

Perspectives of patients' significant others in dialysis modality decision-making

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Abstract

Objective

To understand the experiences of the dialysis decision-making process from the perspective of the significant other, specifically their role, influencing factors and the supportive interventions of the interprofessional team.

Method

An interpretive description qualitative study was conducted using individual interviews and results were triangulated with decisional conflict and decisional regret quantitative results.

Results

Ten participants described their role as advocating, providing a positive outlook, 'being with' the patient, learning together, sharing opinions, and communicating about values, preferences, feasibility of options. Environmental factors that influenced decision making included unexpected life change, choosing life, and personal health problems. Factors related to implementation of the treatment modality decision were unanticipated events, relationship changes, recreational travel changes, and the caregiver role. Nursing interventions are required to realign treatment expectations.

Relevance

Significant others have an important role in supporting the patient making the dialysis decision and are often instrumental in implementing the decision.

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Chapter One

Overview and Organization

Over thirty-five thousand Canadians suffer from inadequate renal function requiring them to seek life-sustaining renal replacement therapy (Canadian Institute of Health Information, 2010). Without a renal transplant, the patient may have treatment modality choices including whether to begin hemodialysis or peritoneal dialysis either in-center or at-home. Currently, there is an initiative in Ontario to increase the proportion of patients receiving home dialysis from 14.7% to 30% (CIHI, 2010; Oreopoulos, Coleman & Doyle, 2007). Individuals and families suffering from Chronic Kidney Disease (CKD) are therefore not only faced with the uncertainty and unfamiliarity of this chronic disease, but also are facing decisions surrounding the method and use of this life-sustaining therapy.

The area of decision-making in health care is of growing importance with the expansion of therapeutic interventions, the increase in individuals who want to be informed and have a more autonomous role in their health care decision-making, and the progress of evidence-based decision-making that places emphasis on knowing outcomes of different treatment options (Entwistle & Watt, 2009). As nurses often have a unique caring relationship with patients, they can provide invaluable support to individuals facing health care decisions.

As these decisions are rarely made in isolation of the influence of family who have been shown to greatly influence the decision-making process, this study has attempted to further understanding of the experience of the significant other (Rapley, 2008; Stiggelbout et al., 2007; Legare et al., 2011). For the purposes of this study, significant other is defined by the individual

suffering from CKD as the person most important to their well-being. Given that the decision about the type of dialysis has a significant impact on those living with the patient, particularly when home dialysis is chosen, it is important for health care professionals to be aware of the decision-making process from the perspective of the significant other in the patient's life.

Although there have been two recent systematic reviews of decision-making in CKD, neither review includes studies of the significant other's perspectives as being independent from the individual suffering from CKD (Morton, Tong, Howard, Snelling & Webster, 2010; Murray et al., 2009). Evidently, there is a gap in knowledge as it relates to the role of the significant other in the dialysis treatment modality decision-making process.

1.1 Interprofessional Shared Decision Making model

Shared decision-making (SDM) is a concept referring to patient/health care professional dynamics in decision-making. SDM is defined as a partnership between health care practitioners and patients where communication and deliberation about a health care decision takes place (Makoul & Clayman, 2006). SDM has many essential elements including the weighing of benefits and risks, the incorporation of patient values and preferences, and the use of best evidence (Makoul & Clayman). Whereas SDM theories are historically patient-physician centric, the IP-SDM model includes an equally represented interprofessional team and describes an ideal of a collaborative, supportive team with a common goal of a quality decision (Legare et al., 2011). The model also recognizes three levels of health care systems and their influences on the decision-making process: the micro level (individual), the meso level (health care teams within organizations), and the macro level (broad policies and social contexts). This inclusive perspective of the decision-making process benefits the study of the significant other's

experiences because the decision about dialysis treatment modality options is influenced by all of these levels. Also, unique from other conceptual models, the IP-SDM model makes explicit the role of the family/significant other as being independent from the patient and includes feasibility of implementation as a step in the SDM process. These are important elements for patients and their families when considering dialysis options.

The IP-SDM model (Appendix A) was developed by an interprofessional team to move the concept of SDM beyond the patient-physician dyad to a model which is inclusive of others involved in the process (Legare et al., 2011). This model illustrates the role of the family, surrogate and/or significant other's perspective as being important to consider during the decision-making process with their views on a parallel plane to the patient and health care professionals. According to this model, the process by which a decision is made involves a series of stages that may occur iteratively. This includes making explicit the decision that needs to be made, the exchange of information (discussion of benefits and harms), a process of values clarification, a discussion about feasibility of options, the deciding on a preferred choice, and the implementation of the decision. Although at each step of the process there is a common understanding among the individuals involved in the IP-SDM process, different individuals may be more strongly implicated at different stages of the process. However, the patient remains central in the model and his/her perspective needs to be considered as ultimately informing the process.

The model was validated in primary care by conducting focus groups and individual interviews at three levels: micro, macro, and meso (Legare et al., 2011). The IP-SDM model does have two limitations for use in this study. First, the model has not been validated in a

tertiary care environment and, second, little is known about the role of the family, spouse, and significant other (Legare et al., 2011). This study attempted to further inform the IP-SDM model by exploring the perspective and the role of the significant other in this particular venue.

1.2 Research questions

The aim of this study is to understand the experiences of the dialysis decision-making process from the perspective of the significant other. More specifically, the study will attempt to answer the following research questions:

What is the role of the significant other in the decision-making process about dialysis treatment modality?

What factors influence making and implementing decisions from the significant other's perspective?

How can nurses better support the role of the significant other in the decision-making process?

Chapter Two

Literature Review

A literature review was conducted to identify peer-reviewed scholarly publications pertaining to dialysis and decision-making. MeSH terms for renal replacement therapy, peritoneal dialysis, hemodialysis, chronic kidney disease and decision-making were used in Medline, PsycINFO, CINAHL, Embase, and Google Scholar. As well, journals were screened by reviewing tables of contents, and reference lists of relevant publications were searched for additional articles. This chapter is organized using the concepts from the Interprofessional Shared Decision Making model (IP-SDM): the decision to be made, information exchange, values and preferences, and the environment (Legare et al., 2011). Finally, recent studies on caregiving in the CKD population are discussed.

2.1 Decision to be made

According to the IP-SDM model, the first step in the decision-making process is making explicit the decision and presenting the options available to the patient (Legare et al., 2011). Individuals with CKD who have inadequate renal function to sustain life and opt for renal replacement therapy can be faced with the difficult choice between which type of dialysis to receive, and whether to dialyze at-home or in-center (community or tertiary hospitals, clinics) (Benavante et al., 2008). Many individuals who develop renal failure are identified by their primary health care team and access dialysis in non-emergency settings, having received and acted on information on dialysis options. However, a large percentage of individuals start dialysis as the result of an emergency admission and are thus typically initiated on hemodialysis either in the emergency room or in the intensive care unit. In these cases, the decision of dialysis

treatment options needs to be introduced to the patient promptly after emergency initiation as dialysis patients are shown to be unlikely to change therapy choices once they are implemented (Morton et al., 2010; Murray et al., 2010). To provide an understanding of CKD treatment modality options, the following section provides information on the disease process and modality choice.

CKD is categorized on a grid, starting with Stage 1 as being early kidney damage and progressing to Stage 5 as being kidney failure (Benavante et al, 2008). Self-management of early stages of this chronic disease may prevent the progression of renal dysfunction. Strategies of self-management include strict dietary practices, weight reduction, increased physical activity, and close monitoring of kidney function. Once the kidneys have reached Stage 5, the individual requires renal replacement therapy. Dialysis imposes greater lifestyle demands with time needed to be devoted to treatment, strict dietary protocols, the prevention of health complications, symptom control, and management of social isolation, and continuous adjustment to the peaks and troughs of this chronic disease trajectory. Adding to these lifestyle changes are the multitude of comorbidities, such as diabetes and cardiovascular disease, and their impact on the individual's daily life.

Once dialysis is required, there are two treatment modality options: hemodialysis and peritoneal dialysis. Hemodialysis is the use of an extra-corporeal machine to filter the blood of toxins and remove excess fluids from the body through a vascular access device (Ponferrada, Prowant, & Satalowich, 2008). This modality is typically delivered three times a week for a four-hour period at the hospital or in a satellite clinic. Blood is removed from the body through venous access by catheter or fistula. The second option, peritoneal dialysis, is the use of the

peritoneal membrane as a filtration membrane to clear the blood of toxins and remove excess fluids (Amato, Hlebovy, King, & Baltz Salai, 2008). This modality requires daily dialysis and can be achieved either intermittently several times during the day, or nocturnally with an external cycling device. Filtration is accomplished through a catheter located in the abdomen where fluid is introduced into the peritoneal cavity and remains there for diffusion to take place.

After the individual has chosen a dialysis treatment modality, there can be the further option of dialysing at-home or in-center. Individuals may choose to conduct either peritoneal dialysis or hemodialysis at-home. Although with at-home dialysis, patients are conducting treatments with a high level of autonomy, they have varying levels of access to nursing support by telephone and their health is closely monitored at dialysis clinics.

2.2 Information exchange

According to the IP-SDM model, information exchange is the discussion of potential benefits and harms of the options among the health care professionals and the patient/family team (Legare, 2011). In order to support deliberation on dialysis treatment modality options, health care professionals need to communicate information of the options based on the best available evidence, while patients need to reciprocate by communicating their understanding of the options (Legare et al., 2011).

The IP-SDM model is ideal for exploring the decision about dialysis treatment modality given there is ambiguity of the treatment benefits of peritoneal dialysis and hemodialysis. Vale and colleagues (2003) published a Cochrane systematic review finding only one study which met the criteria of adequately comparing dialysis modalities in a randomized controlled study. This

study, later published by Korevaar et al. in the Netherlands (2003), attempted to compare the quality of life and survival between the two treatment delivery methods. However, once patients received education in order to obtain informed consent, only 38 of 773 patients wished to participate and be randomized in the study; the other participants wanted to explicitly choose their own dialysis option. This example clearly illustrates the difficulty found by researchers when comparing treatment modalities.

A more recent study compared 1800 Dutch patients receiving both hemodialysis and peritoneal dialysis treatment options over ten years and adjusted for co-variables such as age and diabetic status (Van der Wal et al., 2010). Findings demonstrated an increased survival rate for peritoneal dialysis patients when compared to hemodialysis patients at one, and at three years. These findings are further supported by two other studies conducted in Denmark and the United States, both of which reported lower mortality rates with peritoneal dialysis than with hemodialysis for the first two years (Heaf et al., 2002; Jaar et al., 2005). Maier et al. in Germany (2009) found similar results in their study and added that diabetes and age were overall better predictors of mortality than dialysis modality.

Khawar, Kalantar-Zadeh, Lo-Johnson & Mehrotra (2007) provide three hypotheses for the difference in survival rates in a literature synthesis. First, they state that the early survival of peritoneal dialysis patients in the first few years of therapy may be attributed to residual renal function. Second, they hypothesize that individuals from the peritoneal cohort group may have received a transplant which would eliminate the healthiest group members in the study and therefore account for the predicted decline in survival rates after the first few years. Finally, these researchers theorize the latent decline of peritoneal dialysis survival rates occurring after

the first few years may be attributed to worsening of fluid status. Hence given the current state of evidence indicating the ambiguity in survival benefits across dialysis options, the key to decision-making may depend on the weighing of adverse effects, personal conveniences and inconveniences.

Adverse effects of both treatment modality options are nausea and vomiting, headaches, muscle cramps, hypotension from fluid imbalances, and the loss of hormones and nutrients (Benavente et al., 2008). Individuals may often feel physically exhausted, particularly from hemodialysis, and require rest after treatments. Individuals may also feel discomfort and experience the feeling of abdominal fullness from peritoneal dialysis. Finally, there are the high risks of infection inherent to all dialysis accesses, and the compromised immune system of individuals suffering from CKD.

There are also many lifestyle inconveniences to be discussed with the patient. For example, individuals receiving in-center hemodialysis must travel to and from the hospital at least three times a week and to additional clinic appointments. Peritoneal dialysis requires the individual to make a fluid exchange in a clean environment several times each day. If dialysis is performed nocturnally, there is also the possibility of irregular sleeping patterns as the individual may be affected by noises from the dialysis machine or general discomfort from being connected to an external device (Benavente et al., 2008).

Given the lack of clear evidence for one dialysis approach over the other, this dialysis treatment modality decision may be defined as preference sensitive. A preference sensitive decision is when there are two or more acceptable options and the choice depends on patient

preferences (Wennberg, 2002, p.962). Health care professionals therefore need to be cognisant of factors identified as important to the patient when supporting the decision-making process.

2.3 Values and preferences

The following step in the IP-SDM model is that of becoming aware of patients values and preferences (Legare et al., 2011). This is accomplished by assessing and identifying what is important to the patient. Common values influencing preference for dialysis options have been identified in two systematic reviews. A meta-synthesis of factors affecting individuals and ‘carers’ in dialysis treatment decision-making identified in 18 qualitative studies revealed values associated with decision making such as being a burden, maintaining the current lifestyle, maintaining the ‘status quo’, and the importance of family and peer in decision making (Morton et al., 2010). In this study ‘carers’ were defined as relatives and non-relatives in a paid or unpaid supporting role. A second systematic review of factors affecting individuals with CKD in decision-making found similar inter-related themes: interpersonal relationships; the preservation of current well-being; normality and quality of life; the need for control; and the personal importance of benefits and risks (Murray et al., 2009). Interestingly, although both reviews explicitly refer to the role of the family and significant others, neither includes a study of family members’ perspectives independent from the individual suffering from CKD.

