Conceptualizing Chronic Kidney Disease Dialysis Modality Decision-Making and Home-Service Usage

by

Lori Elizabeth Harwood

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Abstract

People with Chronic Kidney Disease (CKD) are asked to make important decisions about if, where and how they will receive dialysis. As the population in Canada ages with increased co-morbidity such as diabetes and hypertension, the need for high cost treatments for CKD such as dialysis will persist. However, understanding the complexity of these decisions and influences of decision-making related to these treatments is limited. This work was undertaken to conceptualize the complexity of CKD modality decision-making with a focus on home-dialysis and older adults. Critical realism provided the framework for this inquiry.

This paper-based dissertation includes an introductory chapter, four publishable papers and a discussion chapter. The first paper conceptualizes dialysis modality decision-making using critical realism and serves as the theoretical framework for this work. The second paper is a systematic literature review and meta-ethnography of the qualitative research on dialysis modality decision-making. The third paper is a quantitative study which examines the relationship between chronic kidney disease stressors as determinants of dialysis modality service usage. The forth paper, describes a qualitative study exploring home-dialysis modality decision-making for aging adults with advanced kidney disease. The conclusion of this dissertation is a discussion of the complete thesis, and includes implications for practice, policy and research.

Preface

This thesis is original work by Lori Harwood. Some of the research published for this thesis was collective work and each contribution of the authors is described below.

The components of Chapter 1 of this thesis were published as; Harwood, L., & Clark, A.M. (2012). Understanding health decisions using critical realism: Home-dialysis decision-making during chronic kidney disease. *Nursing Inquiry, 19*(1), 29-38. The authorship of this paper is shared with my supervisor (AMC). I performed the primary researching and writing of this paper. The co-author provided overall supervision to the writing and his expertise in the subject area of critical realism.

The components of Chapter 2 of this thesis were published as; Harwood, L., & Clark, A.M. (2012). Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies. *International Journal of Nursing Studies, 50*, 109-120. Authorship of this publication is shared with my academic supervisor and co-author (AMC). My role as the primary author for the paper included researching, performing the meta-synthesis and writing of the paper. My co-author provided overall supervision and expertise in the method of meta-synthesis.

The components of Chapter 3 of this thesis were published as; Harwood, L., Wilson, B., Sontrop, J., & Clark, A.M (2012). Chronic kidney disease Stressors influence choice of dialysis modality. *Journal of Advanced Nursing, 68*(11), 2454-2465. The authorship of this paper was not mine alone. Acknowledgement is required as my co-authors contributed to the research and publication. I developed the overall conceptualization of the study building on my previous research (Harwood, Locking-Cusolito, Spittal, Wilson, & White, 2005; Harwood, Wilson, & Sontrop, 2011), directed the study, collected the data and wrote the majority of the paper. My co-author (BW) also participated in some of the writing of the paper. The statistician (JS) performed the data analysis, provided statistical advice, wrote the majority of the results section as well as designed and created the tables and figures. The remaining author (AMC) provided overall guidance to the study and writing of the paper. This study had ethical approval from the local research ethics board.

The components of Chapter 4 of this thesis were published as; Harwood, L., & Clark, A.M. (2014). Dialysis modality decision-making for older adults with chronic kidney disease. *Journal of Clinical Nursing, In press*. Authorship of this paper is shared with my academic supervisor (AMC). In my role as primary author for this paper, I designed, conducted, and analyzed the results of the study and performed the majority of writing in the paper. My co-author provided overall guidance to the design, conduct, data collection, and data analysis of the study and the content of the paper. This study received ethical approval from the local research ethics boards.

Acknowledgements

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I am grateful to the many people in the renal program at the London Health Sciences Centre (LHSC) who have made this work possible. Ms. Janice McCallum, Director of the renal program, supported me to be able to complete this degree and conduct the research in the clinical setting. My NP colleagues were present for the successes and challenges throughout this process and covered the clinical issues during the coursework. I am very grateful to the two RN Case Managers in the CKD clinic, Terri McCallum and Sandra Bartlett, for their great work in asking patients to participate in this study. I am sincerely thankful to the nephrologists at LHSC who are supportive of nursing research in the renal program and enabled people from their CKD clinics to be approached for this study. I am indebted to Joanne Clark who continues to provide me with assistance formatting documents.

I am grateful that people from the CKD clinic volunteered for this study, invited me into their homes and shared their experiences. I am also thankful for the CKD staff who also volunteered for this study and shared their experiences.

