not all people will embrace their illness. Nor do all families want to be fully engaged, but for those that do, communication is of the utmost importance (Cherlin et al., 2005; Fried et al., 2005; Winzelberg, 2005). Mabel summarized this fact well. She stated:

“And if someone has a closed mind, no matter what you think to say, they’re not going to do it but there are those few that will appreciate that and that’s worth everything” (1\_2\_3066-3071).

Families describe feeling isolated and ‘out of the information loop’ regardless of whether they come regularly to the HD unit or not. The patient has the healthcare team but their family may not. Consequently, they want the option to be better informed of what care the patient is

receiving. The participants I spoke to were also careful to clarify that they did not want to overshadow the patient or take control of the communication. Family members simply want to regularly engage in dialogue with HCPs about the patients' progress and be asked how they, as a family, are coping. Families are the caregivers to the patients but are also clients themselves with a separate set of needs that may differ significantly.

Robinson and Wright (1995) discussed the elements of a therapeutic relationship, indicating that trust and comfort are imperative. Allowing the family to meet with the team fortifies this relationship by "providing an opportunity to have access to the team's collective perspective and thoughts" (p. 336). The literature highlights HCPs' misperceptions of families as being a nuisance, troublemakers and barriers to patient care (Thorne, 1993). Levine and Zuckerman (1999 and 2000) contest these perspectives given how dependent our current healthcare system is on families for providing both direct and indirect care and management that more frequently occurs during a patient's hospital stay. They argue that HCPs' common "negative presumptions" (p. 6) of families must shift to a partnership in which their ongoing involvement is acknowledged such that they are part of the decision-making and the care delivery. However, it is important to reiterate that family involvement must occur with the patient's permission and that a careful assessment of family members' abilities and intentions are explored in detail as previously noted in the literature review in chapter 2.

Study participants reflected on their interactions with HD staff and offered several suggestions on how to improve communication pathways while still honouring the patient's autonomy. Suggestions included how families could receive a monthly progress report that summarized any occurrences, changes in care or planned treatments. Their rationale for this request included that if there was an emergency outside of the HD unit, the family member could provide a brief summary of how the patient had been responding to the dialysis treatments. The

staff could give this summary to the patient who could then decide whether to pass it on. Mabel also recommended the following:

“To be more approachable with it, to maybe because of you being professional, to come to me and talk to me is there anything we can do for you...could there be something we can help you with? I would have appreciated that...[for] a professional to sit down with me...says, look, this is what’s going to happen, this is what you have to expect. That’s what I think is important me” (1\_2\_10/11).

An additional approach that could facilitate improved communication was having family meetings at set intervals within the HD trajectory. In particular, this was identified as important when patients were admitted to the hospital for extended periods of time. Families indicated that many issues could be addressed at once in a consistent manner, possibly alleviating future tension and emotional distress. The ACPF concurred with these suggestions further stating:

“Why ACP is a tool because it is just part of care, right and life, to me, a family meeting should be routine. You know we would find out all kinds of things about how people were doing before a crisis...I mean it’s not /// /// time and yet if we did it we would be saving time” (1\_ACPF\_10).

This approach would also enable HCPs to know more about family dynamics and other issues that may be going on.

Another challenge the ACPF experienced was in trying to separate the ACP piece from the patient’s illness experience stating, “it’s to do with [the patient’s] own goals” (2\_ACPF\_59). The facilitator argued that ACP was an integral component of HD and questioned how the patient’s values, beliefs and wishes could be separated when they were starting an ethically burdened long-term life sustaining treatment. Furthermore, making this separation contributes to the barriers associated with communication breakdown.

### Communication Breakdown in Advance Care Planning

Communication breakdown within ACP is multi factorial. It encompassed such factors as the families’ lack of awareness in the existence of ACP on the HD unit, the need for an established professional rapport, and the need for some established trust prior to engaging in

ACP with patients and their families. Communication breakdown also highlighted the ongoing issue of HD staff's continued discomfort in talking about death. Within this latter factor were additional layers of complexity that contributed further to the notion of death being regarded as a 'taboo' topic.

Advance care planning has been active on this HD unit for several years now but, based on the participant interviews, not all HD patients are aware of the term and its meaning. For some, the reason is because they are new to the unit. However, I question how much time constitutes 'being new'. Is it one month or six months? All of the study participants indicated that they were not aware of the existence of the ACPF prior to being approached. The ACPF confirmed that only on a handful of occasions have families been the instigator of an ACP conversation.

I find these observations to be of great interest, given that HD patients receive dialysis three times a week for approximately four hours each session over many months to years and therefore I would assume that they are aware of the ongoing activities in the unit. Yet none of the study participants indicated ever noticing a poster or leaflet about ACP unless it was put directly into their hands. Rebecca indicated that she saw posters with the health regions' logo on them but did not know what they were about. As I pointed out in chapter 3, study participants also indicated not having noticed any of my study poster advertisements. This observation was also noted by the ACPF who stated:

“ I don't know if they're as aware as I'd like them to be; the [ACP] posters [are] out there in the waiting room and pamphlets. I don't think they're hardly ever removed you know they're not missing. I sometimes referred a patient to one of the pamphlets and they don't seem to have seen it” (1\_ACPF\_533-555).

The ACPF further explained that patients frequently missed 'fun' announcements about upcoming social events. Perhaps the current tools and processes in place for communicating with patients are ineffective for this particular group, and the lack of patient awareness is

multifaceted. The ACPF and I explored this realization in depth, concluding the following. Many HD patients are dependent on public transit for their commute to and from HD. They often arrive late and leave early because they only have the one Handidart riding time as an option. Given this tight timeframe, perhaps patients feel they do not have the time to read any communication within a poster. Another possibility compounding this issue is that many HD patients are experiencing multiple co-morbidities, some of which may impact their vision (such as diabetes mellitus and peripheral vascular disease) and thus may prevent them from being able to read the notices. Determining the cause for the lack of awareness of ACP on the HD unit requires additional attention that exceeded the scope of this study.

A second factor contributing to communication breakdown is the need for an established professional rapport and trust prior to engaging in ACP with patients and their families. Rebecca and Veronica's experience was described in chapter 4. Part of their frustration--in particular Veronica's--was that she did not know who the ACPF was or the relationship she had with her mother, Rebecca. During the interview, Rebecca described her memory as clouded and feeling in a daze. Numerous changes were occurring simultaneously in her life, all of which had an impact on her experience. Veronica was busy with her own family and described not having the time to attend many HD sessions. She also explained how she struggled with the change in communication pathways that occurred in the HD environment where most if not all communication was routed through her mother. Prior to this transition, Veronica or another family member regularly attended their mother's healthcare appointments. Within the context of discharge planning from the hospital, the family described how they felt they were kept involved throughout the process and consequently were surprised when this changed upon entering the HD unit. Veronica raised concerns with the choice of communication pathways, particularly when the patient may not be a good communicator, a poor historian or may not be in a clear mind at the time, as was the case with her mother. Veronica stated:

“...But it would have been good to just have everything flowing with the family together, than this, that I do see as, and [ACP] was just directed towards her in that sense, it was like, you go home and you discuss it with your family. I mean, not that she’s not capable of that, but it’s, um, because that’s the way it goes, because she’s the one in the renal clinic. You know, and when you’re in the hospital, families there often get to talk to different people, there’s just more opportunity of course...” (5\_9\_1856-1900).

Veronica’s perception of the story lends itself to the research findings by Fried et al. (2005), who highlighted that communication breakdown is not isolated to the HCP-client relationship but also exists between the patient-caregiver relationship.

Each person has diverse needs, different perspectives and varied expectations regarding the amount and quality of the communication they felt they needed and wanted to share, potentially causing imbalance and dissatisfaction. When this need is unmet, it may lead the family caregiver to rely more heavily on HCPs who may assume that they have already fulfilled their role in discussing things with the patient. This discussion was presented in chapter 1 and further explored in chapter 2. Winzelberg et al. (2005), and Fried et al. (2003) both found that often times the patient and family’s lack of readiness or willingness to hear certain news, particularly when it was perceived as bad, contributed to ineffective communication. Moreover, Cherlin et al. (2005) determined that the difference between what physicians thought they were saying and what caregivers actually heard them say led them to draw different conclusions, potentially introducing further conflict. In addition, any cognitive impairment, regardless of its cause, also contributed to communication breakdown.

It is important for HCPs to realize that some HD patients are not good historians, may not fully understand or want to hear what they are being told, and/or may not feel the need to communicate this information in detail to their family caregivers. With respect to quality of memory, several other study participants had to remind each other of their reactions at the time to aspects of the ACP process. In the above narrative, Veronica had to remind her mother of their ACP time line, clarifying what documents were read and when they were signed. Similar

scenarios occurred with two other families. Mabel had to remind her mother that the ACP process, at the time they were going through it, was not as easy as she now described it to be. After some probing, Sue remembered how much she had struggled with coming to terms with her mortality and her readiness to talk about ACP.

A third example involved Joanne not remembering the emotional difficulty she too experienced at the time. It was Lucy who clarified that Joanne struggled to come to terms with facing, then talking openly about her mother's mortality. Joanne then concurred. The confusion and forgetfulness experienced by some study participants (family members as well as patients) draws attention to the need for a careful ACP process that involves more than one person.