As these reviews include studies of various decisions made throughout the CKD trajectory, the following commentary discusses findings from the only available studies that focused specifically on the decision between peritoneal dialysis and hemodialysis. Major common values considered important in the decision between dialysis treatment modalities identified in a qualitative study of 27 Danish patients and 18 of their relatives, and another study

of 40 Americans, included: flexibility, security, independence and travel (Lee, Gudex, Povlsen, Bonnevie & Nielson, 2003; Wuerth et al., 2003). Both studies were conducted using a convenience sampling of individuals undergoing both dialysis modalities. Additionally, a qualitative study conducted in the United Kingdom of 9 patients identified similar values as important in the decision (Tweed & Ceaser, 2005). These included: maintaining one's integrity, forced adaptation, identification with other patients, peer comparisons, staff and social support, and the experience of illness. These studies illustrate important themes in the decision-making process. Specifically, patients who value security/support may find in-center dialysis more suitable to their preferences, whereas patients who value independence/minimal travel find at-home dialysing preferential.

From a historical perspective, at-home dialysis has been purported to be the treatment of choice since the beginning of dialysis in the 1960s as it inherently increases an individual's independence and self-care (Blagg, 2007). Several studies indicate increased quality of life over in-center treatment options (Fleming Courts, 2000; Loos-Ayaz et al., 2008). However, despite the freedom and increased independence provided by at-home dialysis, research shows declining rates in North America (Sands et al., 2009) that have been attributed to patient factors, such as available lack of space to perform peritoneal exchanges at-home, the patient's education level (McLaughlin et al., 2008; Neil et al., 2009), and the increasing age and number of co-morbidities in the CKD population (Blake, 2009).

2.4 Significant others and decision-making

The IP-SDM model identifies the significant other as an important member in the decision-making process (Legare et al., 2011). There is, however, limited knowledge of the role

of significant others and their influence in the decision deliberation. As the IP-SDM model provides little detail on the significant other, the significant other is defined operationally in this study as the individual identified by the patient with CKD as the person most important to his/her well-being. For the purposes of this study, the concept of the significant other was further contextualized using Wright and Leahy's (2000) Calgary Family Assessment Model (CFAM). In the CFAM model, the family unit is viewed in context of three dimensions: structural (e.g. gender, ethnicity), developmental (e.g. life cycle stage) and functional (e.g. activities of daily living, expressive capacity).

The importance of the family and significant other in the decision-making process is acknowledged throughout studies that are primarily focused on the patient's perspective (Morton, Tong, Howard, Snelling & Webster, 2010.) Studies of the CKD population have found the family role is often defined as being a neutral 'sounding-board' in treatment decisions, especially when patients are in a uremic or a confused state (Lin, Lee & Hicks, 2005; Tweed & Ceaser, 2005). However, relatives want to be involved and patients have reported that their decision-making process has been influenced by their relatives, including significant others (Lee, Gudex, Povlsen & Nielson, 2003; Wuerth et al., 2003). Although there is limited knowledge about the role of the family in decision-making, Young (2006) explored the decision needs of terminally ill patients and their families when considering location of care at end of life. The study found that these family members have supportive needs in the decision-making process such as the need for individualized decision support and more tangible resources (Young, 2006).

An important theme in examining the relationship between family members, including the significant other, and the individual suffering from CKD are the patient's concerns about

family burden. This feeling of burden has been identified as a negative characteristic of renal replacement therapies and was found in studies conducted in many countries, including China, America and the United Kingdom, to be a deciding factor when opting for palliative care as a treatment (Morton, 2010). Tong et al (2009) reported that dialysis patients felt guilty regarding not participating in family life, depriving the family of freedom, and being dependent on family members. Thus further understanding of the perspective of the significant other may also illustrate how health care professionals can help the patient navigate and communicate these concerns.

Although patients repeatedly acknowledge the importance of the family and the significant other in their concern about their treatment decision (Morton, Tong, Howard, Snelling & Webster, 2010), there is a clear gap in knowledge about the role and specific experience of the significant other in health care decision-making. Furthermore, it is not clear how health care professionals can enhance decision support for these individuals who are important to the patient's well-being.

2.5 Caregivers in the CKD population

Given the potential role of the significant other in the well-being of the individual with CKD, it is important to investigate the role of the caregiver within this patient population. Friend and family support has been shown to decrease technique failure in peritoneal dialysis and increase fluid control adherence (Carey et al., 1990; Kara, Caglar, & Kilic, 2007). Although the current rate of unpaid caregivers of patients on dialysis is up to 57% and these individuals can clearly influence the patient's well-being, there has been limited research to date on caregivers of

individuals with CKD (Suri et al., 2011). In fact, Tong and colleagues (2008) found that dialysis patients want more research of the support of their caregivers.

Another study in Brazil of 84 caregivers of dialysis patients found that 33% of these caregivers were symptomatic of depression (Belaso, Barbosa, Bettencourt, Diccini, & Sesso, 2006) The study illustrated how the quality of life of caregivers can be significantly affected, especially when caring for elderly patients and those who conduct peritoneal dialysis treatments. Schneider (2004) supported these findings in a study of 80 caregivers in the United States and also found that caregivers were physically and mentally fatigued.

Despite the growing recognition of the need to increase knowledge and support of the caregivers in this patient population, there are few studies on potential supportive interventions. A review of literature conducted by Tong, Sainsbusy, & Craig (2008) found only 3 studies on support interventions for caregivers of people with CKD. Adding to the fact that there are so few studies was the homogeneity of educational interventions. Two of the studies were pre-post surveys evaluating the effect of educational material on caregiver knowledge and another one was a participatory action development of an information handbook for transplant patients and their caregivers. Studies consistently found that providing information to caregivers improved knowledge.

2.6 The environment

Consistent with the IP-SDM model, individual dialysis treatment decision-making can also be influenced by factors in the environment. The environment includes micro factors (individual and their health problem), meso factors (the organization and health care team) and

macro factors (social norms, organizational routines, and institutional structure) (Legare et al., 2011). In Canada, many of these influences can be attributed to our current health care system and health care costs. Internationally, the dialysis treatment decision has been studied from an economic perspective and there has been some agreement of the economic benefit of peritoneal dialysis, especially in developed countries (Blake, 2009; Just et al., 2008; Neil et al., 2009). In a Canadian cost analysis of treatment modalities, the annual cost for each patient was calculated as \$51,000US for in-center hemodialysis versus \$26,959US for self-care peritoneal dialysis (Lee et al., 2002). Thus in a publicly funded medical system, there may be an economic and social incentive to being financially responsible by increasing peritoneal rates in those patients who are medically suitable.

The influence of other economic factors in decision-making has been well studied in the province of Ontario. Prior to 1998, nephrologists were historically reimbursed at higher rates for in-center hemodialysis patients. One study by Mendelssohn, Langlois and Blake (2004) demonstrated that after initiating a fee structure which equalized physician billing across all three dialysis treatment options, there was a steady increase in peritoneal and home dialysis rates in Ontario as compared to the rest of Canada. In 2005, the Ontario government established a Peritoneal Dialysis Coordinating committee with the province-wide goal of obtaining home dialysis rates of 30%, including 20% peritoneal dialysis and 10% home hemodialysis (Jindal, 2007). The committee recognized the dialysis modalities as being equally effective but believed that if patients were offered non-biased information regarding their treatment choices, 30 to 40% would choose peritoneal dialysis as their modality of choice due to its ability to provide increased independence (Oreopoulos et al., 2007). The current provincial rate of peritoneal

dialysis is 12.1% and home hemodialysis is 2.6% for a total of 14.7% of patients currently performing at-home dialysis (CIHI, 2010).

Other studies have identified additional environmental factors that influence peritoneal dialysis rates (Sands et al., 2009; Blake, 2009). For example, barriers to peritoneal dialysis include the availability of in-center hemodialysis units, and a medical interest in hemodialysis. Prakash et al. (2007) found an increase in hemodialysis in the elderly population in Ontario since the installation of satellite units and posits that patients' age and likelihood of comorbidities is responsible for the selection of hemodialysis over peritoneal dialysis. It also has been shown that increased funding in hemodialysis, proliferation and availability of in-center tertiary nephrology programs (Khawar, Kalantar-Zadeh, Lo, Johnson & Mehrotra, 2007), and low reimbursement for particular treatment modalities widely affect dialysis treatment modality rates (Bouvier et al., 2009).

Some patients may not be fully cognisant of the pressure or bias from health care professionals and the health care systems to choose one dialysis treatment option over another but these environmental factors are sometimes significant influences in the delivery of information to the patient. If patients and their significant others are not adequately engaged in the decision-making process, they may not realize the impact of the decision on their lifestyle and eventually regret the option chosen.

2.7 Summary

Despite the evidence that the options for dialysis (hemodialysis, peritoneal dialysis, and self-care/ at-home dialysis) appear relatively equal in effectiveness, choices are influenced by

personal characteristics, knowledge of options, perceptions of negative impact on significant others, and factors in the health care systems. To date no studies have specifically explored the involvement of the significant other in this challenging decision. Although the importance of these supportive individuals is clear, their role and influence within the decision-making process remains elusive. One problem hindering further knowledge in this area is that there are few studies which examine the role of the significant other independent from the role of surrogacy or caregiver (Bochmer and Clark, 2001; Hilton, 1994; Ohlen, Blaneaves, Bottorff and Brazier, 2006). However, what limited research on the significant other has demonstrated is that these individuals do, in fact, influence the decision-making process (Stiggelbout et al., 2007; Wuerth et al., 2003). It is therefore important to understand the experience of these significant others and their interaction and influence in the decision-making process for the dialysis modality decision.

Chapter Three

Methods and Procedures

The discipline of nursing easily lends itself to a qualitative methodological approach where researchers can focus on understanding the subjective worlds of the populations and the individuals they study. Nursing qualitative research uses processes of inquiry in exploring phenomena where there is the potential to further enhance nursing care through knowledge development (Morse & Field, 2002). This method is particularly useful for the study of the significant other in dialysis decision-making as there is limited prior knowledge of significant others in health care decision-making (Legare et al., 2011). The following chapter provides an outline of the research design, procedure and data collection methods used.

3.1 Design

An interpretive description (Thorne, 2008) design was applied to this study of the significant other in dialysis decision-making. This methodology has strong philosophical underpinnings in naturalistic inquiry and provides clear principles for the novice researcher in data collection and analysis (Thorne, Kirkham & O’Flynn-Magee, 2004). This methodological approach uses a variety of research strategies provided by social science qualitative research but emphasizes the importance of having a “responsible epistemological approach to research in a practice discipline such as nursing” (Thorne, 2008, p.108).

Interpretive description recognizes that the researcher and the object under study do, in fact, influence each other (Thorne, 2008). Through a process of examining the ‘theoretical forestructure’ of the study, the researcher explores theoretical alliances and the evolution of

knowledge and research in the nursing discipline. The end-product of this methodology is the interpretation of the researcher and is contextually bound. Given there are no all-encompassing theories for populations, this approach to qualitative research provides a rich description of the participants in the study within their health care system and their home contexts.

The product of interpretive description research is a thematic summary of the phenomenon produced within the context of current knowledge of the phenomenon (Thorne, Kirkham, O'Flynn-Magee, 2004). Interpretive description provides a detailed process of 'scaffolding' where the research questions are situated within knowledge and current research (Thorne, 2008). This approach allows for the use of explicit mechanisms to advance existing theories. This method of constructing practical, clinically-oriented research products allows for the growth, clarification, and validation of contemporary nursing knowledge. In this study, the perspective of the significant other has been situated within a current clinical background of dialysis decision-making and is grounded in a theoretical 'scaffold' provided by the IP-SDM model.

3.1.1 Situating self

It is important in an interpretive description study to situate the researcher within the study in an attempt to appreciate the influence and interaction they may have (Thorne, 2008). Before beginning my graduate degree, I worked at a large tertiary acute care center in the dialysis unit. During this time, I found a passion for nephrology and for the care of the CKD patient population. I received my Canadian Nursing Association Certificate in Nephrology in 2009.

As a hemodialysis staff nurse, I did not feel confident in advising my patients regarding treatment modality choices. The unit where I worked has a population of primarily emergent-start dialysis patients who require a high level of care for physical and cognitive impairments. I often felt conflicted with the knowledge of how peritoneal dialysis may potentially increase the patient's independence and the realities of my patient's ability to implement treatments.

3.2 Description of setting

The process of developing the focus for the study and identifying specific research questions was conducted over a period of seven months together with several members of the nephrology department. The inclusion and awareness of the community in the research idea proposal before the formal REB review is recognized by the Tri-Council Policy Statement (2009) as being a sometimes necessary step in gaining support in qualitative research. Key informants included several dialysis managers, the Department Director, Advanced Practice Nurses, social workers, and staff nurses. This iterative process of topic development allowed the researcher the opportunity to find an area of interest to the nephrology program and to ensure the topic would add not only to the overall nursing knowledge in nephrology but also would have practical utility.

The study took place in the regional nephrology program situated in a large tertiary acute care center. The department includes three in-center dialysis campuses and four hemodialysis satellite units serving a population of 1.1 million. The program admits over 650 patients every year and currently has approximately 20% of their patients conducting home dialysis. Within this program there are two unique elements that are designed to support patients and their families in

the process of starting on dialysis treatment: the treatment options nurse and the pre-renal insufficiency education program.

The Nephrology Treatment Options Education Registered Nurse position was new to the nephrology department as of April, 2010. The goal of this nursing position was to ensure emergent start patients did not become “lost” within the larger dialysis program before making a treatment modality choice. The role includes following patients through the initiation of dialysis treatments and providing expert nursing knowledge and counselling in treatment choices.

The pre-renal insufficiency (PRI) education program is offered to individuals diagnosed with CKD in the community who have renal dysfunction and will eventually require renal replacement therapy. The program consists of 4 half-day seminars aimed at providing: general education of the renal system, at-home and in-center treatments, transplant, and the special dietary and pharmacological needs of the patient with CKD. There is no information provided that is specific to making the decision but information presented does help prepare patients for deliberation on their options.