Lastly, I am grateful for the support from my family with their best wishes during this process. My dalmatian Toby was always there to listen. Many thanks to all of you.

Definitions

Chronic Kidney Disease is the presence of renal damage greater than 3 months and not on dialysis (Levin et al., 2008).

Complex/Complexity is a situation/event/state that is composed of many underlying mechanisms that link causal factors and context to a range of outcomes (Sword, Clark, Hegadoren, Brooks, & Kingston, 2012).

Conceptualizing the object of study is a priority in critical realist research in which the researcher seeks substantial connections among phenomena as opposed to formal associations or regularities. Conceptualizing provides an explanation of the social world, its stratification, emergent powers and the ways causal mechanisms depend on the constraining and enabling effects of context (Sayer, 2000).

Frailty is a multidimensional construct often seen in elderly persons with a decline in health and functioning and resulting in a risk for disability hospital admissions, placement in long term care facilities and death (Johansen, Chertow, Jin, & Kunter, 2007). It is a state of high vulnerability for poor health outcomes (Fried, Ferrucci, Darer, Williamson, & Anderson, 2004).

Decision-Making is based on the philosophy of critical realism. Critical realists believe that individuals have the power or agency to make decisions and change, but that decisions are also constrained by structural factors, and that each are given equal weight (Wainwright & Forbes, 2000).

Hemodialysis is a type of therapy where substances move across an artificial semi-permeable membrane to remove unwanted solutes and fluid and restore acid and electrolyte balance (Latham, 2006).

Informed Decision-Making is "a reasoned choice being made by a reasonable individual using relevant information about the advantages and disadvantages of all the possible courses of action in accord with the individual's beliefs" (Bekker et al., 1999, p. iii).

Mechanisms are "underlying entities, processes or structure which operate in particular contexts to generate an outcomes of interest" (Astbury & Leeuw, 2011, p. 368).

Peritoneal Dialysis is a treatment that uses the peritoneal membrane for fluid and solute exchange (Kelman & Watson, 2006).

Social Support (functional) is the perceived availability of interpersonal relationships to serve functions such as emotional support, instrumental/tangible support, information, appraisal, companionship (Sherbourne & Stewart, 1991).

Social Vulnerability is a population that is vulnerable on the basis of belonging to a social group such as race, age, and socio-economic status.

Socioeconomic status is a person's position in society determined by income, occupation, education, wealth and housing (Plantinga, 2013).

Uncertainty is the inability to determine the meaning of events of a situation where the person making the decision is unable to assign values to events and objects and unable to predict outcomes (Mishel & Braden, 1988).

Vulnerability is “being capable of being affected by a circumstance” which provides “the chance, openness or susceptibility to an outcome” (Purdy, 2004, p. 29).

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Chapter 1: Understanding the Complexity of Health Decisions

Preamble

Why wouldn't a person with Chronic Kidney Disease (CKD), facing a future with dialysis, choose a dialysis modality that allows them to dialyze in their home, is free, widely available and has quality of life benefits over a hospital based treatment? The area of inquiry for my doctoral work is CKD decision-making with an emphasis on understanding the complexity of home-dialysis selection for the older adult. This program of study used critical realism to conceptualize dialysis modality decision-making as complex and informed the methodology of the studies. The requirements for this 'PhD by papers' contains four peer-reviewed papers encompassing the theoretical and empirical elements of this work. My desire to explore this topic originated from my clinical practice working as a nurse practitioner in the area of kidney disease for many years.

The first paper describes the philosophical framework for the conceptualization of CKD decision-making and discusses how critical realism informs CKD decision-making.[1] This paper was published in *Nursing Inquiry* (Harwood & Clark, 2012a). The second paper is a systematic review of qualitative research on dialysis modality decision-making processes with a meta-

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[1] A version of this chapter has been published. Harwood, L. & Clark, A.M. (2012). Understanding health decisions using critical realism: Home-dialysis decision-making during CKD. Nursing Inquiry. 19(1), 29-38.

synthesis (meta-ethnography) for people with CKD. This is published in the *International Journal of Nursing Studies* (Harwood & Clark, 2012b). The third paper has been published in the *Journal of Advanced Nursing* and was a prospective quantitative study examining stressors as determinants of home-dialysis service usage (Harwood, Wilson, Sontrop, & Clark, 2012). The remaining paper addressed in this proposal, contains the findings from the analysis of a qualitative study on home-dialysis decision-making for the older adult with stage 4-5 CKD. This paper is currently in press with the Journal of Clinical Nursing.