The potential risk that is highlighted by the above scenarios is worrisome. If the context were to change in which the patient were left to recount their ACP experience to family or friends at a later time, or if the patient was to confuse the timing of ACP events in the story, it may lead the family to jump to conclusions, whereby they might question whether the patient was coerced into signing a document that was not fully understood by the patient. The family may then question the integrity of the HCPs. Moreover, even though only 1 out of 5 families interviewed described their ACP experience as negative, if this one family were to share their experience with other families it may create a cascade effect. Other families may choose to not come forward in working through ACP after hearing this family's negative experience. Additionally, such a negative story might create distrust and animosity towards the ACPF thus damaging their relationship before it even started.

### Discomfort in Talking about Death

The topic of death on the HD unit from the study participants' perspectives contributes to communication breakdown because it prevents patients, family members and staff from openly posing questions, discussing their concerns or expressing any trepidation. As I indicated in chapter 2, death is a complex subject under which its layers of complexity are contributing

factors to communication breakdown. This study's findings resonate with Dinwiddie et al.'s (2003) statement that "a culture of death denial prevails in dialysis units among renal staff, patients and families" (p. 3). It is a person's cultural and social background that shapes EOL care preferences (Crawley et al, 2002). Given the diversity of HD patients and staff on the unit, the current challenges are not surprising. As was previously discussed in the literature review, differences in culture, religion and ethnicity regarding individual and collective attitudes towards openly naming and discussing disease, dying and death often create misunderstanding, false assumptions and misinterpretations between all parties involved (Crawley et al., 2002; Larson & Tobin, 2000; Kawaga-Singer & Blackhall, 2001; Mazanec & Tyler, 2003). Furthermore, the staff's approach in addressing death on the unit, as explained by the participants, is to avoid it. Though, they understand the staff's intentions to be well meaning, this avoidance is perceived as unhelpful.

The staff's paternalistic approach contributes to this breakdown in communication. Study participants argue that more harm is done by this act of protection than good. HCPs' paternalistic behaviour may be more accurately described as having a personal discomfort with the topic of death. Factors such as being uncomfortable with the notions of dying and death, a lack of professional training, a perceived lack of time in daily practice (Ferrell et al, 2000; Jezewski et al., 2003; Jezewski et al., 2005), and anticipating a negative reaction from families (in particular from younger patients) all unintentionally create barriers. Additionally, patients' only learning of their peers' deaths 'through the grapevine', rather than 'first hand' from staff fortifies this notion of death being a 'taboo' topic. Mark's statement reinforces participants' dismay:

"There's got to be a warmer way of talking about [death] instead of leaving everybody out in the cold you know" (2\_4\_1218-1222).

This lack of awareness and denial regarding death on the unit may be intentional, given North America's death denying practices. Similar findings were noted in Jezewski and Meeker's

(2005) study and Dunbrack's (2006) report in which they both commented on society's, families' and HCPs' denial of death as major barriers to patients' comfort in exploring their meaning of death. Jane shared her experience:

“...All I know is like with the nursing staff I don't mean to be critical of them or anything but it's just that they... it's something they don't want to talk about. Well nobody really wants to think about death and we don't like to think about it either but it's part of something that we have to face every day and cause I don't know if I'm going to go in the hospital tomorrow and my friend might be gone...”(2\_3\_1275-1292).

Jane further described how she continued to feel isolated in her struggles with working through the deaths of peers and noticed how other patients also struggled with facing mortality. She explained how upsetting it was for her to hear about another HD patients' deaths through 'the grape vine' rather than 'first hand' from staff.

“...I get out in the handy dart and [the driver] says: “Oh did you know [patient] passed away?” Well you know, just the way you find out. It's not right. Especially when [the staff] know I'm the one that always helps [these patients] out every day... we do dialysis together. I'm the one that brings their blanket or their ice or whatever and then find out this way, it's not right” (2\_3\_1081-1109).

In her interview, Jane requested that she be told more directly about patients' deaths whether that was via a verbal or written communication. She could then grieve the loss rather than be kept in the dark, wondering what had happened to an HD peer. Jane suggested the unit keep:

“...A little book about people that have passed away if they kept it up to date or did something or...put it on the little bulletin board in memory of [patient]...just so that we know. You know, it'd make it easier” (2\_3\_1063-1077).

Jane thought that such an approach enabled individual patients and families to inquire about certain patients' whereabouts discreetly without the risk of upsetting others who might remain uncomfortable with the issue. Jane recounted an unpleasant experience with another HD patient who “told her off” for inquiring about the whereabouts of a peer, who all of a sudden had stopped coming to dialysis.

“And I thought, what the heck was going on and then one... somebody [a patient] said, “don't talk about her she's gone” and I thought, well I didn't know... it was just the way I was

told not to talk about it because she was gone, as if I had known and I didn't know and I was just wondering what happened to her" (2\_3\_1151-1173).

Patients and families understand the actions of HCPs and other family members to be well intended. However, they point out that the bottom line is "[we] are all going to die at some point" (2\_4\_2). Therefore, they ask, why not face mortality now, either individually or as a family, while still being relatively healthy and able to make well-informed decisions? The ACPF shared several stories that alluded to patients' readiness in facing their mortality, thus highlighting the need for HCPs to overcome their discomfort with the topic and start engaging more frequently in such discussions. The ACPF exclaimed:

"...Actually he just opened right up. When somebody realizes that you are listening, they just pour...he just poured out things that I really didn't expect..."(2\_ACPF\_pg.2).

At the same time, study participants acknowledged the challenges in both talking about death and planning for it. In particular, they felt that younger HD patients who were most likely not finished achieving their dreams might have a harder time confronting death. Veronica explained:

"...For a younger person it would be hard cause you think here I am I'm young and want to do things...I think if you talked DNR to them it'd be a hard one, especially from their perspective" (4\_8\_3393-3411).

Veronica spoke of her older brother who had experienced a recent heart attack and how such an event can make a person think about their own ACP.

"...But at 47 it really scares you because you have potentially so much more to go right, so it kind of gets you really thinking...It's actually sad and a nightmare but that's the way it goes" (5\_9\_408).

The ACPF validated the participants' observations and recounted feeling more challenged in initiating conversations with younger patients (younger being less than 50 years old). Initially, the facilitator worried that they may not think such a topic applied to them. The ACPF described how these up front worries and anticipations experienced acted as a barrier to engage in conversations. Over time, however, as the facilitator continued to converse with younger HD

patients, s/he described how their positive feedback about the process provided comfort and affirmation of the topic's applicability.

“I haven't found anybody to not be receptive... I mean they receive what I've got to say. They look into it” (2\_ACPF\_6).

The ACPF recounted two stories in particular, in which a male HD patient affirmed the importance of the ACP process and paraphrased the following anecdote:

“You're an angel this is an important thing to be talking about.” The ACPF's reply to me during the interview was, “...Surprising how once you do ask you sometimes get a surprise that they are open” (2\_ACPF\_pg.5).

The difference between younger and older HD patients appears to be about optimism. The ACPF recounted how younger patients have things left to do, hope for a transplant, dreams left to accomplish. They are not finished living. They often have young families and are developing education or careers. In contrast, older patients, who have potentially lived a good part of their life, often use ACP as an opportunity for completing a life review in which they have more of life to celebrate and reflect on accomplishments. The older study participants spoke of these very issues as being part of their process in facing their mortality and making advance care plans. It is important to acknowledge, however that this discussion does not exclude the notion of many older patients potentially not feeling satisfied with their lives lived. They may still have unfulfilled dreams remaining and may not embrace ACP as an opportunity but rather as something else.

The issue of death remains a sensitive topic from both the perspective of patients and staff. I could not find any nephrology-based research that further informed these findings. However, Ferrell et al. (2000) presented findings on this perceived barrier from the oncology nurse's perspective. Oncology nurses described patients' avoidance of death as somewhat of a barrier in practice 70% of the time, and family member's avoidance of death 73% of the time.

Contributing to these barriers were HCPs' personal discomfort with death that oncology nurses perceived as a severe barrier 17% and somewhat of a barrier 56% of the time.

The findings from my research demonstrate how HD staff, like many patients, still requires more time and supportive measures in order to facilitate future growth in coming to terms with the notion of death. Coming to terms with personal discomfort is imperative in order to facilitate comprehensive EOL care decision-making. Identifying the reasons for the breakdown in communication and disconnect within the HD unit with respect to death remains to be uncovered. However, this study was able to draw attention to its pervasiveness.

A Paradox in Communication Breakdown. Three cumulative circumstances create a paradox thus adding a layer of complexity to understanding the notion of communication breakdown. The three circumstances are the perception of the HD unit as being a family, the lack of personal privacy on the unit, and the open group discussions occurring amongst staff, patients and families. On the surface these three circumstances appeared to facilitate a more open response to talking about death. Paradoxically, they perpetuate it to remain underground.

The research literature (Swartz & Perry, 1999), several study participants and the ACPF refer to HD units as being a 'family'. Long-term relationships are formed amongst patients, their families and with staff. They can see each other thrice weekly for years on end. For instance, one man in the dialysis unit where I work has been dialyzing in this same unit now for over 15 years along with a handful of the same staff. The relationships they have developed are very strong and long lasting. Jane described this relationship within the context of experiencing death on the unit.

“Because we've become like a family. The handy dart drivers, the patients, the nurses, we've become like a small family...so when somebody lets you know somehow that this person is passed on, it just makes it easier to go on with your life...” (2\_3\_1382-1386).