3.3 Participants

Participants for this study are the significant others of dialysis patients at the tertiary acute care hospital. The status of the significant other was defined by the patient requiring renal replacement therapy. Dialysis patients were initially contacted by hospital staff to determine if they had a significant other and if they wanted their significant other to participate in the study. Participants were eligible for inclusion if they met the following criteria:

1. Significant other of a patient on dialysis who has made a decision about dialysis treatment modality within the past six months
2. Adult over 18 years of age
3. English speaking and able to answer questions in English
4. Freely given informed consent to participate

Participants were not eligible if there was a language barrier or any interference with the ability to hear, read, or understand the English language.

After confirming eligibility, purposeful sampling was used to ensure participants represented significant others of patients on peritoneal dialysis, hemodialysis, and/or at-home dialysis treatment modalities. Purposeful sampling is a technique of selecting participants to represent particular settings or characteristics (Thorne, 2008). Participants were sought to reflect the current demographic range of Canadian dialysis patients. Recruitment was conducted concurrently with analysis to ensure a sampling frame inclusive of multiple perspectives including demographic characteristics, life cycle, and stage of decision implementation.

Sample size was determined using saturation. Saturation in qualitative research is largely recognized as occurring when no new themes are found and data is repeating (Streubert & Rinaldi Carpenter, 1995). Although, Thorne (2008) states that it is inherent in a health care context to have an infinite number of variances, interpretive description allows for arbitrary sample limits with the recognition that there is always potential for knowledge growth with a larger sample. In this study, recruitment, interviewing and analysis occurred in an attempt to achieve a representative sample of significant others of a dialysis patient undergoing dialysis.

The recruitment continued until no new themes emerged from the analysis and saturation was achieved.

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3.4 Data collection

Study participants were identified by the Nephrology Treatment Options Education Registered Nurse and the home dialysis unit nurse case managers. Patients were initially contacted by hospital personnel and provided with an information letter explaining the study. Interested participants were then referred to the researcher.

Interested participants were informed of the purpose of the study, what participation would involve, confidentiality in which data would be handled, and the fact that the care of the individual receiving dialysis would not be influenced by their participation (or non-participation) in the study. Subsequently, participants signed the consent form.

Interviews were conducted at a place convenient to the participant and included the conference room in the dialysis unit (n=2), the participant's residence (n=1), and over the telephone (n=7). The choice of location was made by the study participant and allowed for a natural and comfortable setting for the study participant. Also, the option of conducting the interview using the telephone allowed for a more inclusive population as some eligible participants lived in rural areas and some were experiencing health problems which influenced their ability to travel.

Interviews were audio taped and transcribed verbatim. Notes were also taken by the researcher before, during, and after the interview process. At the end of the interview, the participants were asked standardized questions from the SURE tool, the Decisional Regret Scale (DRS), and key demographic characteristics (Appendix F).

3.4.1 Interview questions

Participants were asked open-ended questions aimed at describing the experience with the dialysis decision-making process (Appendix D). An interview guide was developed to ensure a standardized process across interviews and questions asked (Appendix E). The specific questions were:

- 1) Can you tell me about how the choice of dialysis treatment option was made for your ... (spouse, mother, father, daughter, son, partner, or friend)?
- 2) What are the changes to your life since the treatment decision?
- 3) Tell me about your role in the decision.

- 4) As an important support person for _____, are there things that could have been done to better help you in your role in the process of deciding about type of dialysis?

Questions were designed to provide insight into the participant's perspective of the decision-making process and to thereby address the lack of evidence in this area. The Interpretive Description approach builds on existing knowledge of the phenomenon being researched with the aim of producing a coherent description (Thorne, Kirkham & O'Flynn-Magee, 2004). This use of existing knowledge in the area provided 'theoretical scaffolding' for the development of research questions (Thorne, 2008).

Question 1 was designed to encourage a full description of the process of choosing a dialysis treatment modality, and designed to highlight important factors of the significant others involved in the dialysis treatment decision-making process. Prompts were designed to extrapolate values, information, and other factors which are viewed as important influences in the decision-making process (Legare et al., 2011). Further probing into this question was based on the systematic review which identified knowledge and lifestyle as themes in decision-making in the CKD population (Murray et al., 2009). Questions 2 and 3 were aimed at exploring the implementation process and the self-perceived role of the significant other in the decision. These questions explore the significant other's reflections on the implementation of the treatment modality, and reflect upon the feasibility of treatment modalities as described in the IP-SDM model (Legare et al., 2011). Question 4 was aimed at gathering data on how health care professionals can provide additional support to the significant other in the decision-making

process. Questions were reviewed by experts in decision-making and health care professionals with expertise in care of patients receiving dialysis treatment.

3.4.2 Measurement tools

Use of the Decision Regret Scale and the SURE tool are part of the process of ‘scaffolding’ the research within existing theoretical and discipline knowledge (Thorne, 2008). Using the interpretive description approach, a researcher need not subscribe to a traditional dualistic stance on research by exclusively choosing a qualitative or quantitative method but is able to use various methods to describe the concepts under study. The use of the following measures aimed at further ‘triangulating’ the decision experience from the perspective of the significant other and, through the use of a mixed methods approach, attempts to create a “whole greater than the sum of its parts” (O’Cathain, Murphy, & Nicholl, 2010, p.1).

The Decision Regret Scale was chosen to determine if there was regret about the selected dialysis option. The scale consists of five statements which participants rate on a five-point Likert scale from strongly agree to strongly disagree with neutral in the centre (Brehaut et al., 2003). The scale has good internal validity (Cronbach’s $\alpha = 0.81$ to 0.92) as demonstrated in four different health care decision populations. Convergent validity was measured by correlating regret to other constructs hypothesized to be associated with decision regret (e.g. health outcome). It has been validated in English.

The SURE Test (Legare et al., 2010c) was chosen specifically to evaluate the certainty of the participant about the dialysis treatment modality choice. This instrument is a brief 4-item version of the Decisional Conflict Scale that can be used to screen for decisional conflict within

health care clinical practice. The four items include feeling sure of the decision, feeling knowledgeable about the options, feeling clear about what is important, and feeling supported. This instrument was shown to have good internal validity in English (Cronbach's $\alpha = 0.65$) in prospective studies outside of dialysis.

The demographic questions were based on the decisional needs of Canadians, research characteristics of patients undergoing dialysis treatment, and the Calgary Family Assessment model (CFAM) (Wright & Leahy, 2000). This CFAM concept of a family aided the research process in the development of demographic questionnaire by providing a description of the family as a system with importance placed on interpersonal relationships. Also informing the development of the demographic questionnaire was a survey on the decision needs of Canadians (O'Connor et al., 2003). The study concluded that variables of age, education, gender and marital status were demonstrated to affect the decision-making process in health care. For example, women who were unmarried were found to have higher rates of decisional conflict. Participants who were less educated had more physician involvement in their decision-making process. In several other studies from a dialysis decision-making perspective, age, employment status and education have also been identified as factors correlated with treatment choice (Blake, 2009; McGlaughlin et al, 2008; Neil et al., 2009).

The CFAM (Wright & Leahy, 2000) is a theoretical perspective for nursing family assessment. For the purposes of studying the significant other, the CFAM contextualizes the family unit within three dimensions: structural, developmental and functional. The significant other is defined within the CFAM concept of family, and is therefore viewed structurally,

including gender, developmentally in life cycle stages, and functionally including activities of daily living and expressive capacity.

3.4.3 Follow-up interview

Thorne (2008) supports the use of repeat interviews, “as a mechanism of confirmation, clarification, and elaboration on the essential relationships you are beginning to suspect within the overall data set is a powerful tool . . . and for testing out the impact that giving the ideas some shape will have upon their understanding and experience” (p. 159). The goal of this follow-up interview was for the participants to review the interpretations of the findings from the analysis of all of the interviews. Also, the follow-up interview provided an opportunity for participants to contribute any additional information and to check for accuracy.

The second interview was optional and occurred within 3 months of the initial interview. Three of ten participants were re-interviewed over the telephone. Participants were selected based on their rich descriptions of the decision-making process from the first interview. Interviews were recorded for reference and accuracy. Recordings were deleted after review by the interviewer. The researcher took notes before, during and after the interview. A standardized interview guide was used during the interview and a narrative was used (Appendices G, H). Notes and tapes from the second interview were used to confirm, enhance and rearrange themes from the initial interview (Thorne, Reimer Kirkham, & O’Flynn-Magee, 2004).

3.5 Data analysis

Transcripts were analysed using the philosophical approach to interpretive description qualitative inquiry provided by Thorne (2008). One important distinguishing characteristic of

this methodology is the emphasis placed on not over-coding during the analytic process.

Recognizing the nurse researcher has prior knowledge and clinical expertise, and has conducted a thorough analysis of the literature, this approach is aimed at producing theory relevant for a particular audience. Specifically, interpretive description uses constant comparison in data analysis and uses steps that can be broadly described as synthesizing, theorizing, and recontextualizing.

The following are the steps to data analysis that were applied to the interview data:

1. Transcripts were read in their entirety while listening to the audio-recording.
2. Data was coded using the research questions guiding the study through the recognition of patterns and relationships.
3. Using a constant comparative approach to the analysis of themes and relationships, insights in the form of conceptualizations about the experience of the significant other of a patient in the dialysis decision-making emerged.
4. Interpretations and insights were validated with the research team and subsequently with study participants using the second interview.
5. Findings were recontextualized within existing knowledge using the IP-SDM model. (Legare et al., 2011). As the model was used to inform the research question, several findings were found to be related specifically to particular steps within the model's decision-making process.
6. Findings were audited by the research team.

Data collected from measures were double entered into Excel and screened for missing or erroneous data. The DRS and SURE tool were scored using guidelines (Legare et al., 2010b; O'Connor, 1996). Descriptive analysis of quantitative data was used given the small sample size and a goal of triangulating with qualitative data. Data from the interviews and measurement tools were triangulated by integrating the qualitative and quantitative findings to identify convergence, complementarity or discrepancy (O'Cathain, Murphy, & Nicholl, 2010).

3.6 Ethical considerations

Several strategies were used in order to ensure the protection of human rights: the approval from the Research Ethics Board (REB), the use of informed consent with full disclosure, and respect for anonymity and confidentiality when collecting, processing, and storing data.

Participants were notified of their rights as a study participant according to the Tri-Council Policy Statement (2009). The participant could refuse consent or terminate participation at any time. The participants were informed before signing the consent that direct quotes may be used from the interview, but that no identifying information would accompany these quotes. Participants were given contact information for the researcher, the supervisor and the ethics board to use if there were any concerns regarding the conduct of the study (Appendix C). Also, participants were given an opportunity to debrief following the interview with the interviewer if needed. This provided an opportunity for the researcher to demonstrate interest in study participants and allow any concerns regarding interpretation to be expressed (Polit and Beck, 2008).

In order to maintain confidentiality, information gathered from demographic profiles, audio tapes and transcripts is kept securely in a locked file cabinet in the locked research unit at the University of Ottawa. Electronic data is stored on password protected computers with password protected files. Paper data with identifying information is stored in filing cabinets separate from the main study files. Participants are only identified by number. No names accompany interview transcriptions and no identifying information is kept with the interview transcripts. In fifteen (15) years, all paper data will be shredded and electronic data will be deleted.

3.7 Rigour

Lincoln and Guba's (1985) framework was used as a guide to enhance rigour in the study. This framework provides criteria to assess qualitative research designs: credibility, dependability, confirmability, and transferability. Credibility is recognized as the overriding goal of qualitative research and is achieved through "establishing a confidence in the truth of the data and interpretations" (Polit & Beck, 2008, p. 539). Credibility was achieved by ensuring a natural setting for data collection to occur, continuous auditing by research team members, and by meeting the remaining the criteria.

The criterion of dependability is achieved by the study's potential to be repeated over time (Polit & Beck, 2008). To accomplish this, the study used strict research methods with all participant interviews recorded and transcribed. The research also compiled a detailed audit trail of decisions and thoughts made during the research process.

Confirmability, or the objectivity of the researcher's interpretations, was sought through the researcher's awareness of prior knowledge and from a broad social context of data. Consistent with an interpretive description approach, the researcher used a process of reflexivity and journaling to be aware of assumptions, conclusions and thoughts throughout the research process (Thorne, 2008). This criterion was also addressed with the second interview which allowed an opportunity for participants to review the results of the analysis, address any incorrect interpretations, and discuss any influences at the time of the interview. This step further increased the study's credibility trustworthiness and authenticity (Polit and Beck 2008).

The final criterion, transferability, was addressed by providing a rich description of setting and participant characteristics to enable future users of the research to apply data elsewhere at their own discretion (Polit & Beck, 2008). Within an interpretive description approach to research, the researcher cannot be isolated from their findings and therefore it is important to provide contextual information of both the interviewer and participant (Thorne, 2008).

Chapter Four

Results

Thorne (2008) describes the product of data analysis as a thematic summary. The aim of a thematic summary is a coherent report of concepts “developed in situ” from research data with utility for a particular area of clinical work. In this case, themes are presented with concepts of the IP-SDM model in order to further enhance knowledge of the significant other in dialysis treatment modality decision-making.

The process of data analysis answered the following questions: What is the role of the significant other in the dialysis decision-making process? What are the factors that influence making and implementing the dialysis treatment modality decision? How can nurses better support the significant other during dialysis treatment modality decision making? The following chapter presents research results including participant characteristics and themes related to the dialysis treatment modality decision.