My Assumptions and Beliefs

My assumptions are based on my own values, beliefs and my experience and commitment of over 20 years of working with people with kidney disease in Ontario, Canada. These assumptions were stated in the proposal development stage and assist the researcher with reflexivity. Reflexivity is fundamental to the qualitative research process. For the purposes of this thesis reflexivity will refer to being attentive to how and why decisions and interpretations are made (Mayan, 2009) and how my experiences have shaped thinking and my actions. In qualitative research the researcher is very engaged in the research process and analysis. As such “bias” is unavoidable however, “bias” can be reduced (Tong, Sainsbury, & Craig, 2007). My own personal assumptions regarding home-dialysis and decision-making are as follows:

- People make decisions by weighing the risk and benefit to their life.
- Our actions and decisions are influenced by our personal attributes such as motivation and our situation such as socioeconomic status.
- Making decisions about dialysis modalities is frightening, difficult and uncertain.
- Health care providers in this area often find people avoid making a modality decision.
- Home-dialysis has many benefits however, should not be imposed on a person due to fiscal benefit to the health care system.
- More elderly persons could do home-dialysis if adequate resources and supports were in place in the home.
- Many elderly people with CKD are frail and vulnerable.

Background, Issue and Central Concerns

The classification of CKD by the National Kidney Foundation is the generally accepted criteria for kidney damage based on estimated glomerular filtration rate (see appendix A). The later stages 3-5 indicate more severe kidney disease. The treatment plan for these individuals not only includes efforts to delay progression of their kidney disease but also to provide information on their treatment options and preparation for choosing a Renal Replacement Therapy (RRT). The options for people with late stage CKD include conservative management or RRT. Conservative management emphasizes maintaining quality of life and includes control of symptoms, non-dialytic correction of electrolyte and fluid imbalances, anemia management and end-of-life care (Alston, 2013). RRT encompasses treatment for kidney failure with dialysis or renal transplantation (CIHI, 2013). This thesis focused on dialysis modality decision-making.

People with CKD are asked to make important choices about renal replacement therapy. Kidney transplantation is the most effective renal replacement therapy (Johansen, 2011) and replaces all aspect of kidney function (Adey, 2013) however, eligibility is limited due to age and health status and thus declines in the older population in Canada (CIHI, 2013). Hemodialysis (HD) is a process in which substances in the blood transfer across the semipermeable membrane (commonly referred to as an artificial kidney) removing solutes and fluid (Latham, 2006). Hemodialysis is predominantly performed in an in-centre setting such as a hospital or community setting but can be performed at home (Home HemoDialysis, HHD). Peritoneal dialysis (PD) uses the peritoneal membrane as the semipermeable membrane for fluid and solute removal (Kelman & Watson, 2006) and is almost exclusively a home-based modality.

The most recent information reports that 5,489 people in Canada in 2011 started RRT and this has doubled since 1992 (CIHI, 2013). The aging population has had an impact on the need for dialysis with 53% of those who started dialysis being 65 years of age or older compared to 38% from a decade ago (CIHI, 2013). The highest Rate Per Million Population (RPMP) of people starting dialysis are older adults; RPMP 517.4 (25.2%) for people aged 65-74 and 668 RPMP (28%) for people 75 years of age and older (CIHI, 2013). Canada is similar to other developed countries where this cohort is also the largest growing segment of the dialysis population in the United States and the United Kingdom (Brown & Johansson, 2011) and is expected to accelerate as the baby boomer generation ages (Berger & Hedayati, 2012). Dialysis modality service usage in Canada remains unchanged since 2002 with 80% of people requiring dialysis initiating therapy with hemodialysis (CIHI, 2013). However as age increases so does the likelihood of starting on hospital hemodialysis at 86% (CIHI, 2013).