The second circumstance contributing to the paradox is best described by the ACPF. The facilitator conducts most initial ACP conversations at the patient's bedside well in earshot of

surrounding neighbours. The dialysis stations are spaced several feet apart from one another within an open area often without the benefit of a surrounding curtain. Discussing a private matter during dialysis is a challenge, conversing in a whispered voice is one of few options. In fact, maintaining privacy becomes a greater challenge when an interpreter is required.

Interestingly, patients, family and staff appear to accept this lack of privacy as commonplace and do their best to respect their neighbours' space. It is not uncommon to have group conversations taking place as a particular topic becomes of interest to the surrounding neighbour(s) and staff.

This open group dialogue that often takes place on HD units is the third circumstance that contributes to creating the paradox in communication breakdown. The ACPF reflected on such occurrences and stated:

“The patients seem very open to letting us talk at their bedside [during dialysis] but it should be better that we have a private space to go with their family, you know. Most for some reason they don't seem to be awfully private about these discussions. Maybe they don't think other people can hear although... heavens with interpreters it's really something because any other Punjabi patient wants to hear probably just exactly like English people... and they [other HD patients] sometimes will, from two beds away will respond to what we're saying over at this bedside and actually they carry on then as friends would, which is what happens in this English speaking world too. They actually are supporting one another in some kind of way” (1\_ACPF\_1955-2014).

Based on the ACPF's account it appears that most patients adapt to this loss of privacy in the unit. Many experiences within the trajectory of ESRD are not exclusive, thereby creating context for shared dialogue. However, I find it puzzling to understand why it is then that there is little overt discussions about ACP and death. The majority of study participants indicated that if asked by others, they would share their ACP experiences, yet they have never been approached. My intent in sharing this observation is to draw attention to the complexity of this topic. Exploring this issue in greater depth is a topic for another study.

Positive Change. Two positive occurrences are slowly evolving on the HD unit that acknowledge death as a natural part of life on HD. The first is the frequency of HD staff

attending patient funerals and the latter is the introduction of a memory tea, honouring deceased HD patients. The ACPF indicated noticing an increased rate of staff invites to patients' funerals.

In years past, receiving invitations to patients funerals was not a regular occurrence yet recently it has become commonplace. I have noticed this frequency within the HD unit where I work. Moreover, families routinely acknowledge the staff's contribution to patient care in local newspaper obituaries. Individually, staff may attend a patient's funeral to say farewell, enabling them to have some closure in their relationship with the patient and possibly the family as well. The funeral also invites staff to learn about who the patient was outside of the disease. However, what is interesting is that only recently have families been offered a similar invitation from HD staff where they attend a memory tea to honour the patient's death along with the unit's staff. I am told that pastoral care assists with hosting this event.

The memory tea is held quarterly to honour the memory of the deceased within the HD unit. A notice is posted inviting HD peers to attend the event along with invitations mailed to the families of the deceased. The names of the deceased are written on cards displayed on a table. Families and staff are encouraged to share their memories of how they remember each patient. I am told that initially several staff expressed their trepidation in the potential emotional risks for other patients by openly acknowledging death on the unit. The ACPF recalled, "I haven't heard of any negatives on that, but we ask. We're also open to hearing that" (1\_ACPF\_1652). In support of the practice, Jane articulated her frustration with patients not being provided with an opportunity to mourn the loss of their peers. She said:

"And I just wish there was a way that they could let us know...have an easier way to face the death because it'd make it easier on us patients too if we knew there was something that was in memory" (2\_3\_1306-1317).

What I find interesting about HCPs' concerns is the apparent contradiction in thinking that inviting families and HD peers to a memory tea is somehow different from families inviting staff to a patient funeral. I have never heard of a staff member commenting on the

inappropriateness of attending a patient's funeral, rather, it is considered to be very meaningful within the HD unit where I work. Attending patient funerals and the memory teas are opportunities for celebrating the lives of those who have died. It is an opportunity to say farewell and share stories amongst caregivers who knew the patient in a potentially different light. As I see it, each event offers the occasion for highlighting one side of who the patient was in their life. However, I do not have evidence that other renal staff have considered this perspective before.

The ACPF recounted how one family upon attending a memory tea shared their surprise in learning that HCPs "did this [sort of thing]" (1\_ACPF\_1592). The ACPF also shared two other similar situations. The first was when a family member brought another fellow along with him who also had recently lost his wife and "...they both sat there, the other fellow cried more than the one we knew and thanked us for soothing him..." (1\_ACPF\_1633). The second story described the reaction from a visiting family who upon learning about the event stated: "Oh for heaven sakes, you have a memory tea. Does everybody do that kind of thing? It's wonderful..." (1\_ACPF\_1788).

Many people do not realize how patients' deaths significantly impact staff nor are they aware of the amount of death present in HD units. The ACPF reflected on the reaction of the hospital chaplain soon after the first memory tea was held in which there had been 15 patients remembered. Three months later, they were making plans for the next tea when the chaplain questioned it being too early, until the ACPF clarified that 12 patients had died in the past month alone. HD patients also notice the amount of death around them as Jane recollected,

"Last year I think I lost 5 or 6 people at the hospital here that I was close to and I was helping and became friends..." (2\_3\_136).

Hemodialysis patients' funerals and attending the memory tea are two positive steps towards "saving death" (Nelson, 1999). Perhaps the families and staff attending such events can

create “compelling testimony that death can be experienced in a better way” (Nelson, 1999, p.777). Furthermore, collectively honouring these deaths assists family and HCPs to move forward in the process of bereavement. I think a fresh perspective on the meaning of death is needed within this HD unit and other HD units because “saving death” is equally important and rewarding as “saving lives” (p.777).

### Chapter Summary

Communication breakdown is a major theme derived from the data analysis. It extended well beyond ACP to involve families’ complete illness experience. Embedded in all of the participants’ stories was a message of how destructive a lack of communication is to their confidence in HCPs and trust in the HCP-client relationship. Communication breakdown primarily occurred during three main time frames in the family’s illness trajectory. The first period encapsulated families’ interactions with HCPs prior to ESRD and when the patient’s other co-morbidities were the issue.

In the next segment, families entering the renal program described how they had to remain strong advocates for not only themselves but for the patient as well. Upon entering the HD unit, families shared how they had to learn to navigate a new system in which they felt that most interactions occurred between the patient and staff rather than communication with the family. Dialysis was received with mixed emotions. For some patients, it offered a bit of a new beginning but often for the families, dialysis meant another upheaval in their lives. Amongst all of the chaos, families described feeling left with the responsibility for initiating communication with HCPs. A reoccurring statement that kept surfacing throughout participant interviews was the notion that “knowledge is power.” Participants expressed their frustration in not receiving the whole story about a situation unless they were present at the time.

Communication breakdown within ACP was multi factorial due to its complexity. It encompassed such factors as the families’ lack of awareness in the existence of ACP on the HD

unit, their need for an established professional rapport, and trust in the HCP-client relationship. The other factor was HD staff's continued discomfort in talking about death, which seemed to remain a 'taboo' topic on the unit. When participants were asked whether they had ever heard of ACP or been approached by their peers about it they unanimously replied no. HD Staff, like many patients, still require more time and supportive measures in order to facilitate future personal growth in coming to terms with the notion of death. Identifying the causes for this disconnect within the HD unit remains to be uncovered. Death is a complex topic and certain factors, such as anticipating a negative reaction from families, in particular from younger patients, unintentionally create further barriers.

Three cumulative circumstances create a paradox in understanding the notion of communication breakdown. These circumstances included the perception of the HD unit being a family, the lack of personal privacy on the unit, and the common group discussions occurring amongst staff, patients and families. On the surface, these issues appeared to facilitate a more open response to talking about death, but instead forced it to remain underground. Luckily there have been two positive events on the unit that are steering a more positive course towards accepting death as a natural part of HD.

Attending patient funerals and the memory tea are opportunities for celebrating the lives of those who have died and are two strategies on the unit that are attempting to incorporate a better acceptance of death. On the basis of what I have learned in this study, the memory tea has a great deal to offer families, renal staff and peers of deceased HD patients. It provides the occasion to mourn who the person had become because of the disease and to learn how the staff regarded him/her through the sharing of their stories. It also informs families of the level of caring that does go on within the unit and that the patient was valued as a person.

## CHAPTER SIX

### Summary, Limitations, Conclusions and Implications

Chapter 6 provides a summary of the study, highlighting its main points for consideration. Every study contains both strengths and limitations that contribute to its rigor. This study's strengths were discussed in chapter 3, under the heading of *Rigor*, and now its limitations are presented. The ten conclusions that were drawn from chapters 4 and 5's study findings are summarized and discussed in detail along with their implications for individual practice, patient education, organizational structure and policy, and further research.

#### Study Summary

Chapters 1 and 2 discussed how ESRD and the treatment of HD incur a complex and often uncertain illness trajectory. The impact on the family is intense and invasive. Family members often become the informal caregiver and in times of health crisis the patient appointed SDM. Families have a fundamental role in EOL care and require immense support and resources from HCPs. One effective resource is ACP. It offers a comprehensive approach to addressing EOL care, promotes collaborative communication, and facilitates effective partnerships among patients, their families and HCPs. This study was undertaken to explore, from the family members' perspectives, the experience of participating in facilitated ACP conversation(s) with the HD patient. Providing families with an opportunity to share their perspectives, identify their potential needs and voice their wishes in planning for their loved one's eventual death recognizes their inherent role in the illness trajectory and validates that they too are clients within the HD setting.