4.1 Characteristics of participants

A total of 10 significant others participated in semi-structured interviews (Table 4.1). The interviews ranged from 6:22 to 17:46 minutes (mean of 11:36). The sample was representative of both sexes with an age range from 42 - 71 years (median = 54.5). Significant others were most often spouses of the patient making the dialysis treatment modality decision, but the sample also included two daughters. All dialysis treatment modalities sought during the process of sampling were represented: 6 at-home peritoneal dialysis, 3 in-center hemodialysis, 1 at-home hemodialysis. Most participants had met with the dialysis treatment options education nurse and 3 had attended the pre-renal insufficiency education program.

Participants either had a community college or high school education level. Half of the participants were unemployed at the time of the interview. The remainder worked either full-time or part-time. One participant was retired. Participants were at various stages of treatment decision implementation, ranging from not yet implemented up to 6 months in treatment. Participants were from either rural or urban residences.

From the perspective of the significant other, 8 patients were identified as decision maker. One significant other felt they equally shared the decision with the patient, and another significant other felt the decision maker had been the patient's daughter.

4.2 Results from measurement tools

Of 10 participants, 4 were experiencing decisional uncertainty related to feeling unsure about the best choice, feeling uninformed of their options, and/or feeling unclear about their values associated with their options (Table 4.2). Of the 4 participants who experienced uncertainty, 2 participants experienced low level decision regret (Table 4.3). Participants who demonstrated decision regret or uncertainty during the analysis of the measurement tools were more likely to be college educated, work full-time, and have attended the formal pre-renal insufficiency education program. All study participants felt supported in the decision process.

Table 4.1. Characteristics of participants

Characteristic of participant	I.D. 1	I.D. 2	I.D. 3	I.D. 4	I.D. 5	I.D. 6	I.D. 7	I.D. 8	I.D. 9	I.D. 10	Total (N = 10)
Sex M = male, F = female	F	M	F	M	F	F	F	M	F	F	M = 3 (30%) F = 7 (70%)
Age (years)	63	54	43	53	42	54	71	58	56	51	Range = 42- 71 Median = 54
Relationship W = wife H = husband D = daughter	W	H	W	H	D	D	W	H	W	W	W = 5 (50%) H = 3 (30%) D = 2 (20%)
Dialysis method PD = home peritoneal dialysis HD = in-center hemodialysis HHD = home hemodialysis	PD	PD	PD	PD	HD	PD	HD	HD	HHD	PD	HPD = 6 (60%) ICHHD = 3 (30%) HHD = 1 (10%)
Work status R = retired FT = full-time PT = part-time UE = unemployment	R	FT	UE	UE	UE	UE	UE	FT	PT	FT	R = 1 (10%) FT = 3 (30%) PT = 1 (10%) UE = 5 (50%)
Highest education C = college H = high school U = university	C	C	C	C	H	H	H	C	C	C	C = 7 (70%) H = 3 (30%) U = 0 (0%)
Stage of implementation 1 = not implemented 2 = < 1 month 3 = 2- 6 month	3	3	1	1	2	2	3	3	1	1	1 = 4 (40%) 2 = 2 (20%) 3 = 4 (40%)

Table 4.2 Decisional conflict among participants (N = 10)

SURE tool items	I.D. 1	I.D. 2	I.D. 3	I.D. 4	I.D. 5	I.D. 6	I.D. 7	I.D. 8	I.D. 9	I.D. 10	Participants with decisional conflict
<i>Certainty</i> Do you feel SURE about the best choice for your (spouse, sister, brother, friend, etc)?	1	0	0	0	0	0	0	0	0	1	N = 2 felt unsure N = 8 felt sure
<i>Knowledge</i> Do you know the benefits and risks of each option?	0	0	0	0	0	0	0	1	0	0	N = 1 felt they had inadequate knowledge N = 9 felt knowledgeable
<i>Values</i> Are you clear about which benefits and risks matter most to you?	1	0	1	0	0	0	0	1	0	0	N = 3 felt they had unclear values N = 7 felt they had clear values
<i>Support</i> Did you have enough support and advice to make a choice?	0	0	0	0	0	0	0	0	0	0	N = 0 felt unsupported N = 10 felt supported
Total score (0-4)	2	0	1	0	0	0	0	2	0	1	N = 4 participants were experiencing decisional conflict

*The total SURE tool is scored 0 = no decisional conflict and 1-4 = decisional conflict.

Table 4.3 Feeling of decision regret among participants

DRS item	1	2	3	4	5	6	7	8	9	10	Total
1. It was the right decision	4	4	4	4	4	4	4	4	4	3	N=9 strongly agreed N = 1 agreed
2. I regret the decision that was made*	0	0	1	0	0	0	0	0	0	0	N = 9 strongly disagreed N=1 disagreed
3. I would go for the same choice if we had to do it over again	4	4	4	4	4	4	4	4	4	3	N = 9 strongly agreed N=1 agreed
4. The choice did a lot of harm*	0	0	1	0	0	0	0	0	0	0	N = 9 strongly disagreed N= 1 disagreed
5. The decision was a wise one	4	4	4	4	4	4	4	4	4	3	N = 9 strongly agreed N= 1 agreed
Total score (n/100)	100	100	85	100	100	100	100	100	100	85	N = 2

* Participants rated statements on a scale from 4 (strongly agree) to 0 (strongly disagree). The DRS provides a score between 100 (no decision regret) and 0 (high decision regret)

4.3 The dialysis decision process environment

The IP-SDM model recognizes the influence and interaction of the global context of the individual and family and their environment during the decision-making process (Legare et al., 2011). During analysis of the narratives, it became apparent there were environmental factors influencing the disease process and dialysis treatment modality decision which were paramount in understanding the experiences of the participants. Themes identified in the environment of the significant other include choosing life, unexpected life change and health problems of the significant other.

4.3.1 Choosing life

During the interviews, three participants identified this decision as choosing life-sustaining therapy. ‘Choosing life’ is defined as the point in the chronic kidney disease trajectory when the choice to initiate renal replacement therapy is made. As kidney failure is insidious in nature, many individuals and families are emergent starts with no prior knowledge of renal failure. These individuals may be faced with the decision to begin dialysis treatment modalities in the intensive care unit or the emergency room.

One participant described his wife as making the decision: *I think she was flipping back and forth for a while. She had no choice in the end... She was flipping between no dialysis and dialysis.* Another spouse significant other described her family’s experience in deciding to begin renal replacement therapy: *At first he didn’t want to go through it and then we decided, me and my daughter, we talked them over and we finally did it for him. I said, “You have to do it for us and you have to do it for yourself.” So that’s when we decided to go on dialysis.*

4.3.2 Unexpected life change

Many participants described being abruptly faced with altering of their life paths as a result of the need for dialysis. ‘Unexpected life change’ is defined as a variance from one’s expected life path. Not only does the morbidity associated with chronic disease impact the daily activities of the family, but also there are momentous changes related to the execution of therapy on a regular basis. One significant other explained: *The last year has been all that [changes]... before last year she had never had anything wrong with her.* One participant related her experience of her husband’s chronic disease: *I wasn’t expecting him to have a triple bypass or heart problems or kidney problems...Like no family history. If he came to me at 70 [current age 55] and said he had kidney problems, I wouldn’t have been so surprised.*

4.3.3 Health problems of the significant other

Another important theme in describing the environment of dialysis decision-making is ‘health problems of the significant other.’ This theme is defined as the adverse health states of the significant other. Although only two participants described experiencing health problems, the physical health of the supportive other was recognized as being an important element in the overall context of the dialysis treatment modality decision. One participant described: *I had a problem myself, I had questionable lung cancer... the day they told him the kidney had failed I was having a biopsy for my lungs.* Another participant explained how her own health problems affect their lives and function: *I have retinitis pigmentosa so I am eventually going to go blind... We didn’t know about that eight years ago either... And he’s my transportation.*

4.4 Roles of the significant other

There were several roles taken on by the significant other and identifiable throughout the dialysis decision-making process which are not specific to a step of the IP-SDM model (Legare et al., 2011). The model currently describes the significant other as having a supportive role that collaborates with the interprofessional team. This research found additional broad role themes identified were: providing a positive outlook, being with, and advocacy.

4.4.1 Providing a positive outlook

Several participants described their role as ‘providing a positive outlook’. This theme is defined as the conservation of a positive perspective. The word ‘conservation’ is used as the participants described the necessity to maintaining a positive outlook: *It is not all roses but with a crisis like this I believe you have, have to stay positive and you have to believe in hope.*

Another participant recalls: *...but you have to keep moving and keep things positive.* Another spouse significant other described the importance of her husband being positive: *We’ll see how it goes but I’m very positive. My husband has a good, positive outlook. So that’s what counts.*

4.4.2 Being with

The supportive role theme of ‘being with’ emerged repeatedly during the analysis of the narratives. The theme of ‘being with’ is defined, using Hunter’s (2002) definition, as the supportive presence of the significant other during decision-making. The concept of ‘being with’ was found to be most fitting as it includes the emotional, physical, psychological and spiritual presence/support provided by the individual in contrast to ‘being there’ which describes a physical presence.

The statements revealed an intuitive and encompassing role of support. One participant relates: *My part is just to support*. One spouse described her role in the decision to begin peritoneal dialysis as: *being there and listening and supporting the ideas*. Another spouse related her experience through the treatment modality decision: *My role was, I think, just being very supportive of him when I finally got used to the idea... I did struggle with it at first but I know if there would be any issue in health or anything he would be there to support me... it's just coming full circle*.

4.4.3 Advocacy

Another element of their role identified by participants was advocacy. The role of 'advocacy' is defined as the active support provided by the significant other in the contact with the healthcare system in the process of dialysis decision-making. One significant other described his role of advocating for his wife: *...the nurses are great and if they are not, we tell them...I don't take any BS so I'm pretty rude at times and to the point. I like to get to the end of the problem*. Another participant described his experience with the doctor who explained treatment modality options to his wife: *[The] doctor told her at one point that she wasn't a good candidate for transplant and that kind of upset me, quite a bit. I couldn't believe a doctor telling a patient without having all the facts*. One participant related her role in advocating for services to enhance safety with an at-home dialysis treatment modality: *I've been really pushing for the life line [direct line to emergency services at-home]. Cause you never know*.

4.4.4 Being a caregiver

One of the most significant roles related to the implementation of the treatment modality decision is the caregiver role. The 'caregiver role' theme is defined as the act of helping the

dialysis patient with activities of daily living. Participants with caregiver roles described a range of activities where they assisted the individual with CKD. One participant described her role in helping her husband conduct peritoneal dialysis exchanges: *I do everything for him. I get to prepare everything and he just gets to sit and hook himself up.* Many participants described being involved in some aspect of treatment delivery. One participant shared: *...some days I set up for him or I'm always taking it down and cleaning the machine after so it's both us that are involved.*

Some of the participants had more complex or broader caregiver roles. One example was provided by a young mother who felt she took on additional caregiver roles with her daughter while also providing care for her husband. She stated: *...he can't help my daughter who is 8 years old around the house...like I can't even go to work really even if I wanted to.* Another participant described caring for her elderly mother: *She was going to stay at home and we were going to take care of her.* Yet another participant described the care of her husband suffering from cognitive impairment: *I... do everything because he has dementia.*

It became apparent during data analysis that even when a participant didn't describe themselves as being a caregiver, they were still involved in the well-being and dialysis treatment implementation of the patient. For example, one significant other described caring roles in her relationship with her mother. Her roles included driving her mother to the hospital, being with her during treatments, and providing her daily insulin injections. She related: *I do live in the same apartment and I see my mother every day... so if there's anything that ... [arises] like there's a call that maybe I should take it... I'm not working presently so it has worked out ok.*

During the analysis of the measures it was apparent that the two participants who experienced regret and uncertainty were also in complex caregiver roles. Not only were they involved in the caregiving of the person receiving dialysis, but they also cared for small children.

4.5 Factors related to making the dialysis treatment modality decision

The themes about factors influencing the process of making the dialysis treatment modality decision have been organized within the IP-SDM model steps. Themes were identified under the information exchange, values and preferences, feasibility and preferred choice steps of the decision-making process.

4.5.1 Information exchange: learning together

Seven participants discussed ‘learning together’ as an important step in the decision-making process. ‘Learning together’ is defined as the process of acquiring knowledge to inform the dialysis treatment modality decision and was categorized in the IP-SDM step of ‘information exchange.’ This step is when the patient and significant other enter a process of acquiring information on options, discussing harms and benefits, and exchanging information related to emotional and affective aspects of the decision (Legare et al., 2011).

Knowledge and information was acquired from eclectic sources including the healthcare team, multi-media educational resources, structured education programs, discussion with peers, and experiential knowledge. One participant described the health care team: *The [nurse] came down and explained all the procedures. The first time was with the doctor at the hospital... Then someone came to our home and explained different procedures.* Another participant explained feeling she had acquired knowledge from working in the hospital as part of the health care team: *It [working in the hospital] made me understand a little faster. And to explain to him what can*

happen if he didn't go through with this [peritoneal dialysis]. Only one participant, who had implemented treatment for over one month, indicated that decisional conflict was due to feeling uninformed (Table 4.2).

4.5.2 Values and preferences

Several themes related to the step of 'values and preferences' arose during interview analysis and were aligned to at-home treatments and those related to in-center treatments. The step of 'values and preferences' is when the individual making the treatment modality decision and their significant other discuss and clarify values and preferences (Legare et al., 2011). Although during interviews participants easily described their own and their perception of the patient's values, their decisional conflict scores indicated that 3 of the 10 participants were unclear about what matters most to them. Of these 3 participants who had unclear values and preferences, 2 were significant others of patients who had implemented the treatment modality for over one month and 1 was the significant other of a patient who had not yet begun the chosen treatment modality.