Home-dialysis has many benefits. HHD offers superior survival when compared to incentre HD (RR 0.03 $p<0.0001$) (Woods, Port, Stannard, Blagg, & Held, 1996) particularly when it is done more frequent such as nocturnal HHD and daily HHD. HD and PD are generally accepted to have equal survival rates during the first one to three years (Nesrallah, 2006) and possibly five years (HR, 1.03; 95% CI, 0.99-1.06, $p=0.10$) (Mehrotra, Yi-Wen, Kalantar-Zadeh, Bargman, & Vonesh, 2011), after which HD outcomes exceed PD (Blake, 2000; Heaf, Lokkegaard, & Madsen, 2002; Murphy, Foley, & Barrett, 2000; Termorshuizen et al., 2003). However, the survival benefit for older adults on dialysis is less clear (O'Connor & Kumar, 2012) (See Chapter 4).

There are also lifestyle and quality of life benefits for people on home-dialysis including more flexible dialysis schedules, greater opportunity for adequate dialysis, convenience, comfortable environment, less travel to the hospital, more time with family, greater independence and control over treatment

(Harwood & Leitch, 2006) and less exposure to organisms found in hospital settings. Dialysis treatments are effective, however they are costly with in-centre HD the most expensive and home-dialysis the most cost efficient.

The current assumption in Ontario is that home-dialysis is beneficial for the person with CKD and the economic sustainability of the health care system, yet it is underutilized. The Ontario Renal Network (ORN) was established by the Ministry of Health and Long Term Care of Ontario to provide overall leadership and strategic direction to effectively manage and organize renal service delivery in Ontario. Improving the uptake of independent dialysis (henceforth; home-dialysis) is one of the strategic priorities of the ORN. Targets have been established: 40% of new patients will be on a home-dialysis modality within six months of starting dialysis in Ontario (ORN, 2013). There is room for improvement as currently 32.9% of new patients within six month choose a home-dialysis (ORN, 2013).

Not everyone who is aware of home-dialysis and given a choice for a dialysis modality selects a home-dialysis therapy. This suggests that despite the benefits to the person with CKD and the healthcare system other factors are at play. Personal values and other factors which influence health decision-making may not equate to assumptions and values held by health care funding sources. Having a greater understanding of how and under what circumstances people make modality decisions will increase our understanding when personal and system assumptions are similar or in opposition.

Many clinical practice guidelines for CKD recommend educational programs to support patients' understanding of their options and make reasoned choices regarding dialysis decision-making. Education has consistently demonstrated an increase in home-dialysis selection (see Table 1.1) however not everyone who is educated about home-dialysis selects it. This suggests that modality decision-making is more complex and other factors likely influence home-dialysis selection. A deeper understanding of the complexities involved in modality decision-making for this specific population is important for the health service delivery and economic sustainability of dialysis services in Canada.

Decision-Making Theory

Decision-making is complex and decision-making theories frame how we think about and research decision-making. How do people make decisions in their life, particularly as it pertains to health decisions? It is generally agreed upon that three generic decision-making theories identified in the literature form the components that most individuals use to reach a decision (Bekker, 2009). These theories are; 1) Normative, which outline theories how people think, 2) Descriptive, theories explaining how people think in the real world and 3) Prescriptive, theories regarding how people should to make better decisions e.g.) smoking cessation (Bekker, 2009).

Expected utility theory, an example of a normative theory is the most widely recognized decision-making model which involves rational behaviour, logic and decisions to maximize expected utility (Bekker, 2009). An example of CKD modality decision-making based on a normative theory could examine the decision-making of the trade-offs of the requirements of dialysis to the benefits of quality of life. Descriptive theories tend to focus on how decisions are made or the processing of information. These are often unobservable and the person is assumed to be active in problem-solving (Bekker, 2009). Conceptualizing CKD dialysis decision-making based on a descriptive theory might include examining the effect of uremia and aging on cognitive processing for treatment decisions. If a prescriptive decision-making theory was used to understand CKD modality decision-making it could focus on helping people make good decisions reducing the gap between preferences and decision-making consequences. These theories could be helpful in finding ways to help patients make modality decisions pertaining to the frequency of dialysis such as choosing dialysis daily to increase survival.

In most cases people with CKD are asked to be involved in choices regarding the use of a dialysis modality. Clinical practice guidelines emphasize shared decision-making between physicians and people with CKD for modality decision-making (Renal Physician’s Association (RPA), 2010). This is generally due to dialysis being a life sustaining therapy with a high burden of illness and no one ideal modality. Dominant conceptualizations of patient involvement in shared decision-making tends to focus on an exchange of information between the patient and health care providers on understanding the options and the influence the patient has on the selection (Entwistle, 2009). The most common definition of shared decision-making is decision-making which involves both the patient and physician who both share information and try and reach consensus about the preferred treatment (Charles, Gafni, & Whelan, 1997). Edwards and Elwyn (2009) comment that the slow general acceptance of shared decision-making where the individual exercises their own agency rather than the physician/health team making the decisions warrants reflection and a deeper understanding of how decision-making is occurring (Edwards & Elwyn, 2009).