When HCPs more fully understand family interrelationships and see the family as a whole, HCPs are more able to understand how the family situates themselves both in the illness experience and in EOL care. Therefore, an effective approach to studying how families experience ACP conversations is to use ethnographic research. The purpose of ethnographic

research is to acquire cultural knowledge of a person's own society, recognizing that human behaviour is contextual. It assists outsiders to understand the world through the participants' eyes, what they perceive as meaningful, while revealing the subtleties in how they negotiate its complex processes. Thus, having applied an ethnographic approach to study families' perspectives on ACP conversations in an HD unit was appropriate. This approach revealed thick descriptions that shed light on the family's unique perspective that has received little attention in previous research.

Five families and an ACPF were recruited into this study through purposive sampling. The families participated in one interview each and the ACPF participated in two. Each family consisted of an HD patient and one chosen family member whom the patient had appointed as the SDM. The patients had been receiving HD treatments within this particular unit for between 3 months to 5 years. The family members' ages ranged from mid 30s to mid 80s. There were two spouses and 3 adult daughters. The families had gone through their initial HD related ACP conversations on this unit anywhere from several months after starting HD to 3 years ago. The ACPF acted as a key respondent and had at least a decade of renal experience and over 3 years of facilitator experience.

After the first 3 family interviews, the ACPF was used as a key respondent to validate, compare and assist in the interpretation of emerging ideas. Preliminary insights were minimally explored in the subsequent family interviews, as new information kept arising. Only one negative case occurred in which further validation of findings were not possible due to time constraints and a limited population group from which to recruit. A reflexive journal was maintained throughout the study to record researcher insights and to critically evaluate my influence on the study process and emerging data. Extensive fieldnotes were kept that documented study implementation and established an audit trail. Data analysis revealed several themes under which multiple subthemes were identified.

In chapter 4, a detailed description of the ACP process within the context of HD from the family's perspective was presented in which the themes of timing, readiness and finding meaning emerged. Several subthemes under each of these themes also became apparent. The notion of timing was interwoven throughout the ACP process in which the patient or family member(s) had to determine when to introduce the concept within the illness trajectory. Advancement depended on where the HD patient and/or family member(s) were at in their personal lives and whether they were ready to explore the topic. Taking the time to plan ahead meant that family members could consider their roles within a serious health crisis, reflect on how they might handle such stressful situations, and seek meaningful clarification. Each family was unique in the amount of time they took to work through the various stages of the ACP process. Participants also mentioned needing time in the future to potentially revisit ACP if the circumstances of the illness or their lives changed.

Initially, readiness entailed each family member coming to terms with death and facing mortality. Finding meaning meant that each member had time to explore both individual and collective perspectives of the illness experience. Once this was achieved, family members decided on whether they could commit to this process and their role within it, understanding the difficult EOL care decisions that had to potentially be made on behalf of the patient. The issue of readiness from a broader sense encompassed both the ACPF's readiness in this role and that of the HD unit to embrace ACP. Both of these factors were essential in facilitating the continuation of ACP.

Study participants provided a detailed discussion of the role of an ACPF and the ACP workbook, identifying both strengths and opportunities for improvement. Families then reflected on their complete ACP experience and considered what advice they would give to families new to HD and ACP. They also shared what going through the process had done for them. Regardless of the study participants' diversity, they consistently had similar statements. Additionally,

participants provided constructive feedback to this department's ACP program. Communication was identified as a valuable component, and families perceived their role as essential, extending beyond this process to encompass the trajectory of ESRD.

In chapter 5, the major theme and findings related to communication breakdown that was encountered along study participants' illness trajectory was explored in detail. Communication breakdown often began before ACP was introduced and could persist long after the initial process was completed. This breakdown started with families' healthcare experiences prior to ESRD and continued throughout their HD experiences. The participant families' accounts shed light on the inadequacies of an overstretched healthcare system fraught with unrealistic expectations and unreliability. Their stories portrayed how destructive a lack of communication can be to a person's confidence in HCPs and trust in the HCP-client relationship. The complexity of each individual's needs, expectations and understanding regarding what gets communicated, how it is said and how it is heard either facilitates or hinders communication. The issue of ACP was only one event along a continuum of experiences in which families emphasized the need for absolute interaction.

Families indicated that the presence of ACP on the HD unit was covert and they felt this was in part due to the HCPs' and patients' denial and/or discomfort with death. Their observations draw forth a paradox in practice where the HD unit has introduced a progressive ACP program to facilitate patients and their families discomfort in facing mortality, but has not sufficiently acknowledged the renal staff's discomfort in discussing death. The findings from this study can inform future HCP practice within this HD unit. The renal staff can come to understand how their unintentional actions contribute to communication breakdown and how their discomfort with death hinders the integration of ACP as a component in renal care. The limitations of this study are first presented followed by an exploration of the conclusions and implications drawn from this study.

## Limitations

Every study contains both strengths and limitations that contribute to its rigor, such as this study's sample size (Sandelowski, 1995) and using retrospective data collection (Meeker & Jezewski, 2004). The strengths within this study were previously discussed in chapter 3 under the heading of *Rigor*. The limitations included the following issues. My professional and political stances could have created untoward biases in the collection and interpretation of data because as a nephrology nurse, I am enculturated in the HD setting with an invested interest in advancing ACP within HD care. This potential bias may have created cultural blind spots and contributed to making certain assumptions or discounting information. My being an HD nurse could have set limits on the amount and type of information participants felt at liberty to disclose.

My participant observations were limited to participant interviews and not in the field. It was hard to predict the appropriateness and client reactions of me attending ACP conversations with the ACPF. However, I could have observed family interactions within the field and possibly attended the memory tea. These actions would have at least made contributions towards the analysis of client and HCP relationship dynamics. Another study limitation is reflected in the literature by Roper and Shapira (2000) who noted that participants are a good resource for providing feedback on potential hypotheses regarding what is happening or why things occur. Unfortunately, this was not feasible because of participants' busy schedules and the sensitivity of the topic.

The study's small sample size became a limitation in achieving redundancy or saturation because it created insufficient repetition or consistencies in findings. Furthermore, making any definitive conclusions of the findings would require a larger sample size. Having only encountered one negative case, and having a limited number of family member position perspectives set limits on the transferability of study findings to the larger HD unit patient

population. Moreover, only 1 out of the 11 study participants was not Caucasian and the patient population in this particular HD unit is multi-ethnic, with Caucasian patients being the minority.

The study participants' ACP conversations were from one moment in time of their illness trajectory. Therefore, details and events may have been forgotten or distorted by the lapse of time, potentially contradicting initial perceptions, and consequently weakening the reliability of their experiential accounts. This perspective poses limitations on the findings as fixed in time rendering the interpretation of findings as situated within the limitations of this thesis project.

### Conclusions

My conclusions are from the findings of this study and are based on the participants' feedback of their ACP experiences. The following ten conclusions summarize their perspectives and are as follows:

1. Advance care planning is a valuable experience that every HD family should be offered the opportunity of completing. It can provide peace of mind to those struggling with death, facing mortality and finding meaning in the illness experience. It is a flexible process that can be tailored to address families' individualized needs. Advance care planning creates a supportive environment for exploring future health uncertainties, encouraging critical reflection and open dialogue among its members. It is important that this exploration of perspectives and opinions be discussed well in advance of a health crisis.
2. The ideal time for initiating ACP conversations is when everyone's health is stable and people are calm in order to think clearly. No one can foresee how large or small a health event will be. It is important not to assume what the other person's wishes are or that everyone involved is of the same understanding. Unless the questions are asked upfront nobody can predict how another person will react or what actions they will take and in whose best interest these decisions will be. The study participants' perspectives are well

grounded and resonate with a number of research studies previously discussed in chapter 2's literature review (Caplan, 2000; Ditto et al., 2001; Fagerlin et al., 2001; Fried et al., 2003; Moss, 2003; Nolan & Bruder, 1997; Pruchno et al., 2005; Singer, Martin & Kelner, 1999; Tulsky, 2005). The participant families' spoke from experience when they described how emotionally distressing it was to make critical decisions during a time of crisis and "would not wish a similar experience on anyone." Additionally, ACP provides an opportunity to bring family members closer together.

3. Advance care planning provides an opportunity to face mortality and come to terms with it by finding meaning in the illness experience. It brings talking about the patient's mortality into the open where it can become a "non-issue" and can be revisited at anytime in the future. The message from families about their experiences in confronting death was that human beings are mortal and there is no denying that fact, but people make a conscious choice in whether they chose to face their mortality or hide from it. Regardless of whether HCPs decide to engage in EOL care discussions and ACP in particular, the bottom line remains that patients will still continue to die, and many families will experience emotional turmoil. Dying is fact it cannot be controlled, but how a person dies can be well supported and is at least partially controllable. Therefore, implementing initiatives directed at alleviating some of this turmoil is essential. Several participants also indicated that families who do not talk about the patient dying and the circumstances under which it may occur are more likely to fight and experience greater conflict when the time comes to make these decisions.
4. "Knowledge is power," described many family members who often felt ill equipped to handle aspects of the patient's illness experience and its uncertain trajectory. Families felt that the ACP process provided them with comprehensive information and contributed to

their knowledge of EOL care issues. The use of an ACPF and workbook were considered fundamental components of this process.