Table 4.4 Values and preferences of treatment modalities identified by significant others

Delivery setting	Values and preferences of the significant other
At-home treatments	<p>Being home - the importance of being in the home environment.</p> <p>Taking control - the importance of taking authority over one's health problem.</p> <p>Flexibility - the importance of additional freedom attributed to at-home treatments.</p>
In-center treatments	<p>Keeping home separate - the importance of not medicalizing the home environment.</p> <p>Differing responsibility of treatments - the feeling of concern for the responsibility of at-home treatment execution.</p>

4.5.3 Values and preferences: At-home treatments

Several significant others of patients receiving at-home treatments identified ‘being home.’ This theme is defined as the importance of being in the home environment. One significant other commented: *He was happier at home... we realized that the best thing was at home.* Another participant described her view of dialyzing at-home: *[the at-home treatment option] was most suitable because we could do it at home. Then it's done every day so it seemed like it would be better for her.* Finally, one participant stated being home as being simpler for those involved in her mother's care: *Because it is easier at home for everybody.*

Another important theme that arose during analysis of the interviews was ‘taking control’. The theme of ‘taking control’ is defined as the importance of taking authority over one's health problem. This was a salient theme in the significant other's description of making the decision to conduct at-home dialysis. One spouse described her husband as: *... always been... independent with any of his health issues.* Another spouse similarly described her husband's value of taking control: *You're there [in-center receiving treatment] from 6p.m. to 11p.m... like I say, I think he feels more in control of his situation.* Another participant commented on feeling a lack of control when in the hospital: *...and every time you go to the hospital there is some sort of delay or all these going on. And it is not their fault; it is the way things are. It's life but if you do it at home at least you can control it.*

Another example of ‘taking control’ was described by a significant other who wanted more flexibility to travel and decided to buy a van to fit the peritoneal dialysis supplies. He emphasized the independence he sought by buying the van and not having to arrange travel through the hospital: *Bought myself a van so it will carry all her supplies... We've been there before relying on others...we got unofficially screwed. It always cost us way too much money.*

There is a perception of increased flexibility described by significant others related to conducting dialysis treatments in the home environment. ‘Flexibility’ is defined as the importance of freedom attributed to at-home treatments. For example, one participant explained: *We sort of saw all the options... this [peritoneal dialysis] seemed to allow the most flexibility and so we opted for that.* Another significant other described the anticipated freedom nocturnal peritoneal dialysis would give them: *I think once we start doing it at night and we have our days free to do what we want... we’ll have a bit more freedom.*

4.5.4 Values and preferences: In-center treatments

‘Keeping home separate’ is the first theme identified as being associated with values and preferences of in-center treatments. It is defined as the importance of not medicalizing the home environment. One significant other related the experience of the medicalization of the home with peritoneal dialysis: *I worked in a hospital for thirty-six years and now I’m at home. I feel I have returned [to work]... I feel it’s my second home now. I’ll never leave the hospital.* Another significant other described her struggle with the idea of bringing hemodialysis into the home environment. She stated: *Originally, my feeling on it was I didn’t want to because I wanted to keep the dialysis separate from our home lives.*

Several participants described this feeling of not wanting take the responsibility for at-home treatments. ‘Differing responsibility of treatments’ is defined as the feeling of concern for the responsibility of at-home treatment execution. One participant described their spouse’s decision: *...she doesn’t think she’d be able to do it at home anyway... I’m not exactly sure, the set-up for one thing... and that [peritoneal dialysis] would take a lot of changing so she preferred to go to the hospital to get it done.* A daughter described her elderly mother’s decision

to have in-center hemodialysis: *...because it [peritoneal dialysis] has to be done every day, or what was it 4 times a day...she goes "Too complicated. I'm lazy. I cannot do it." She chose to have it done at the hospital. She felt more safe knowing there were doctors around.*

4.5.5 Feasibility: travel to in-center

The main factor participants identified relevant to feasibility was traveling to the hospital. The theme of 'travel to in-center' is defined as the influence of travel to the hospital including time, distance, and feasibility. The IP-SDM model recognizes the importance of assessing feasibility of the option before expressing the preferred choice (Legare et al., 2011). The model recognizes that not all resources and healthcare options are available across healthcare systems. The ability to travel to the hospital to receive in-center dialysis was a common concern in participants who live in rural communities.

One participant describes the impact of traveling to the hospital on decision-making: *If there was a snow storm... it would take us 2 and a half hours to get to the hospital and... would take us 2 hours back so that's a big chunk of time.* Another participant described the impracticality of traveling: *We live out of town...we can't drive because he's got limited eyesight so driving in... 3 times a week would have been difficult.*

4.5.6 Preferred choice: sharing opinions

Many participants described a process of sharing opinions during interviews. 'Sharing opinions' is defined as the deliberation and communication about treatment modality choice between patient and significant other. The theme of 'sharing opinions' was identified under the step of 'preferred choice.' In the IP-SDM model step of 'preferred choice', the patient and significant other express their dialysis treatment modality choice (Legare et al., 2011). Four of

the 10 participants experienced uncertainty about the treatment modality choice; of these 2 had already implemented the decision and two were in the process of deciding.

One significant other described this deliberation: *I think we have a pretty open relationship so we talked about it right from the start.* Another significant other described the communication between herself and her mother: *I would give my opinion and, most of the time, I agreed with her because I understand through her eyes and age.* One significant other shared their view: *I just thought it was a decision that should be made within husband and wife. We're the ones at home.*

4.6 Factors related to dialysis treatment modality decision implementation

The themes that were related to factors influencing the process of treatment modality decision implementation were unanticipated events, relationship changes, impact on recreational travel, worry about individual with CKD, and being in a caregiver role. According to the IP-SDM model, important aspects of the decision quality are the degree to which the decision is implemented as planned and the health outcomes (Legare et al., 2011). During this process, the patient and significant other must be supported to enhance the health outcomes valued most by the patient.

4.6.1 Unanticipated events

Firstly, the theme of 'unanticipated events' is defined as unforeseen and unprepared events during treatment implementation. One participant describes: *There've been surprises but nothing someone could have warned us... like the tubes getting damaged or whatever.* One participant described the experience with getting her home ready for hemodialysis:

We didn't have an idea. You have an idea but you don't about how much equipment will be coming into your home as far as supplies...we changed our closet in the hall into a storage area because...there is nothing wrong with me right now but if I'm carting heavy stuff up and down stairs who knows how long my knees are going to last.

A participant described the experience of having complications which led to not being able to conduct nocturnal peritoneal dialysis. *He was thinking [night-time peritoneal] cyclers and would have had three days off...but that didn't happen for too long.* Another significant other described the realization that travel was not as easy as anticipated: *We can't travel anymore and this BS about... "We'll just tell people ahead of time where you're going to go and they'll set you up."* Two of the 4 of the participants who felt uncertain about the dialysis modality choice also experienced these unanticipated events. Of these 2 participants, 1 was the significant other of a patient who had implemented their treatment modality choice and 1 was the significant other of a patient who had not yet implemented the treatment modality choice.

4.6.2 Relationship changes

During data analysis, it became apparent that significant others experienced a variety of changes in relationships after the implementation of the dialysis treatment modality decision. The theme of 'relationship changes' is defined as a change in interpersonal relationships and behaviours. For example, one participant described the need to stay at home in the evenings while her husband was performing dialysis:

I'm still having a bit of a hard time because we're doing it in the evening...We try and get him on at least by six so at least he's off by ten so then by the time we clean up and everything. You know, I have to be home. Somebody has to be home.

One participant shared her difficulty in finding a job to suit her husband's needs for dialysis treatments: *...now it's really hard because I've lost my job, and now I can only find a job so many days cause he's in [the city] on dialysis.* Another significant other shared her experience of a social role change with family relationships: *...he doesn't want his family to know about it [dialysis] and mine. So we don't see much of them either. That's a little dilemma.* Finally, one participant commented on the anticipated change in intimacy behaviours: *You know he'll be hooked up to that [night-time peritonealycler] at night. You can see, you know, interfering a little with intimacy.*

4.6.3 Recreational travel

The theme of 'recreational travel' is defined as the perceived inability or change in recreational travel. Half of the participants expressed how they could not travel anymore: *We don't travel as much as we used to.* Another participant described travelling in anticipation of the lifestyle change caused by dialysis treatment modality implementation: *My husband and I were doing a lot of traveling because we knew it was going to happen sooner or later. So of course it is a little more difficult now to do that travelling.*

4.6.4 Worry about the individual suffering from CKD

Some of the participants described their worry over the individual with CKD. The theme of 'worry about the individual suffering from CKD' is defined as a feeling of concern over the person receiving dialysis when he or she is alone. One husband related his concern over his wife when he is at work:

I worry constantly because her balance is off and I, when I am at work, I'm afraid that she might take a fall. She has fallen in the past and she broke her hip one time and she broke her

leg after that. I kind of worry especially when she's at home alone and going up and down stairs and...well I'm constantly worrying about her doing that.

This statement illustrates how symptoms specific to certain treatment modality options, such as hemodynamic instability following in-center hemodialysis, can cause concern.

Another significant other also expressed his concerns over his wife's well-being. In this case, the patient was experiencing large blood sugar fluctuations commonly found when diabetic patients begin peritoneal dialysis. *I work shiftwork...I do worry about her 'cause she's a diabetic and like I said, if she's home alone...* Another example of significant other worry during the implementation process was concerning conducting the peritoneal dialysis exchanges: *I think I'm mostly worried because my husband has learning problems, and it might be harder for him to understand and... I am a little afraid one time he'll forget.*

4.7 Supportive interventions needed

Two themes emerged directly from participant narrative: peer support and assessing patient and family educational needs. These themes are under the broad category of supportive interventions provided by the interprofessional team. Results of the SURE tool indicated all participants felt they had enough support and advice in their decision-making process (see Table 4.2).

4.7.1 Anticipatory peer support

Participants expressed a desire to see how other patients in a particular treatment modality option managed their dialysis treatments. The theme of 'anticipatory peer support' is defined as the giving of guidance and support in advance of making the dialysis treatment

modality decision. They envisioned this peer support as a valuable step preceding implementing dialysis at-home. One participant related:

...they could team [us] up with someone who has been on the same dialysis... we wanted to see the way it was done with another person. And there was no teaming of a novice and someone who has done it... I wish there was something like that.

Another participant supported this idea by describing the benefit of seeing how a peer dialysis patient was successfully implementing home hemodialysis:

The hospital has an idea of who would have a good set up for you to see... before you actually get set up cause it might give you some ideas... if they had a few families... say if someone wants to come home and see our setup before they set up at home then that would be a good idea.

4.7.2 Assessing patient and family educational needs

Another theme that emerged from interview transcripts was the need to assess the learning needs of patients and families. ‘Assessing patient and family educational needs’ is defined as the on-going evaluation of overall patient and family education needs and perception of information given. One participant described the unique experience of beginning at-home dialysis treatments when the patient suffered from severe learning disabilities:

I think partly if they found out someone had learning problems maybe they could bring... their person [nurse] more into it. He can't read. OK. He's been trained... when he was younger. They have a certain name for it back then but basically he's got a full range of dyslexia... but there are certain points I miss out on which he may not.. I'm worried we've missed some information.

4.8 Follow-up interview

Of 10 participants, 3 were contacted by telephone within three months of the first interview. When presented with the findings, all 3 indicated that they agreed with the findings. Furthermore, participants emphasized the importance of their role as remaining positive and the need for receiving adequate support and complete information on the options.

4.9 Summary

Through an interpretive description approach, (Thorne, 2008) themes emerged from data which illustrated both physical and psychological contextual factors influencing the significant other and illuminated broad support roles assumed by the significant other during the decision-making process (Table 4.4). Other themes described the roles of the significant other relating to specific steps in the decision-making process using the IP-SDM model (Legare et al., 2011). Finally, themes and trends emerged addressing areas of health care professional support.

Table 4.5 Summary of themes defined**The environment of the decision-making process**

'Choosing life' is the point in the chronic kidney disease trajectory when the choice to initiate renal replacement therapy is made.

'Unexpected life change' is a variance from one's expected life path.

'Health problems of the significant other' are the adverse health states of the significant other.

Significant other roles

'Providing a positive outlook' is the conservation of a positive perspective

'Being with' is the supportive presence of the significant other during decision-making.

'Advocacy' is the active support provided by the significant other in the contact with the healthcare system in the process of dialysis decision-making.

Factors influencing dialysis treatment modality decision-making process

'Information exchange - learning together' is the process of acquiring knowledge to inform the dialysis treatment modality decision.

'Values and preferences of at-home treatment'

'Being home' is the importance of being in the home environment.

'Taking control' is the importance of taking authority over one's health problem.

'Flexibility' is the importance of additional freedom attributed to at-home treatments.

'Values and preferences of in-center treatments'

'Keeping home separate' is the importance of not medicalizing the home environment.

'Differing responsibility of treatments' is the feeling of concern for the responsibility of at-home treatment execution.

'Travel to in-center' is the influence of travel to the hospital including time, distance, and feasibility.

'Sharing opinions' is the deliberation and communication about treatment modality choice between patient and significant other.

Factors related to implementing the modality decision

'Unanticipated events' are the unforeseen and unprepared events during treatment modality implementation.

'Relationship changes' is a change in interpersonal relationships and behaviours.

'Recreational travel' is the perceived inability or change in recreational travel.

'Worry about the individual suffering from CKD' is the feeling of concern over the person receiving dialysis when he or she is alone.

'Caregiver role' is the act of helping the dialysis patient with activities of daily living.

Supportive interventions needed

'Anticipatory peer support' is the giving of guidance and support in advance of making the dialysis treatment modality decision.

'Assessing patient and family educational needs' is the on-going evaluation of overall patient and family education needs and perception of information given.