Decisions made in the context of shared decision-making are likely to be highly influenced by personal preferences, experiences, relationships and structural constraints such as culture, ethnicity, education and class (Edwards & Elwyn, 2009). Dialysis modality selection done in the context of shared decision-making adds to the complexity of this decision–making influenced by many personal and varied experiences and social structure. Existing grand theories of decision-making (descriptive, normative and prescriptive) are generally cognitive based and do not take into consideration the influence of social factors which limits their usefulness in the examination of complex decision-making. This thesis is situated in social theory, specifically critical realism. Critical realism is well suited to provide a deeper understanding and conceptualize the complexities of CKD dialysis modality decision-making and how the personal and structural factors influence this decision-making.

In summary the issues and central concerns of CKD modality decision-making are as follows:

- Home-dialysis is an effective treatment with benefits for the patient and the health care system.
- It is a strategic priority of funding providers in Ontario to increase home-dialysis usage for people with CKD requiring dialysis.
- The older adult (> 65 years of age) is a growing cohort requiring dialysis but least likely to start on a home-therapy.
- Education is an important factor that can influence home-dialysis selection.
- Dialysis modality decision-making if it is done in the context of shared decision-making is likely to be highly complex, varied and influenced by many factors.
- Gaps exist in our understanding of the complexities involved in modality decision-making.

This body of work addresses these problems herein:

1. A theoretical conceptualization using critical realism to examine complex CKD decision-making.

2. A systematic review and meta-synthesis of the qualitative literature on dialysis modality decision-making.
3. A quantitative study examining the wider determinants such as socio-demographics, stress and coping on home-dialysis service usage.
4. A qualitative study advancing our understanding of the context of home-dialysis decision-making for older adults.

In order to conceptualize CKD decision-making and home-dialysis service usage the objectives of this thesis are:

1. Explain the complexity of CKD modality decision-making using critical realism.
2. Review and interpret, in a systematic manner, the qualitative literature on dialysis modality decision-making.
3. Examine the effects of CKD related stressors and coping on dialysis modality service usage.
4. Explain the personal and structural factors which contribute to home-dialysis modality decision-making for older adults with CKD.

Table 1-1

Effect of Education on Dialysis Modality Service Usage

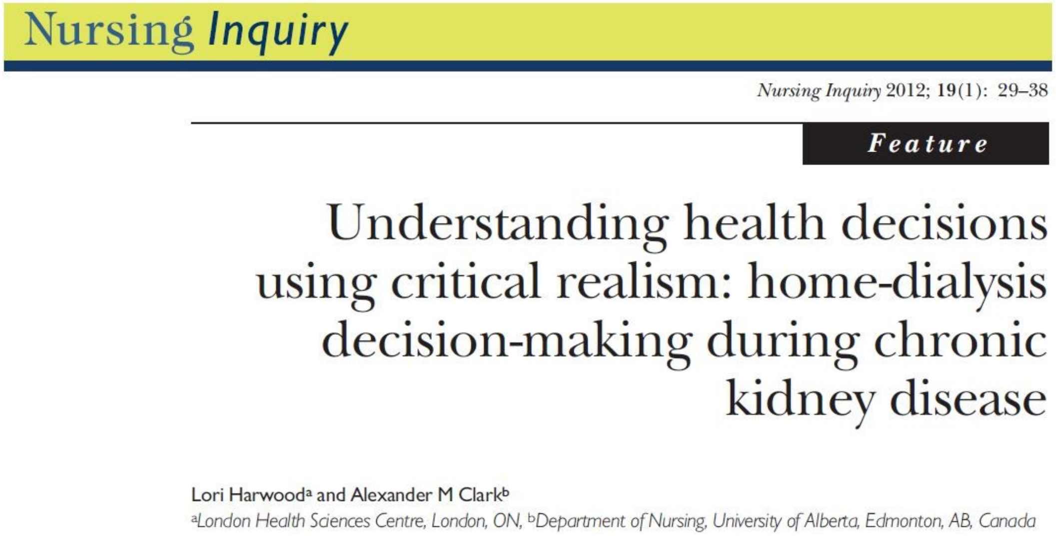
Author/Reference	Interventional Education Group Dialysis Modality	Standard Care or No Education Dialysis Modality
(Chanouzas, Ng, Fallouh, & Baharani, 2012)	PD 50% HD 32% p=0.011	N/A
(Gomez, Valido, Celadilla, de Quiros, & Mojon, 1999)	In-centre Hemodialysis 57% PD 43%	In-centre Hemodialysis 83% PD 17% pvalue-not reported
(Goovaerts, Jadoul, & Goffin, 2005)	In-centre Hemodialysis 40% Self care dialysis 55% -Home HD 9% -PD 31% -Self care HD 16%	N/A
(Hanko et al., 2010)	27.8% of urgent incentre HD changed to a home modality PD n=7, Home HD n=1 (OR 3.75, 95% CI 1.08-13.05)	N/A
(Klang, Bjorvell, & Clyne, 1999)	100% has sufficient knowledge to choose modality	79% did not have sufficient knowledge to choose p<0.01
(Lacson et al., 2011)	Selection-Home therapy 24% In-centre HD 26.9% Undecided 34.5% Transplant 12.5% 25% started on a home therapy PD selection OR 8.45 (95% CI, 7.63-9.37) Incentre HD OR 2.14 (95% CI, 1.96-2.33)	3.3% started on a home therapy
(Maaroufi et al., 2013)	PD 42% HD 33% Undecided 20% Reluctant for RRT 5%	N/A
(Manns et al., 2005)	Self care Dialysis 82%	Self care Dialysis 50% p=0.015