5. The role of facilitator in the ACP process is pivotal to the success of the program. The ACPF helped bring the topic into the open, taking the time to ensure that everyone understood the facts and were clear about potential health outcomes. Families received ongoing support and validation of their ideas that further empowered them in their role as informal caregiver and SDM. Participants appreciated the gentle reminders from the facilitator in moving the process forward, as they got easily caught up in their hectic lives, frequently pushing ACP to the background. Families often needed someone else to assist them with keeping on top of the patient's health issues. This joint effort made family members feel more involved and informed of the patient's well being on the unit. Study participants provided key characteristics of the ACPF, such as having a gentle manner and being supportive. It was equally important to be flexible, open-minded and non-judgemental. Families indicated that it was not only about who did the talking but how it was said. The ACPF needed to have the right balance between being persistent with gentle nudging but not be overly aggressive, and to be assertive without being overly confident. It also took great skill for the ACPF to recognize and work closely with families whose perspectives often differed from other members in the family and from HCPs. Finally, the ACPF described a valuable feature of the facilitator's role was how it demonstrated to HD families the amount of caring HCPs provided to their loved one's within the unit.
6. The ACP workbook is used as a tool for conversing about ACP. It is not a legal document, but is, rather, a resource to the family and ACPF that outlines treatment preferences based on the patient's beliefs, values and wishes. Study participants also highlighted the challenges they foresaw and, for some actually experienced, in

comprehending the necessary yet complex medical terminology. Additionally, several participants expressed that a person had to be (well) educated in order to comprehend the implications of certain medical terms. A critical issue they identified was that some people would not seek clarification or ask for assistance if they did not understand all of the medical terminology. This situation may be compounded by additional factors, such as individuals who are unfamiliar with our healthcare system, who may be illiterate, and/or who are non-English speaking or have English as a second language. Findings from the literature suggest to not assume that completion of an AD document confirms a person's full comprehension (Jezewski et al.'s, 2007). Thus the ACPF's presence creates an opportunity for addressing potential confusion, validating the extent of an individual's comprehension, and providing any additional supportive resources.

7. Study participants shared some challenges they encountered with HCPs in the ACP process. They situated this discussion in the context of communication breakdown. Communication breakdown encompassed factors, such as the families' lack of awareness in the existence of ACP on the HD unit; the need for an established professional rapport and trust prior to engaging in ACP; and finally, the ongoing issue of not only staff but also other patients' continued discomfort in talking about death. In fact, communication breakdown exceeded the boundaries of ACP to encompass each participant family's illness experience. Study participants posited that the deficits in the current health care system, financial cut backs and decreased availability of resources to support HCPs in their daily jobs significantly contributed to the breakdown of communication.
8. Death remains a 'taboo' topic on this HD unit. The study participants viewed the staff's approach to addressing death, though understood to be well intended, as not being constructive. Their paternalistic approach hinders opportunities to facilitate a supportive conversation. Study participants argue that more harm is done from this act of protection

then good. Furthermore, HCPs' paternalistic behaviour can be more accurately described as having a personal discomfort with the topic of death. If HCPs were to more outwardly acknowledge death on the unit it would assist other patients, families and themselves to move forward in the process of bereavement. Although identifying the reasons for the breakdown in communication and disconnect with death in the HD unit remains to be uncovered, this study was able to draw attention to its pervasiveness. Two proactive approaches that create safe environments for mourning the loss of patients on this HD unit are the increasing number of staff invitations from families to attend patients' funerals and the memory tea commemorating the recent deaths of HD patients. These approaches are also two introductory steps towards acknowledging death and supporting bereavement.

9. If ACP is left up to the patient to communicate with the family then many opportunities for improving professional relationships with families will be lost. Any one of the following barriers, as previously described in the literature review, puts this passing on of information at risk. If the patient is too fearful of facing mortality, doesn't perceive there to be any concern or reason to talk about ACP, or is anxiously anticipating a negative response from family, then that information will not be passed on. Meanwhile, the family may be experiencing distress, feeling isolated and worrying about the patient's mortality. Independent of the patient's needs, the family may require an outlet of their own. Additionally, providing direct family support may inadvertently create a more positive supportive experience for the patient.
10. Many families want to be more involved in the patient's care not only in the context of ACP but also in HD and throughout the illness trajectory. They too are part of the illness experience and are affected by it. Their lives are not stagnant and neither is the trajectory of ESRD. Therefore, their needs too will fluctuate over time thus should be frequently

reassessed. Families want to engage in dialogue with HCPs, receive feedback and ongoing updates on the patient's progress and prognosis but understand that patient autonomy must still be valued. They want to be asked how they are coping as a family, because many members feel they are outsiders. Upon entering the renal program, families described having to learn to navigate a new system where they perceived most interactions occurred between the patients and staff rather than communication with the family. Healthcare providers can inform families, especially those not familiar with the Canadian healthcare system, of what services and resources they are entitled to. Healthcare providers can also provide families with supportive ways of working through health events and provide guidance in knowing what questions to ask that will assist them in making critical decisions. Not all families will want to be fully involved in the patient's illness experience nor will some patients embrace their illness, however for those that do, communication is of the utmost importance. Families want to be invited and welcomed into the circle of communication. If ACP is about fostering communication and facilitating relationships, then it should be initiated sooner in the illness trajectory, ideally from day one.

### Implications

The findings from this study demonstrate how the participant families perceive that renal HCPs often make assumptions about HD patients, families and ACP. Evidence from the literature and chapters 4 and 5 support these findings. Healthcare providers who reflect on the participant families' feedback can create opportunities to ameliorate collaborative partnerships with these families, particularly in the context of ACP. The study participants described how several of the assumptions that HCPs make contribute to communication breakdown between HCPs and themselves. These assumptions that the participant families shared are laid out as follows: HCPs assume patients are reliable resources for conveying information to the family.

However, families remind HCPs that this information often gets miss communicated or misunderstood if patients are ill (such as being uremic) at the time of receiving it. Furthermore, families ask that HCPs take extra steps to verify and evaluate the patient's understanding of the information or education they have received.

Families ask that HCPs do not assume that if families have not contacted them that the family is managing well and does not have concerns, or the family would be in touch. Study participants describe a similar assumption being made about death. Families feel that HCPs assume that they do not want to talk about death and dying; that patients do not want to know about the death of their HD peers, be reminded by seeing patients' names posted somewhere, or by having a remembrance ceremony such as a memory tea; yet study participants indicated otherwise. Indeed, there are a select few patients and families that do not want to know of their peer's death or engage in such conversations. Therefore, the challenge is for HCPs to find ways of striking a balance, respecting both perspectives.

The literature review, from chapter 2, demonstrated how many HCPs feel they must protect patients and families from the notion of death. HCPs often perceive they are removing the patients' and families' hope by encouraging everyone to face their mortality, yet evidence from this study and the literature, in particular, demonstrates otherwise. Both the study findings and the literature indicate that ACP is a necessity within the context of HD, that death is inevitable and unpredictable. Therefore, providing patients and families with the building blocks and a supportive environment to explore ACP offers them the potential for closure as they work through the process. Advance care planning creates opportunity for improving relationships thereby allowing families to become unstuck, enabling them to focus on the time remaining, rather than dwell on what is lost or worry over what could happen tomorrow.

It is important for HCPs to consider several factors prior to asking families to make EOL care decisions. The first issue asks them to consider that families remain distressed when placed

in a position of having to make decisions about the incapacitated patient without knowing if it was what s/he wanted. The researchers Strauss et al. (1984) described this experience as follows: “The work of deciding which options to choose in stabilizing a trajectory is, in its uncertainties and perils, not unlike steering a course through a mine field” (p.148). These findings are mirrored in Lynn and Goldstein’s (2003) discussion paper where they explain that families appreciate receiving supportive guidance and suggestions when having to make decisions about withdrawal from treatment. They stated: “This approach allows the family to make sense of their role [in this unfamiliar situation and] in consenting...[families] worry about whether they ‘did the right thing’”(p. 815).

A second important factor for HCPs to consider before asking families to make EOL care decisions is to realize that many families are unable to separate their own views from what the patient would have wanted (Fagerlin et al., 2001). A third factor to consider is that on occasion, as previously discussed in the literature review and in chapter 5, some family members may not act in the best interest of the patient thus it is essential that other supports for the patient are made available. A fourth factor asks us to remember that HCPs do not often know who is the most suitable representative or how to manage family conflict. Finally, the fifth factor for HCPs to consider is about encouraging the patient to speak with family members and determine who is to be involved in the ACP process and who will be the SDM. All of these circumstances can become ethically distressing for all parties involved, leaving the incapacitated patient helplessly in the middle (Larson & Tobin, 2000).

The above discussion demonstrates the many challenges, expectations and barriers present in the HCP-client relationship. Addressing many of these assumptions and issues will take time and necessitate action at all systems levels. A good starting point for HCPs is in their individual practice.

## Implications for Individual Practice

Each renal staff member is well positioned to ameliorate (negative) interactions with families by heeding the advice study participants proposed. Families want to be offered the option to engage regularly in dialogue with HCPs. They want to be kept informed of the patient's progress and prognosis. Every practitioner is in a position to learn how to collaborate with families and not make the assumptions previously outlined; as such behaviour becomes counterproductive and obstructs effective partnerships. An essential element that lies at the core of this collaboration is a commitment to improving open and effective communication.