Chapter Five

Discussion

“The settings in which people live or stay for a while, the social support they have and the people they interact with, have a powerful effect on their lives as well as on health and illness.”

(Holloway & Wheeler, 2010, p.12)

The aim of this study was to explore the role of the significant other in making and implementing a dialysis treatment modality decision and to explore how nurses can, and do, support these individuals through this process. This qualitative study contributes to existing literature on family involvement in shared decision-making and adds knowledge of the significant other's experience in dialysis treatment modality decision-making. The findings provide insight into the experience of treatment modality decisions, and the subsequent implementation issues lived by significant others.

Common themes addressing the role of the significant other were found to be contextual/environmental or about broader roles. Contextual themes found in the environment of the significant other were: choosing life, unexpected life change, and the health problems of the significant other. Broad role themes were: providing a positive outlook, being with, and advocacy. As well, findings revealed that factors influencing making the dialysis treatment modality decision were learning together, being home, taking control, flexibility, keeping home separate, differing responsibility of treatments, travel to in-center and sharing opinions. Whereas factors influencing the implementation of the decision were the impact of lifestyle, including

unanticipated events, relationship changes, recreational travel and worry about the individual suffering from CKD. An important salient theme which emerged is that of the significant other's caregiver role. During the process of triangulating data, two of the ten significant others had decisional conflict and were found to have low levels of decision regret.

This chapter will discuss the findings from the thematic analysis within what is already known from theoretical, empirical and clinical literature. Aspects of the significant other in dialysis treatment modality decision-making which will be discussed include: the environmental factors affecting the significant other, unanticipated events affecting decision quality, the caregiver role of the significant other, and the application of findings to the IP-SDM model. Finally, strengths and limitations and implications for the advanced practice nurse will be addressed.

5.1 Environmental factors of the significant other

Findings from this study illustrated two environmental factors which are recognized as having the potential to influence the dialysis treatment modality decision-making process: the affective state of significant others and their personal health problems. According to the IP-SDM model, contextual factors in a decision-making process can play an important role on the deliberation and outcome of a preference-sensitive health care decision (Legare et al., 2011). These findings can help health care professionals to better understand the environment of the patients and their supportive others, particularly as supportive others may be involved in the implementation of the treatment modality choice.

The significant other may experience varying and profound emotional responses to the enormity of the individual requiring life-sustaining therapy. The theme of 'choosing life' found

in this study illustrates this emotional gravity when deciding to initiate therapy. This theme was supported in Morton's (2010) review of the views of patients and 'carers' in CKD decision-making. The review describes a theme of 'confronting mortality: choosing life or death'. Ten of 18 studies included in the review reported this common post-diagnosis affective state where patients are confronted with the realization that their disease can indeed lead to death. Consistent with these studies, many significant others in this study were similarly affected by the experiences of the individuals' diagnosis and the decision to begin dialysis treatments.

The second theme of the 'health of the significant other' emerged during analysis as a salient environmental factor also with the potential to influence dialysis treatment modality decision-making. Currently, 71% of Canadians between the age of 60 and 79 years of age are living with chronic disease (Broemeling et al., 2008). Given that over half of the current dialysis population is over the age of 65 and most of their designated significant others are spouses of similar ages, the prevalence of chronic disease in significant others may, in fact, be a prevalent issue when providing treatment decision support for patients and their family (CIHI, 2010).

Psychological and physical health problems of the significant other have the potential to contribute to complex interpersonal environments which require additional attention from the interprofessional health care team. Affective factors of the significant other may be important in providing timely decision support for the individual with CKD. Research in CKD decision-making has demonstrated patients and their families can feel rushed and too unwell to receive information about treatment modality options (Morton et al., 2010). The health of the significant other may also contribute to feasibility of treatment modality options by affecting factors such as caregiving, transportation, and ability to assist with at-home dialysis treatment. Both

psychological and physical factors within the environmental context should be considered and/or recognized as influential during the decision-making process and may require additional nursing support.

5.2 Unanticipated events affecting decision quality

During this study, significant others discussed events during treatment implementation that were unanticipated both to them and the individual receiving dialysis. For instance, one participant described how, although he chose at-home nocturnal peritoneal dialysis treatment modalities, complications arose during implementation which caused him to be unable to use a cyclor at night. Another example of unanticipated events described by a significant other was surprise at the amount of equipment needed to be placed in the home to undergo at-home treatments. In this case, the significant other described the need to rearrange living space and have home renovations to accommodate the dialysis equipment. Others shared their surprise at the amount of time required to perform peritoneal dialysis exchanges at-home. One further example which highlights the gap between information provided and expectations of treatment implementation found in this study was the difficulty or inability to travel felt by significant others of patients on at-home treatment. Although purported benefits of choosing a peritoneal dialysis treatment modality are flexibility, independence and ability to travel (Lee et al., 2008; Wuerth et al., 2002), this study found peritoneal dialysis patients still perceived an inability to travel. Causes of the participant's misperception about the flexibility to travel in these situations are founded in inaccurate information received, as well as unrealistic expectations.

Interestingly, significant others who described unanticipated events also experienced decisional conflict. Unaddressed decisional conflict is associated with individuals changing their

mind, regret of the decision made, lack of knowledge, and blaming the doctor for bad outcomes (Sun, 2004; Gatelari & Ward, 2005). Decisional conflict may be reduced through modifiable factors such as tailoring information for individuals and their significant others, and the realignment of treatment expectations (O'Connor et al., 2009).

Individuals and their significant other acquire facts about treatment modality options during the information exchange step of the decision-making process (Legare et al., 2011). Information necessary for the patient/family to make an informed decision include the natural course of the health condition, the procedures involved in the treatments or tests, the potential consequences and their severity, the benefits of the treatment, and the likelihoods of harms occurring. With dialysis treatment modality decisions, it is also important to provide information relating to anticipated lifestyle changes in a manner they can easily understand when faced with a distressing life event. Nursing support in this step of decision-making may involve individualizing information, assessing the individuals' and significant others' perception of what is being explained to them, and adapting the information based on this informal assessment.

Interestingly, the Ontario Peritoneal Dialysis Coordinating committee states that if unbiased information of treatment modality choices were given to the patients, 30 to 40% of these individuals would opt for peritoneal dialysis as their treatment method (Oreopoulos et al., 2007). One method of ensuring the patient receives unbiased information is the use of decision aids. Patient decision aids are an intervention designed at providing balanced information in a way that allows the patient to weigh the benefits and harms of options. A systematic review of studies examining the effectiveness of decision aids indicated that patients exposed to decision

aids had greater knowledge, more realistic expectations, and less decisional conflict than those exposed to usual care (O'Connor et al., 2009).

5.3 The caregiver role

During this research study, many of the significant others described their role as assisting the individual receiving dialysis with both functional and basic activities of daily living. This finding is supported by recent literature demonstrating there is a significant proportion of dialysis patients who have unpaid caregivers who experience the negative physical and emotional effect of their role (Belaso et al., 2006; Schneider, 2004; Suri et al., 2011). Many of the participants from this study had, in fact, key roles in the implementation of the treatment modality, particularly with at-home treatments. Even participants who identified patients as being independent with managing their illnesses were still involved in a variety of caregiver activities.

The role of informal family caregiver described in this study may be a significant factor in the dialysis treatment decision-making process as the decision to implement a dialysis treatment modality choice may also result in additional needs being placed on significant others. In a survey completed by Health Canada (2002), 40% of informal caregivers felt they had no choice in the decision to provide care for the recipient of dialysis. The main reasons family members assumed the caregiver role included feeling it is a family responsibility, believing no one else is available to provide care, and that there is a lack in funded home care services. Another study from the United States of 183 informal caregivers similarly demonstrated how 46% of caregivers did not feel they had a choice in their role and were more likely to experience burden and other negative effects of associated with this role (Winter, Bouldin, & Andresen, 2010).

The emotional and physical effects of caregiving may influence the individual with CKD during the decision-making process. Individuals receiving dialysis feel guilty about not participating in family life, depriving the family of freedom, and being dependent on family members (Tong et al., 2009). This feeling of burden is recognized as an important factor in opting for palliative management instead of a dialysis treatment pathway (Morton et al., 2010).

The role of the significant other as caregiver was common in this study and may have a place in the communication of feelings during the decision-making process. One of the significant other's roles was clearly defined as providing a positive outlook but, given that burden and guilt may be commonplace, it is possible that this positive coping behaviour may disguise the presence of negative feelings. Using the IP-SDM model as a guide, the interprofessional team can include the discussion of affective/emotional aspects during the step of information exchange (Legare et al., 2011).

5.4 Applications to the IP-SDM model

Although research has demonstrated that family, relatives, and significant others want to be involved in the health care decisions of the individual receiving dialysis and patients readily admit that the family influences the decision-making process, the specific roles and influences of these significant others are unclear (Lee et al., 2008; Wuerth et al., 2003). This study found that significant others had broad roles, such as maintaining a positive environment, caregiving, 'being with'/providing support, and advocacy, as well as roles related to specific steps in the IP-SDM model.

The IP-SDM model (Legare et al., 2011), used as a theoretical model to guide this research process, is unique from others as it makes specific reference to the family/significant

others as having a supportive role in the decision-making process and collaborating with the interprofessional team throughout. Within the model's seven iterative steps to the decision-making process, our findings highlighted that the significant other contributes in a variety of roles throughout the process, specifically in two steps: learning together during the exchange of information and sharing opinions on the preferred choice.

Although the patient is always central to the decision-making process, results from this study show that the dialysis treatment modality decision-making can greatly affect the life of the significant other, as well as the life of the patient. The significant other may experience a change in social patterns, negative feelings such as worry, and the addition of caregiver activities. The IP-SDM model was found to be particularly fitting as it includes the discussion of affective/emotional states during the process of decision deliberation (Legare et al., 2011). Furthermore, the model recognizes the importance of including the family/significant other in the whole decision-making process.

5.5 Strengths and limitations

The quality of a research study must not only be examined through evaluative criteria for qualitative research, but also examined with disciplinary knowledge and critical judgment (Throne, 2008). Through the process of conducting this research and during analysis, several strengths and limitations became apparent.

Strengths of the study included a diverse sampling frame representing each element sought during the purposeful sampling process. Participants represented all treatment options, sexes, a wide range of ages, and various significant other relationships (wife, husband, daughter). The diversity in participant perspectives enhanced the study's overall credibility. To address

transferability of the findings, a detailed description of the setting and participant characteristics was provided for readers. Trustworthiness was addressed through reflexive journaling before, after and during interviews, auditing by the research team, and member checking.

Limitations included the use of the telephone for some of the interviews, accuracy of self-reporting, and the potential for participants to perceive the researcher as part of the health care team. The use of telephone for interviews had the potential to influence data collected. Each participant was given a choice of setting for their interview and many chose to conduct it over the telephone. Steps to increase the quality of interpretations were the use of journaling during and after interviews, as well as, re-listening to tapes while reading transcripts.

The influence of studying the perspective of the decision in a retrospect report was recognized as having the potential to influence data. Interview data was reliant on the ability for participants to be able to accurately recall the decision-making process. One strategy to enhance the accuracy of self-reporting was to include only participants who made the treatment modality decision had been made within the past six months. Nisbett & DeCamp Wilson (1977) support the accuracy of reports when influencing factors are salient and plausible within their story. This study found influencing factors for the significant other in dialysis decision-making was reflected in literature making interview data credible.

Another limitation was that during the interviews, participants may have identified the researcher as part of the health care team in nephrology. The main contributing factor was the fact that the researcher was formerly a member of the nursing staff in the dialysis unit and, as such, was very comfortable discussing their dialysis decision-making experiences. This misidentification may also have influenced data as participants may not have wanted to share any

negative feelings about the decision-making process. In an attempt to reduce this potential limitation, participants were informed that the researcher was acting as a nursing student and was on leave from her nursing staff position.

5.6 Implications for the Advanced Practice Nurse

Each role of the APN, including expert clinician, consultant, leader, educator, and researcher, (Hamric, Spross & Hanson, 2009) can be employed to enhance care of the individual with CKD and their significant other in the decision-making process (see Table 5.1). The APN could uniquely contribute to dialysis treatment modality decision support by mentoring and educating the interprofessional team, evaluating shared decision-making interventions, providing expert clinical advice in complex health scenarios, and providing consultation services to the general CKD population. In fact providing decision support falls directly under the clinical competency of the APN (Canadian Nurses Association, 2008).

There may be benefits to further research of the role of APN, especially in the provision of patient decision support in a tertiary care environment as a clinical nurse specialist (CNS). During the last 40 years, Canadian APNs struggled to reach the full potential of their roles (DiCenso & Bryant-Lukosius, 2010). A current drawback to sustainability of the APN roles in tertiary care is the lack of research to support the benefits of these nursing positions. In Canada, between the 1970 and 2009, 124 primary articles concerning the NP role were published compared to only 10 of the Clinical Nurse Specialist (CNS) role (DiCenso et al., 2010). Possible reasons for this dearth of CNS research may include a lack of funding opportunities, a focus on clinical research and few doctorate-prepared CNS (Bryant-Lukosius, 2010). Research supporting the CNS role is difficult as "...the scope of everyday CNS accomplishments is not

completely captured in published work. CNSs improve care practice on a daily basis” (Fulton & Baldwin, 2004, p. 22).

Although there is the difficulty in creating and sustaining these unique nursing roles, the CNS operating in a CKD decision support role can continue to work to create research opportunities. These research opportunities need to continue to demonstrate the benefits of having a nursing role with advanced clinical leadership and graduate educational training. A recent study found that kidney transplant patients who were exposed to an APN-led interprofessional team were more likely to discuss eligible options for end stage renal decisions compared to controls (Bissonette, 2011). Continuing to conduct research in this area will only further justify funding to support these advanced practice nursing positions (Carter et al., 2010). The following discusses the opportunities within the APN role in the chronic kidney disease decision support and how the defined themes from this study can directly influence roles in this position.

Table 5.1 Implications for the advanced practice nursing role

IP-SDM decision-making steps	Advanced practice nurse roles	Supporting themes from qualitative study
Making explicit the decision that needs to be made	<p>Direct care</p> <p>Determine patient's wishes for significant other and their level of involvement in decision-making process</p> <p>Include the informal assessment of the significant other's well-being as it related to the treatment modality decision</p>	<p>Choosing life</p> <p>Unexpected life change</p> <p>Health problems of significant other</p>
Exchange of information	<p>Direct care</p> <p>Assess learning needs, utilize decision aids, assess perception of knowledge</p> <p>Verify accuracy of expectations</p> <p>Encourage communication of affective/emotional factors between significant other and patient</p> <p>Education</p> <p>Increase nurses' awareness of decision aids and guidelines on CKD decision-making</p> <p>Discuss the role of the significant other in undergraduate nursing education as it relates to how health decisions are made</p> <p>Research</p> <p>Evaluate interventions to address decision-making needs of significant others</p> <p>Leadership</p> <p>Ensure organization level policy that includes the assessment of the significant others' well-being in shared decision-making</p>	<p>Assessing patient and family educational needs</p> <p>Learning together</p> <p>Unanticipated events</p> <p>Recreational travel</p>
Clarification of values/preferences	<p>Direct care</p> <p>Encourage significant other to explore important factors in making the decision</p> <p>Explore and reduce concerns of significant other</p> <p>Education</p> <p>Educate other health care professionals on decision support and importance of decisions based on informed preferences</p>	<p>Differing responsibility of treatments</p> <p>Taking control</p> <p>Flexibility</p> <p>Keeping home separate</p> <p>Being home</p>
Feasibility of the options	<p>Direct care</p> <p>Explore feasibility of options with patient, significant other and</p>	<p>Travel to in-center</p> <p>Unanticipated</p>

IP-SDM decision-making steps	Advanced practice nurse roles	Supporting themes from qualitative study
	<p>health care team</p> <p>Consultation Provide consultation services to health care team in the assessment of feasibility</p>	<p>events</p>
Preferred choice	<p>Direct care Encourage sharing of opinions between patient and significant other</p> <p>Collaborate Work with patients and significant others to identify preferred choice and execute implementation</p>	<p>Sharing opinions</p>
Implementation of the decision	<p>Direct care Provide tangible support and referrals where needed Address implementation concerns of the significant other</p> <p>Research Evaluate the effect of supportive interventions targeting caregivers in the process by which decisions are implemented with patients having CKD</p> <p>Education Educate nursing students and staff to have the patient identify significant other in decision support, specifically in areas of assessment and treatment implementation</p> <p>Leadership Advocate for legislation and policy that supports and protects significant others who are caregivers (i.e. funding for tangible support)</p>	<p>Recreational travel Relationship changes Unanticipated events Caregiver role Worry about the individual suffering from CKD</p>

5.6.1 Implications for policy

Research findings from this study may have implications policy. This study found that a high proportion of significant others participated in caregiver activities. These findings are supported with national data demonstrating that 43% of unpaid informal caregivers are partners and spouses of the recipient of care (Health Canada, 2002). Considering the prevalence of informal family caregivers, it is important for health care policy to recognize the needs of the individual on dialysis and the significant other as caregiver.

This study also found that significant others who participated in caregiver activities for the patient conducting at-home dialysis had unforeseen out-of pocket expenses, such as home renovations, or interruptions in work. The above survey by Health Canada (2002) on informal caregiving supports this finding as it found 44% of caregivers are incurring out-of-pocket expenses for transportation, prescription and non-prescription drugs, and medical supplies for the individual receiving dialysis. Furthermore, 20% of caregivers in this survey experienced disruptions in employment. Given that the economic benefit of at-home dialysis treatments for the health care system is well reported (51,000USD for in-center hemodialysis versus 26,959USD for at-home peritoneal dialysis (Lee et al., 2002), it is important that health policy considers the impact of potential hidden costs of at-home treatments on individuals and their families. Nurses can help advocate for health policy changes through professional organizations, by participating in campaigns with local nursing associations to lobby government, by empowering families to advocate for themselves through local representatives.

Health care organization policies could better support shared decision-making in the tertiary care environment by involving significant others when patients feel it would be

appropriate. Specifically, hospital decision support guidelines could include the recommendation of informal assessments of significant others as it applies to their involvement in treatment implementation such as the ability to assist with at-home treatments and the potential influence of the significant others' health issues.

5.6.2 Implications for education

With the expansion of healthcare options and complex health decisions, there is a need for continuing education and undergraduate education in decision support. Examples of continuing education activities to enhance knowledge and skills in CKD decision support include skill building workshops, the use of champions, and mentorship programs (Registered Nurses Association of Ontario, 2009). As the role of decision support naturally lends itself to the daily tasks and activities involved in nursing, education in this area needs to be both pre and post licensure and focus on core competencies of decision support (Stacey et al., 2008). Currently, integration of decision support teaching in undergraduate nursing programs is limited and barriers need to be overcome to be successful (Stacey et al., 2009). Undergraduate nursing curriculum could expand to include teaching students the core concepts of decision support and their application through problem based learning and case scenarios. Findings from this study support the need for education in this area with an emphasis on family-centered (see Table 5.1).

5.6.3 Implications for practice

In 2009, the Registered Nurses Association of Ontario published guidelines to assist nurses in providing decision support for individuals suffering from CKD (RNAO, 2009). The guidelines provide a thorough outline of decisions in the disease trajectory and accompanying recommendations for nurses and organizations. Although the guidelines encourage the

involvement of family members in the discussion and recognizes that they may have a role in decision-making, nurses may need a more detailed description of how the family/significant other can be involved at various specific steps in the decision-making process. Ideally, nursing support would extend to the significant other and decision support would include a discussion of how the treatment modality is anticipated to affect the life of the significant other (see Table 5.1).

The theme of ‘assessing patient and family learning needs’ found in this study supports the need for health care professionals to assess learning needs, especially with patients who suffer from cognitive impairment or learning disabilities. These findings reflect an important subgroup of individuals making a treatment modality decision. Moreover, CKD individuals making a treatment decision may be cognitively affected by a uremic state caused by disease progression. One study of 145 dialysis patients in the United Kingdom demonstrated how individuals who suffer from cognitive impairments have a significantly higher rate of mortality when compared to a control group (Konstandina et al., 2010). Individuals with special learning needs may benefit from tailored teaching and learning approaches. Information on treatment modality options could be tailored to the individual and their significant other, and their understanding of information could ideally be assessed on a continuous basis.

This research study found that significant others experienced worry about the individual suffering from CKD when they were at-home alone. Further supportive interventions during the decision-making process may include addressing concerns in this area for the significant other. In particular, significant others described being concerned over the individual’s risk of falling, or their unstable blood sugar levels. Through the exploration of the root causes of the significant

other's concern, the nurse can mobilize additional support including strategies to enhance safety in the home environment and referral to other members of the interprofessional team.

5.6.4 Implications for research

There are two main implications for further research (see Table 5.1). The first is to evaluate the implementation of the IP-SDM model into the delivery of care in patients and their significant others considering dialysis modality treatment decisions in tertiary care. Currently, the implementation of this model in homecare is being evaluated and involves use of video clips to demonstrate interprofessional shared decision-making, monitor attitudes using a Theory of Planned Behavior designed survey tool, and to train decision support (Legare et al., 2011). Results from this study may provide information on how best to implement the model in a tertiary center. The second research priority is to evaluate interventions to support the significant other as caregiver in the dialysis treatment modality decision implementation. For example, interventions such as patient decision aids to support families in dialysis decision-making are likely to improve their realistic expectations of outcomes. The Cochrane review of 55 trials of patient decision aids showed that the largest benefits to these tools are improving expectations of outcomes, but none of the trials were conducted in patients and their families considering options for dialysis treatment (O'Connor, 2009). Furthermore, the review found that decision aids reduced decisional conflict, an affective state described by some significant others who participated in this current study.

5.7 Conclusion

This research study furthered our understanding of the experiences of the dialysis decision-making process from the perspective of the significant other, specifically their role,

influencing factors, and the supportive interventions of the interprofessional team. Significant others described their role in dialysis treatment modality decision-making as advocating, providing a positive outlook, 'being with' the patient, learning together, sharing opinions, communicating about values, preferences, and feasibility of options. Environmental factors that influenced decision-making included unexpected life change, choosing life, and personal health problems. Factors related to implementation of the treatment modality decision were unanticipated events, relationship changes, recreational travel changes, and the caregiver role. Significant others have an important role in supporting the patient making the dialysis treatment modality decision and are often instrumental in implementing the decision, but evidently more interventions are required to better support them.

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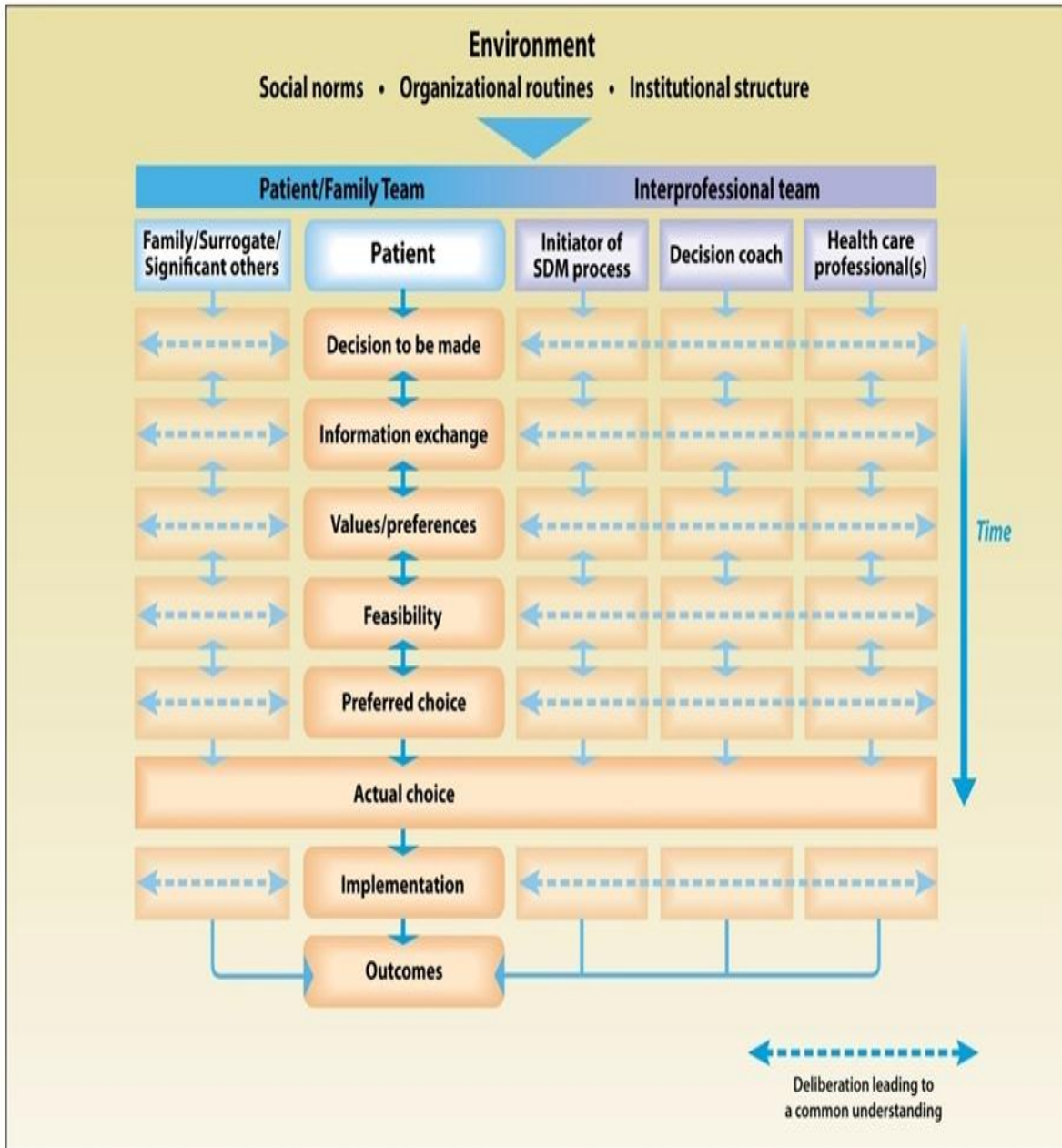
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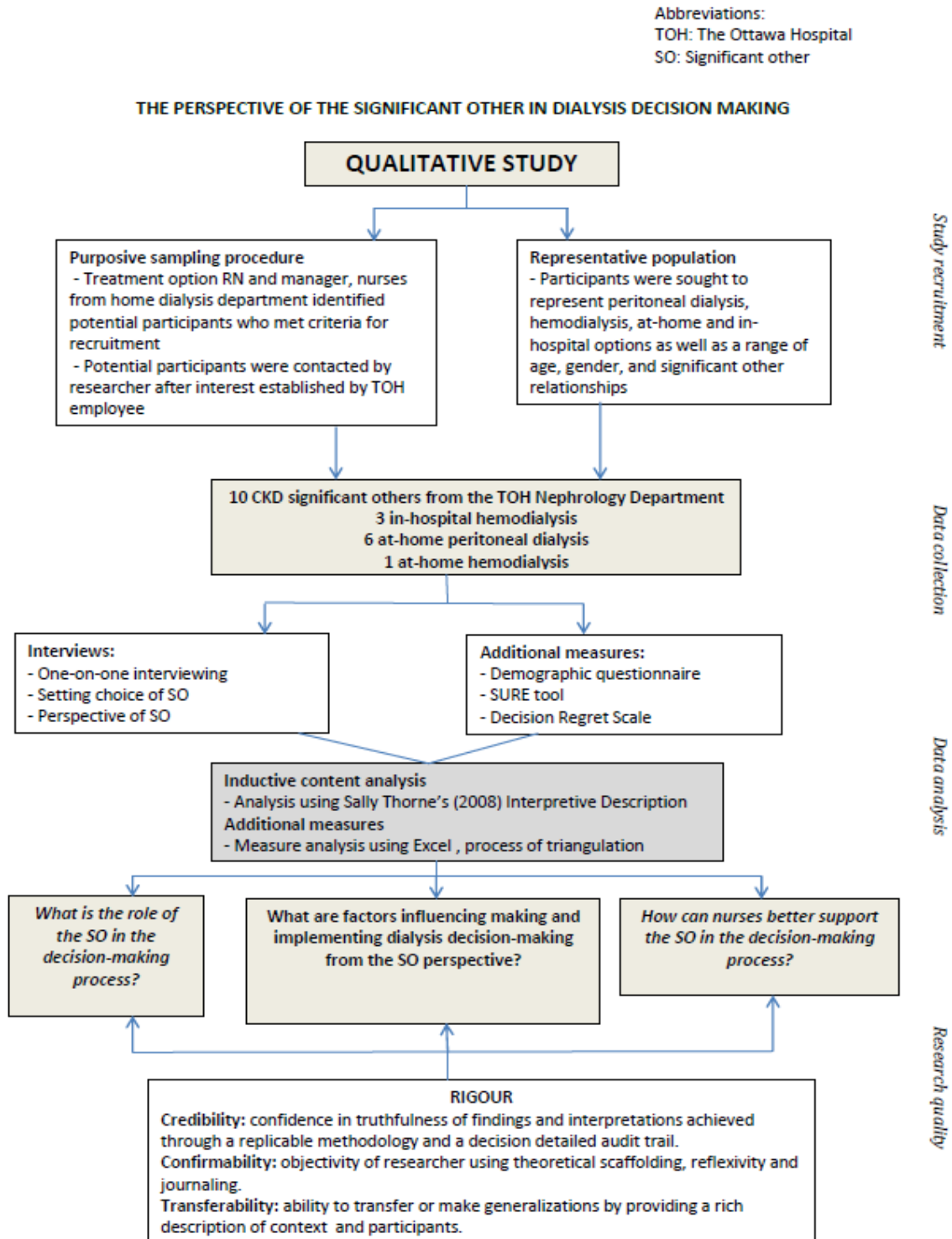
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Appendix A IP-SDM model