It is important that each HCP take the time to explore what personal meanings they attribute to death and self-reflect on how these perceptions influence their professional practice. The findings from my research demonstrate how HD staff, like many patients, still requires more time and supportive measures in order to facilitate future growth in coming to terms with the notion of death. It is important for staff to realize how a lack of action and avoidance of this topic impedes client care, suppresses emotional growth, and reinforces that it is not an acceptable topic for discussion. Death is a natural part of ESRD and HD illness trajectories; therefore encouraging and supporting staff to accept this inherent fact is essential. Study participants encouraged renal staff not to be afraid of asking about EOL care issues, stressing the importance of creating an environment conducive to exploring these issues. Many patients and families require the assistance of a HCP to gently probe and inquire about the topic in order to facilitate its progress where it is brought out into the open.

Individual practitioners must also realize that they have a unique opportunity to challenge many of the ethical barriers in current practice. They can collectively become more involved in organizing staff round table discussions, participate on various nephrology committees, and access available hospital and regional resources. Practitioners can learn how to identify the ethical issues encountered in everyday practice, and articulate how these issues impact their

moral voices. Implementing such strategies provides them with opportunities to create effective and supportive change that benefits not only themselves but their clients as well.

#### Implications for Patient Education

The development of strategies that are based on a comprehensive assessment of not only HD patients' but also their families' needs are essential. Families are also HCPs' clients who often have a unique set of needs that should be equally valued. It is important that the renal staff continue to encourage and support patients and their families to explore the meaning of their HD experience, the notion of death, facing their mortality, and learning how to articulate what quality of life means to them. In addition, the renal team can provide families with a more formal introduction to HD. As part of this introduction, the renal team could assess families' individual and collective needs, and devise a plan of care, involving everyone that can be revisited frequently throughout the illness trajectory. Such an approach validates the family's role, facilitates communication and improves the quality of care being delivered to families as a whole.

#### Implications for Organizational Structures and Policy

Findings from this study and the research literature previously discussed provide a rudimentary argument for incorporating an ACP program into HD units that cannot be implemented 'off the side of a person's desk' but rather be fully integrated into practice, and adopted as a principle standard of the nephrology program. Study participants described the ACP program within their HD unit as fragmented. Staff discomfort with death, factors related to communication breakdown, and the perceived lack of a unified approach to its implementation pose great risk in hindering such a promising program. In order to more fully integrate ACP into the HD unit, a collaborative multi level systems approach is needed that addresses the previously identified barriers. Moreover, incorporating the following two philosophies would lay the groundwork for fostering a change in practice. The first philosophy is derived from hospice

palliative care in which ACP is but one effective approach along a continuum of supportive EOL care strategies. The second philosophy moves away from an acute care model to a chronic disease care model where family-centered care is at its core.

The following example illustrates another opportunity for improving communication in the context of ACP and in HD care not only between the HCP and client but also among different HCP teams. This example is based on the feedback from the ACPF and from my own nephrology nursing experience. When a patient is admitted into the hospital, seldom does staff from other wards and/or departments understand the renal team's level of involvement with their patients. The staff from other areas often do not comprehend the importance in keeping the team informed of decisions impacting dialysis care, especially if the patient is thinking of coming off of HD. Moreover, families frequently find themselves situated in the middle often becoming the go-between. The implementation of routinely scheduled team meetings in which members of the renal team met with ward staff and family members is one strategy that could assist in alleviating the potential for fragmented care that often occurs.

#### Implications for Further Research

This study provides preliminary findings on how five families from one HD unit and a renal ACPF experienced the ACP process. The small sample of participants is not necessarily representative of the larger group of individuals who to date partook in the HD unit's ACP program. Therefore, the interpretation of findings is situated within the limitations of this thesis study. The findings provide insightful and constructive preliminary feedback that contributes to the program's evaluation as to whether ACP is an effective approach to addressing EOL care issues.

The diverse personal accounts from the families and the ACPF consistently revealed the discomfort of HD staff in addressing ACP and death, along with how this discomfort contributed to communication breakdown. Their collective observations along with supporting evidence

from the research literature provide mounting support for the undertaking of more research to further explore whether these findings resonate with the HD unit's larger patient population. A critical examination of HCPs' current attitudes and level of comfort in addressing HD related EOL care issues is needed. Additionally, gaining both an understanding of how staff perceive, interpret and address the notion of death on the unit, and how they perceive ACP and their role within it are essential.

The study participants indicated how the denial of death impacted both the effectiveness of the ACP process and significantly impeded communication. The following series of questions highlight the multiple research topics that could begin to address this issue within the HD unit: What are the renal staff's perspectives on the ethical EOL care related issues they encounter regularly in practice? What resources do they suggest be implemented to effectively address them? What meaning does death hold for patients and HCPs, how is it addressed or acknowledged, how does it influence their interactions, and is sufficient being done to support them in managing it? How does patient death affect staff and patients on the unit? What is it like for HD patients to witness a cardiac or respiratory arrest? What factors contribute to the shadowing of death on the unit, and why does it persist as a 'taboo' topic? How many patients are aware of the memory tea, understand its intent, and what prevents them from attending it? What are the renal staff's perspectives of the memory tea, and what other strategies can they identify that support dying on the unit? Finally, a big challenge for HCPs will be in how they find a balance between those patients and staff who want death to be in the open versus those who do not. Another approach to investigating the notion of death on this HD unit might be to compare the rate of monthly and annual patient deaths with those on a palliative care ward within the same facility. If the findings demonstrate a similar rate then an argument exists for providing additional support resources to HD staff and their clients.

This HD unit has taken on an enormous challenge in adopting an ACP approach, yet it cannot be left up to a small group of HCPs, such as the ACPFs, to maintain it. Rather, a comprehensive team approach that encompasses the majority of HD staff must be implemented in order to ensure its sustainability. Those issues identified as hindering the process need to be brought to the forefront of practice. Such approaches convey to HCPs and clients that their needs are being acknowledged and valued.

Further inquiry with renal patients and their families on the HD unit is needed to determine the most effective communication pathways. All of the study participants indicated that they were not aware of the ACP program prior to the ACPF approaching them even though some had been dialyzing for many months after its implementation. This lack of study participant awareness about ACP also emphasizes the breakdown in a collaborative effort to inform patients and their families of the ACP program, thus further contributing to its lack of presence on the unit.

The study participants also indicated that they were not aware of any posters hanging on the walls of the HD unit regardless of whether they were ACP related, associated with this study or announcing a 'fun' social event. These observations draw attention to the current ineffectiveness of using posters as a communication tool within this unit and suggest that alternate methods need to be assessed. If the renal staff were to ask patients and their families about what types of communication pathways they perceive as being most effective then they would not only create more successful strategies, but also convey to their renal clients that their opinions count.

Another area of ACP needing further inquiry is to continue interviewing families regarding their experiences with ACP. The sample for this study was fairly homogeneous in ethnicity, HD patient age and member position held within the family. It would be useful to include HD patients from more ethnicities, especially since this unit's population is quite

ethnically diverse. Including younger aged HD patients, male HD patients and their female partners, same sex partners, and adult sons would also provide a more comprehensive analysis of the family member's perspective. In addition, it would be interesting to involve families in which the HD patient has died since going through the ACP process to determine whether this is a worthwhile approach from their perspectives.

As an outcome of this research study, there may be an opportunity for a formal evaluation of the ACP program, in particular, to determine how patients and their families are completing the ACP workbook and what their understanding is of the complex medical terminology. Given the risk for miscommunication and miss understanding in the ACP process, it would be worthwhile to encourage the HD patient to involve at least one other person in the process, who can act as a reminder for what transpired. In addition, the facilitator should continue recording the ACP process in detail on a communication page kept with the patient's chart, noting such things as: the overall time line, dates when documents were handed out and returned, who was involved, and whether any issues arose and their outcome. This way, there is always a paper trail, and one can seek clarification of the process when needed.

Communication breakdown was a dominant theme within this study that warrants considerable attention given it is at the core of the HCP-client relationship and an essential element within collaboration and partnership. The study participants indicated wanting to be kept better informed of the patient's care, progress and prognosis, pending his/her consent. Families stressed that many of their perceived needs were not being addressed and offered suggestions on how to ameliorate this process. Given that families are equally impacted by the illness experience and are often challenged in their informal caregiver roles, HCPs should consider taking more action to actively address their needs and concerns. It would be worthwhile to engage staff with patients and their families to problem-solve together. They could work towards developing a survey, for instance, that asks HD families to share their concerns, needs and views

on how to effectively support and acknowledge their role. Such an approach creates the context for exploring what factors contribute to communication breakdown, and what collective strategies can be devised to address these barriers in practice. In addition it sets the groundwork for an inquiry into shifting the current model of care to one that is family-centered, resides within the context of a chronic illness framework, and considers the philosophy of hospice palliative care.

### Chapter Summary

This study provides preliminary findings on how five families and an ACPF perceived and experienced the ACP process on an HD unit. It marks an initial stage of inquiry into the effectiveness of an ACP program in a HD setting from the family's perspective. This perspective, which is limited in the current research literature, strives to acknowledge the major contribution of families in providing patient care and to recognize that they too are HCPs' clients often having individual needs from those of the HD patient. Other studies within the literature proposed a similar argument for families though originate from different stances such as a family-centered care model (Wright & Leahey, 2005), the family covenant (Doukas & Hardwig, 2003; Fins, 1999) and seeking family perspectives as a window into the patient's experience (Chambers-Evans, 2002).