Appendix B Research Study Flow Chart



Appendix C Consent Form

Information Letter for Eligible Participants

The perspective of the significant other in dialysis treatment decision-making

This form is part of a process to obtain your informed consent to participate in a research study. There are 2 copies, one copy is for you and one copy for the researcher. The information presented here explains the research study and what your participation would involve. If you want more information, do not hesitate to ask. Please take the time to read this information and learn about the study.

Why is the research being done?

At some point, most people with chronic kidney disease need to make a decision about type of dialysis treatment. These decisions not only affect the person with renal disease but can have an impact on important people around the patient.

The main objective of this study is to explore the dialysis treatment decision making process from the point of view of these significant others. Significant others are identified by the patient as being important to their health and well-being. They may be a relative or a non-relative.

Who is conducting the study?

What would my participation in this study involve?

If you agree to participate in this study:

1. You will be asked to participate in an interview for about 30-45 minutes at a time and place that is convenient to you. For example, the interview could take place in the dialysis unit conference room, at your own home, or in a coffee shop.
2. You will be asked to have a second interview for about 15-20 minutes over the phone to review the researcher's understanding of the first interview.

What are the risks and inconveniences of participating?

There are no known risks of taking part in this study. Participating in this study will require your time: up to 45 minutes for the interview and a 30 minutes for the optional second interview. You are not required to answer any questions that make you uncomfortable.

What are the advantages of participating?

Participating in this study may allow you to clarify your thoughts about the dialysis treatment decision. Findings from the group of interviews will be used to help the clinic at the [redacted] better understand the decision making process from the perspective of people like you and if necessary, help us identify ways to better support others who are important in the patients' life.

What are your rights?

Joining this study is your choice. Whether or not you decide to participate will have no effect on the care of the patient receiving dialysis. If you decide to participate, you have the right to ask the researchers questions about this study. You also have the right to withdraw from the study at any point.

What happens with your information?

All information collected for this study is confidential. Your name will not be associated with the data. Instead, a number will be given to the interview transcripts. Information collected will be kept for 15 years after termination of the study and then destroyed by shredding any paper files and permanently deleting any electronic files. [redacted] and [redacted] or relevant study file, under the supervision of the researchers, for audit purposes.

What are your costs?

There are no costs to you for participating in this study.

Questions about the Study:

Consent Form

The perspective of the significant other in dialysis treatment decision-making

Consent to Participate in Research

I understand that I am being asked to participate in a research study about the perspective of the significant other in dialysis treatment decision-making. This study has been explained to me by _____.

I have read this 3 page Patient Information Sheet and Consent Form (or have had this document read to me). All my questions have been answered to my satisfaction. If I decide at a later stage in the study that I would like to withdraw my consent, I may do so at any time.

I voluntarily agree to participate in this study.

A copy of the signed Information Sheet and/or Consent Form will be provided to me.

Signatures

Participant's Name (Please Print)

Participant's Signature

Date

Investigator Statement (or Person Explaining the Consent)

I have carefully explained to the research participant the nature of the above research study. To the best of my knowledge, the research participant signing this consent form understands the nature, demands, risks and benefits involved in participating in this study. I acknowledge my responsibility for the care and well-being of the above research participant, to respect the rights and wishes of the research participant, and to conduct the study according to applicable Good Clinical Practice guidelines and regulations.

Name of Investigator/Delegate (Please Print)

Signature of Investigator/Delegate

Date

Appendix D Interview questions

Participants were asked open-ended questions aimed at describing the experience with the dialysis decision-making process.

1. Can you tell me about how the choice of dialysis treatment option was made for your ... (spouse, mother, father, daughter, son, partner, or friend)?

Prompts: What information did you have on the dialysis options (written/verbal)? What was most important to you in the decision? What pressure did you feel, if any, to choose a specific type of dialysis? Tell me about lifestyle changes or specific issues at home that influenced the dialysis option chosen.

2. What are the changes to your life since the treatment decision?

Prompt: What, if any, are the negative or positive impacts of the decision?

3. Tell me about your role in the decision.

Prompt: Was this the role you expected to have and, if not, in what ways was it different? How do you think you contributed to the decision?

4. As an important support person for _____, are there things that could have been done to better help you in your role in the process of deciding about type of dialysis?

Prompt: What could we, as health care professionals, have done to help you better?

Appendix E Interview guide

Date _____
 Interviewee identifier _____

Introduction:

1. The purpose of this interview *is to explore the experience of a significant other in a patient's dialysis treatment decision.*
 2. Assurance of confidentiality – Participants will be assured anonymity and although some information that they provide will be published, their name will not be associated with the specific published information. Participants will be informed that they may stop the interview at any time or refrain from answering any questions, and there would be no negative consequences.
 3. Ground rules – There are no right or wrong answers we are just trying to determine the supports and barriers to nurses providing decision support.
 4. Role of interviewer – Facilitate progress through the questions and to take notes
- Informed Consent - Obtained
 - Sign-in sheet with their email address and/or phone number for optional second interview

Complete measures

- Measures completed

Debriefing at end:

- Ask if there are any other comments the participant would like to share.
- Remind participants that they will have a chance to see the results within 3 months to verify the accuracy of the findings. Confirm contact information if interested.
- Field notes written

Appendix F Measures

(To be completed by researcher)

Study Number: _____

Decisional Regret Scale (O'Connor, 1996)

Please think about the dialysis treatment decision. Please show how strongly you agree or disagree with these statements by circling a number which best fits your views about the decision.

It was the right decision	1 Strongly Agree	2 Agree	3 Neither agree Nor disagree	4 Disagree	5 Strongly Disagree
I regret the decision that was made	1 Strongly Agree	2 Agree	3 Neither agree Nor disagree	4 Disagree	5 Strongly Disagree
I would go for the same choice if we had to do it over again	1 Strongly Agree	2 Agree	3 Neither agree Nor disagree	4 Disagree	5 Strongly Disagree
The choice did a lot of harm	1 Strongly Agree	2 Agree	3 Neither agree Nor disagree	4 Disagree	5 Strongly Disagree
The decision was a wise one	1 Strongly Agree	2 Agree	3 Neither agree Nor disagree	4 Disagree	5 Strongly Disagree

Demographic questionnaire

Sex M/ F

Relationship to patient (brother, daughter, spouse, friend, etc) _____

Year of birth _____

Highest level of education _____

Do you work? Y/N

- Full time
- Part time
- Retired
- On disability
- Student
- Other

SURE Tool (O'Connor & Legare, 2008)

Thinking about the dialysis decision,

Do you feel SURE about the best choice for your (spouse, sister, brother, friend, etc)? Y/N

Do you know the benefits and risks of each option? Y/N

Are you clear about which benefits and risks matter most to you? Y/N

Did you have enough support and advice to make a choice? Y/N

Appendix G Follow-up interview guide

Date _____
Interviewee identifier _____

Introduction:

1. The purpose of this interview *is to share the findings of the interview and get any feedback you may have.*
2. Assurance of confidentiality – Participants will be assured anonymity and although some information that they provide will be published, their name will not be associated with the specific published information. Participants will be informed that they may stop the interview at any time or refrain from answering any questions, and there would be no negative consequences.
3. Ground rules – there are no right or wrong answers we are just trying to determine the supports and barriers to nurses providing decision support.
4. Role of interviewer – facilitate progress through the questions and to take notes

Debriefing at end:

- Ask if there are any other comments the participant would like to share.
- Remind participants that they will have a chance to see the results in early January to verify the accuracy of the findings. GET email addresses (see attached sheet).

Write field notes

- Field notes written

Appendix H Follow-up narrative

Interview step	Key Points
Greetings and purpose	<p>Hello Mr/Ms/Mrs _____. We spoke in January about your experience in the process of making a decision about dialysis treatment with your _____ [husband, wife, mother, father]. We have finished the analysis of all the interviews and I was wondering if you have about 10 to 15 minutes so I could share the results with you. This will give you a chance to learn about the results and also make any additional comments on what we found and/or maybe missed. Last time we spoke, your _____ [husband, wife, mother, father], was on _____ [home hemodialysis, hemodialysis in-center , peritoneal dialysis]. Is this still the case?</p> <p>Would it be alright with you if I record the interviews in case I miss anything you say?</p> <p>Please feel free to stop me at any point.</p>
Theme presentation	<p>I am going to be going over 6 main findings from the research.</p> <p>Q1. The first thing we wanted to understand in the interviews was the role of the significant other during decision-making. There seemed to be three main roles: giving a positive outlook, asking questions of the healthcare team, and providing support. Providing support could be driving your significant other to treatments, helping them around the house or helping them with their treatments at-home. We also heard that the significant other shared opinions and discussed treatment types during decision-making. When you think about the role you had, is this similar to what you did?</p> <p>Q2. The second set of questions we asked were about the things that influenced the way the treatment decision was made. We learned that significant others got information about the treatment options together with the person needing dialysis.</p> <p><i>Q3a. For those who chose at-home dialysis</i>, things that were most important to them were being at home, feeling a sense of control over their treatments, and the flexibility of home treatments. Does this cover how you felt? When making the decision, some said that traveling to the hospital influenced the decision. For example, if they lived far away it would be more difficult to travel to the hospital 3 times a week for treatment. Did it for you?</p> <p><i>Q3b. From those who chose in-center treatments</i>: things that were most important were keeping the home separate from the hospital, and getting help with the actual treatments.</p> <p>Are there any other things that influenced how the decision was made?</p> <p>Q4. We also found that personal circumstances were very important. For example, some people shared how they had found out suddenly about the need for dialysis and the need to make a decision. Other people shared how there were lots of changes going on in their lives, not only day-to-day changes but long-term changes. We also heard from a few people that they had other health problems that had an effect on the treatment options. Does this make sense to you? Or do you have anything to add?</p> <p>Q5. We also asked questions about what it was like after the treatment began. There were</p>

	<p>four main issues for people – unexpected surprises, difficulty with relationships, travel, and worry. For example, for some people there were unexpected things after starting the treatment such as the amount of equipment coming into the home or not being able to conduct dialysis at night. For others, there were changes in their relationships at work or with family because they didn’t want people to see them on dialysis at home. Some people said that there was a change in their ability to travel. Another thing that came up was the worry people felt over their significant other when they were alone. We found many of the people I spoke with help their person receiving dialysis by taking care of them, setting up the dialysis machine or doing housework. Do some of these things sound familiar to you?</p> <p>Q6. Finally, we asked how nurses could better help family members like you during treatment decision. People said that they would like to be paired with someone who had started home treatments so they could see how it worked. Other people said that nurses need to assess the learning needs and provide teaching based on these needs. Are there other ways that nurses could help you?</p>
<p>Thank you and closing</p>	<p>Thank you for your time. I appreciate your honesty in sharing your thoughts with me. I am in the process of finalizing the findings from this project to have a report as part of my studies at the university but also The hospital is interested in the results so they can improve the program. Although we have spoken to you twice about your experience, there will be no information associated with anything that may identify you in this study.</p>

Interview notes:

Appendix I Copyright permission for IP-SDM model

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Sep 21, 2011

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