The success of an ACP program is based on effective, ongoing open communication between all parties involved that not only spans among but across all healthcare system levels. Conversations should start early, well in advance of a health crisis and be revisited as the patient's health and/or cognitive capacity changes. A primary objective of ACP is to bring the notion of death and facing mortality out into the open where families can find meaning in their illness experience. This in turn enables HCPs to gain an understanding of the family's experience as a whole thereby tailoring care that meets their unique needs. The efforts of ACP in addressing the issues of facing mortality, confronting death and communication breakdown is

making headway, but more action and research must be taken at all system levels to bring these issues out into the open where they can be tackled more effectively. ACP is an essential component of HD context and is another step in the ESRD illness experience. Study participants' responses demonstrated the innate knowledge that death is an intrinsic part of ESRD trajectory. It need not be feared but rather embraced; thereby creating an emotional release that potentially fortifies relationships and a person's appreciation for the life remaining. Advance care planning has the potential to be a positive, self-gratifying experience that should not be shunned but rather celebrated. Advance care planning is a celebration of life.

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## Appendix A

### Advance Care Planning Conversations: The Family Perspective Interview Guide

The following are examples of questions that will be used during the family interview(s) to help elicit the participants' experience(s) with ACP discussions and to help them describe the process of decision-making both as an individual and as a family unit.

1. As a nephrology nurse, I have seen the outcomes of families who have and have not had ACP discussions. What I am interested in understanding is what it is like to be a family member in an ACP conversation. Can you tell me what it has been like for all of you to participate in an advance care planning discussion? What kinds of thoughts did you have at first and have they changed over time?
2. Could you start at the beginning and describe for me what was happening in your lives when you had your first ACP discussion? Who was present? How have these conversations come up? Has there been anyone else that has been involved in these discussions such as a close relative or clergy person?
3. Could you describe how you think your family typically makes decisions?
4. Has participating in these discussions affected how you view kidney disease and hemodialysis? Can you tell me more about this?
5. Based on your experience with this topic, what sort of advice would you give me in how my family might approach this same issue? What are the things that we should consider if we were to talk about this topic?

Knowing what you know now about this topic, what advice would you give to the staff in the hemodialysis unit about how they should talk about or think about this issue? What were some helpful and unhelpful things you experienced yourself and as a family that you would ask them to think about?

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## Research Study Information Letter

### Advance Care Planning Conversations: The Family Perspective

My name is Alexandra Kruthaup. I am conducting a study about how families (significant other, immediate family member, relative, and/or close friend) of hemodialysis patients experience initiated advance care planning conversations. I am a student in the Master of Science in Nursing (MSN) program at the University of British Columbia (UBC). This research is being carried out to meet the requirements of a graduate thesis. Professionally, I am a registered nurse and have worked in the specialty of nephrology (kidney) for the past 6 years, specifically within hemodialysis, peritoneal dialysis and the chronic kidney disease clinic. I have been nursing for a total of 9 years.

This letter introduces my study and invites you and the person(s) whom you consider family to participate. **Family** may include one or more person(s) who fit the following criteria: a significant other, immediate family member, relative, and/or close friend with whom you spoke to about your advance care plan; possibly your values, beliefs and wishes surrounding end-of-life care; the person(s) with whom you shared your thoughts about death and dying; or the person you appointed who will speak for you when you are not able to speak for yourself.

I believe that you and your family and/or close friend have first hand experience about what it is like to participate in Advance Care Planning conversations with a certified Fraser Health Advance Care Planning Facilitator. Advance Care Planning is a comprehensive process of planning ahead for health care decisions that may have to be made by an appointed substitute decision maker in the event of incapability of the individual. I am interested in listening to your experiences and perspectives of what it has been like to participate in these conversations and whether they have had an impact on the both of you in some way both individually and as a family. Sharing your perspectives of this experience may assist healthcare professionals to better understand families' overall experiences with Advance Care Planning conversations and how they make decisions. The information you provide may also assist in developing necessary resources that will support future families through this process.

In order to be eligible to participate you and your family/close friend must be the following:

- English speaking
- Able to read English in order to give informed consent
- Be at least 19 years old
- Currently participating in or have completed advance care planning conversations with a certified Fraser Health Advance Care Planning Facilitator

*Please note that all person(s) who participated in the original advance care planning conversation(s) do not have to be present to be eligible for this study.*

There will be one to two interviews each lasting approximately 1-2 hours and will be conducted in a place of your choosing. I, Alexandra Kruthaup will conduct the interviews, asking you questions about your experiences and perspectives as a family with Advance Care Planning conversations. All interviews will be tape-recorded, then copied onto paper by a typist. The interview will be arranged at a time and location of your convenience. Confidentiality will be maintained. The tape and printed copy of your conversation will be coded and not contain any identifying information. Only the typist, three UBC faculty professors, and myself will have access to the collected data. All data will be securely stored in a locked filing cabinet for five years as per UBC and Fraser Health policy. At the end of the study, I will destroy the tapes and printed copies.

You are under no obligation to participate but if you do, you will be asked to sign a consent form. Your participation in this study is voluntary. You are free to withdraw at any time without giving a reason and without jeopardizing your treatment from the hospital staff. You are also free to refuse to answer any question asked. All participants who are interested in learning the results of the study will be sent a copy of the summary once the analysis has been completed.

If you and your family or close friend are interested in participating within my study or want to discuss it further before deciding, please contact me Alexandra Kruthaup at (604) 874-3688 or the Principal Investigator, Barbara McLeod at (604) 587-4677. You can also fill in the tear-off slip below and return it to the unit coordinator who will put it into an envelope that I will pick up regularly. I will then telephone you.

-----Tear here-----

I am interested in participating in or would like to get more information on Alexandra Kruthaup's study of *how do families of hemodialysis patients experience initiated advance care planning conversations.*

Name: \_\_\_\_\_

Telephone Number: \_\_\_\_\_

THE UNIVERSITY OF BRITISH COLUMBIA



**Participant Consent Form**

**Project Title: Advance Care Planning Conversations: The Family Perspective**

**Principal Investigator**

Barbara McLeod, RN, BSN, MSN, CHPCN(C)  
Clinical Nurse Specialist, End-of-Life Care  
Fraser Health  
Phone: (604) 587-4677  
Email: [Barbara.McLeod@fraserhealth.ca](mailto:Barbara.McLeod@fraserhealth.ca)

**Co-Investigator:**

Alexandra Kruthaup, RN, BSN, CNeph(C)  
MSN student, UBC School of Nursing  
Phone: (604) 874-3688  
Email: [harper@rogers.com](mailto:harper@rogers.com)

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You are being invited to participate in this research study because you are the family member of someone receiving hemodialysis treatment and you have first hand experience about what it is like to participate in Advance Care Planning conversations with a certified Fraser Health Advance Care Planning Facilitator. Advance care planning is a comprehensive process of planning ahead for health care decisions that may have to be made by an appointed substitute decision maker in the event of incapability of the individual.

Participation within this study requires that you are able to converse in and read English in order to give informed consent; are at least 19 years of age; are currently participating in or have completed the Fraser Health Advance Care Planning conversations; and have a family member who is or was receiving hemodialysis treatment.

**Your participation is entirely voluntary**, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate, you will be asked to sign this consent form. If you do decide to take part in this study, you are still free to withdraw at any time without jeopardy to your treatment from the hospital staff, and without giving any reasons for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate nor will you lose the benefit of any medical care to which you are entitled or are presently receiving. Please take the time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.

### **Purpose**

The overall purpose of this study is to give families of hemodialysis patients an opportunity to reflect on what it has been like to participate in these advance care planning conversations with a certified Fraser Health Advance Care Planning Facilitator. The interview(s) will invite you to share your perspectives and experiences of these conversations and whether they have had an impact on you in some way both individually and as a family. Sharing your perspectives of this experience may assist healthcare professionals to better understand families' overall experiences with advance care planning conversations and how they make decisions. The information you provide may also assist in developing necessary resources that will support future families through this process.

Participation involves one family interview with the possibility of a second interview based on your family's decision. Each interview will last approximately 2 hours. The co-investigator, Alexandra Kruthaup, RN, will conduct the interviews using a series of guided questions. All interviews will be tape-recorded, then transcribed by a typist. The interview will be arranged at a time and location of your convenience.

### **Risks**

There may be a potential risk to discussing your experiences in that these discussions may bring up unexpected emotional reactions. You will be provided with a list of support resources from the hospital and community. You are free to refuse to answer any question that may produce discomfort, decline further interviews, and ask that the tape recorder be turned off during an interview.

### **Potential Benefits**

You will not receive any direct benefits from participating in this study. However, it is anticipated that your input will lead to the development of patient support resources and healthcare professionals improved understanding of the advance care planning process from the family's perspective.

### **Monetary Compensation**

You will receive no direct monetary compensation for participating in this study.

### **Confidentiality**

Any identifying information resulting from this study will be kept strictly confidential. All documents will be identified by only a code number and will be kept in a locked filing cabinet. Any computer hard drives that contain identifying information or data will be password protected. Identifying information from computer hard drives will be deleted at the end of the project. Only the researchers and a transcriptionist (who will be hired to type the recorded interview) will have access to the data obtained in this study.

Data contained in the transcripts from the tape-recorded interviews will have all identifying information removed. There will be no reference made to individual names in reports or publications coming out of this study. In all final research reports and publications, quotes from participants will remain anonymous and, if necessary, other identifying information will be

altered. At the end of the study, audiotapes will be erased by being demagnetized. However, the typed transcripts obtained in this study will be retained for 5 years by Alexandra Kruthaup to be used for educational purposes, to publish academic papers, and possibly used for secondary data analysis study with the understanding that any additional research projects that use the data will be approved by the appropriate university research and ethics committees.

**Contact for information about the study**

This research is being carried out to meet the requirements of a graduate thesis. If you have any questions or concerns at any time during this study you may contact Dr. Carol Jillings from the University of British Columbia (604) 822-7479 or Barbara McLeod in the Fraser Health Authority (604) 587-4677.

**Contact for concerns about the rights of research participants**

If you have any concerns about your rights or treatments as a research participant and/or your experiences while participating in this study, you may contact either the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at (604) 822-8598, or contact Dr. Marc Foulkes or Dr. Allan Belzberg, Fraser Health Authority Research Ethics Board (REB) co-Chairs by calling (604)587-4681. You may discuss these rights with either one of the co-chairman of the Fraser Health REB.

**Consent**

Your signature below indicates that you have read the above information and have had an opportunity to ask questions to help you understand what your participation will involve. Your signature indicates that you consent to participate in this study and that you have received a copy of this consent form for your own records. You do not waive any of your legal rights as a result of signing this consent form.

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Signature of Subject Date

---

Printed Name of Subject

---

Signature of Witness Date

---

Printed Name of Witness

---

Signature of Researcher (or qualified designate) Date

---

Printed Name of Researcher (or qualified designate)

THE UNIVERSITY OF BRITISH COLUMBIA



**Participant Consent Form  
Interview with ACP Facilitator**

**Project Title: Advance Care Planning Conversations: The Family Perspective**

**Principal Investigator**

Barbara McLeod, RN, BSN, MSN, CHPCN(C)  
Clinical Nurse Specialist, End-of-Life Care  
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**Co-Investigator:**

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You are being invited to participate in this research study because you have first hand experience about what it is like to facilitate Advance Care Planning conversations with hemodialysis patients and their families. If you are an employee of Fraser Health, please note that the investigator in Fraser Health is a Clinical Nurse Specialist and your participation will not affect your employment in any way. You are free to refuse to answer any questions, can ask for any information to be destroyed, and can ask for sensitive information not to be divulged.

**Your participation is entirely voluntary**, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate, you will be asked to sign this consent form. If you do decide to take part in this study, you are still free to withdraw at any time without consequences or explanation.

**Purpose**

The overall purpose of this study is to give families an opportunity to voice their perspectives, potential needs and wishes in planning for their loved ones eventual death. These discussions may shed light on how families make decisions, thus enabling necessary resources that will support them through this process. Your role within this study is as a key respondent who can

validate information obtained from the family interviews and provide three other professional perspectives: an advance care planning facilitator, a healthcare professional, and a hemodialysis staff person.

Participation involves one face-to-face interview with the possibility of two more interviews based on your decision. Each interview will last approximately 1 hour. The co-investigator, Alexandra Kruthaup, RN, will conduct the interviews using a series of guided questions. All interviews will be tape-recorded, then transcribed by a typist. The interview will be arranged at a time and location of your convenience.

### **Risks**

There may be a potential risk to discussing your experiences in that these discussions may bring up unexpected emotional reactions. You will be provided with a list of support resources from the hospital and community. You are free to refuse to answer any question that may produce discomfort, decline further interviews, and ask that the tape recorder be turned off during an interview.

### **Potential Benefits**

You will not receive any direct benefits from participating in this study. However, it is anticipated that your input will lead to the development of patient support resources and healthcare professionals improved understanding of the advance care planning process from the family's perspective.

### **Monetary Compensation**

You will receive no direct monetary compensation for participating in this study.

### **Confidentiality**

Any identifying information resulting from this study will be kept strictly confidential. All documents will be identified by only a code number and will be kept in a locked filing cabinet. Any computer hard drives that contain identifying information or data will be password protected. Identifying information from computer hard drives will be deleted at the end of the project. Only the researchers and a transcriptionist (who will be hired to type the recorded interview) will have access to the data obtained in this study.

Data contained in the transcripts from the tape-recorded interviews will have all identifying information removed. There will be no reference made to individual names in reports or publications coming out of this study. In all final research reports and publications, quotes from participants will remain anonymous and, if necessary, other identifying information will be altered. At the end of the study, audiotapes will be erased by being demagnetized. However, the typed transcripts obtained in this study will be retained for 5 years by Alexandra Kruthaup to be used for educational purposes, to publish academic papers, and possibly used for secondary data analysis research with the understanding that any additional research projects that use the data will be approved by the appropriate university research and ethics committees.

### **Contact for information about the study**

This research is being carried out to meet the requirements of a graduate thesis. If you have any questions or concerns at any time during this study you may contact Dr. Carol Jillings from the University of British Columbia (604) 822-7479 or Barbara McLeod in the Fraser Health Authority (604) 587-4677.

**Contact for concerns about the rights of research participants**

If you have any concerns about your rights or treatments as a research participant and/or your experiences while participating in this study, you may contact either the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at (604) 822-8598, or contact Dr. Marc Foulkes or Dr. Allan Belzberg, Fraser Health Authority Research Ethics Board (REB) co-Chairs by calling (604)587-4681. You may discuss these rights with either one of the co-chairman of the Fraser Health REB.

**Consent**

Your signature below indicates that you have read the above information and have had an opportunity to ask questions to help you understand what your participation will involve. Your signature indicates that you consent to participate in this study and that you have received a copy of this consent form for your own records. You do not waive any of your legal rights as a result of signing this consent form.

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Signature of Participant

Date

---

Printed Name of Participant

---

Signature of Researcher (or qualified designate)

Date

---

Printed Name of Researcher (or qualified designate)

---

Signature of Witness

Date

---

Printed Name of Witness

## Appendix E



The University of British Columbia  
Office of Research Services and Administration  
**Behavioural Research Ethics Board**

### ***Certificate of Approval***

PRINCIPAL INVESTIGATOR <b>Jillings, C.</b>	DEPARTMENT <b>Nursing</b>	NUMBER <b>B06-0368</b>
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT		
CO-INVESTIGATORS: <b>Kruthaup, Alexandra, Nursing</b>		
SPONSORING AGENCIES		
TITLE: <b>Advance Care Planning Conversations: The Family Perspective</b>		
APPROVAL DATE <b>JUL 25 2006</b>	TERM (YEARS) <b>1</b>	DOCUMENTS INCLUDED IN THIS APPROVAL: <b>June 5, 2006, Contact letter / Consent form / Advertisement / May 1, 2006, Questionnaires</b>
<p>CERTIFICATION:</p> <p style="text-align: center;">The application for ethical review of the above-named project has been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <div style="text-align: center; margin-top: 20px;"> <hr style="width: 80%; margin: 0 auto;"/> <p><i><b>Approved on behalf of the Behavioural Research Ethics Board</b></i> by one of the following:                      Dr. Peter Suedfeld, Chair,                      Dr. Susan Rowley, Associate Chair                      Dr. Jim Rupert, Associate Chair                      Dr. Arminee Kazanjian, Associate Chair</p> </div> <p style="text-align: center; margin-top: 20px;">This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p>		

Appendix F



The University of British Columbia  
Office of Research Services  
**Behavioural Research Ethics Board**  
Suite 102, 6190 Agronomy Road, Vancouver,  
B.C. V6T 1Z3

**CERTIFICATE OF APPROVAL - MINIMAL RISK AMENDMENT**

<b>PRINCIPAL INVESTIGATOR:</b> Carol Jillings	<b>DEPARTMENT:</b> UBC/Applied Science/Nursing	<b>UBC BREB NUMBER:</b> H06-80368
<b>INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:</b>		
<b>Institution</b>		<b>Site</b>
N/A		N/A
Other locations where the research will be conducted: N/A		
<b>CO-INVESTIGATOR(S):</b> Alexandra L. Kruthaup		
<b>SPONSORING AGENCIES:</b> N/A		
<b>PROJECT TITLE:</b> Advance Care Planning Conversations: The Family Perspective		

**Expiry Date - Approval of an amendment does not change the expiry date on the current UBC BREB approval of this study. An application for renewal is required on or before: July 25, 2007**

<b>AMENDMENT(S):</b>	<b>AMENDMENT APPROVAL DATE:</b> January 26, 2007	
<b>Document Name</b>	<b>Version</b>	<b>Date</b>
<b>Protocol:</b> Study Thesis Proposal	N/A	December 14, 2006
<b>Advertisements:</b> Study Poster	N/A	December 14, 2006
<b>Letter of Initial Contact:</b> Research Study Information Letter	N/A	December 14, 2006
<b>Other Documents:</b> Script for physician when seeking patient permission to contact about study / Amendment Approved	N/A	January 17, 2007 December 20, 2006
Physician Log Sheet of Prospective Study Patients	N/A	December 14, 2006

The amendment(s) and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

**Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:**

\_\_\_\_\_

Dr. Peter Suedfeld, Chair  
Dr. Jim Rupert, Associate Chair  
Dr. Arminee Kazanjian, Associate Chair  
Dr. M. Judith Lynam, Associate Chair