(Marron et al., 2006)	PD 25%	PD 8% $p<0.001$
(Mehrotra, Marsh, Vonesh, Peters, & Nissenson, 2005)	Probability of Choosing PD 0.05 (0.02-.0.21 CI) $p<0.0001$	N/A
(Pagels, Wang, & Wengstrom, 2008)	Self care Dialysis 52.4% In-centre HD 47.6%	Self care Dialysis 33% pvalue-not reported
(Prichard, 1996)	In-centre Hemodialysis 30%, Selfcare Hemodialysis 20%, PD 50%	In-centre Hemodialysis 100% p value-not reported
(Ribitsch et al., 2013)	n=70 patients (30.8%) PD 38 (54.3%), HD 32 (45.7%)	n=157 (69.2%) PD 44 (28%), HD 13(72%)$p<0.001$

Conceptualizing the Complexity of CKD Decision-Making Using Critical Realism

The worldview of critical realism was used in this thesis to provide the lens to conceptualize CKD decision-making. Critical realism increases our understanding of how complex health decisions are made, and in this case how people with CKD make dialysis modality decisions. The following paper examines home-dialysis decision-making from the perspective of critical realism, posits that these decisions are complex and concludes that a re-conceptualized is required to examine the mechanisms that contribute to decision-making, the underlying social factors and the context in which these decisions are made. Permission to use this paper in this thesis has been granted (See Appendix B).

The Peer Reviewed Publication



Nursing Inquiry

Nursing Inquiry 2012; **19**(1): 29–38

Feature

Understanding health decisions using critical realism: home-dialysis decision-making during chronic kidney disease

Lori Harwood[a] and Alexander M Clark[b]

[a]London Health Sciences Centre, London, ON, [b]Department of Nursing, University of Alberta, Edmonton, AB, Canada

Abstract

This paper examines home-dialysis decision making in people with Chronic Kidney Disease (CKD) from the perspective of critical realism. CKD programmes focus on patient education for self-management to delay the progression of kidney disease and the preparation and support for renal replacement therapy e.g.) dialysis and transplantation. Home-dialysis has clear health, societal and economic benefits yet service usage is low despite efforts to realign resources and educate individuals. Current research on the determinants of modality selection is superficial and insufficient to capture the complexities embedded in the process of dialysis modality selection. Predictors of home-dialysis selection and the effect of chronic kidney disease educational programmes provide a limited explanation of this experience. A re-conceptualization of the problem is required in order to fully understand this process. The epistemology and ontology of critical realism guides our knowledge and methodology particularly suited for examination of these complexities. This approach examines the deeper mechanisms and wider determinants associated with modality decision making, specifically who chooses home dialysis and under what circumstances. Until more is known regarding dialysis modality decision making service usage of home dialysis will remain low as interventions will be based on inadequate epistemology.

Individuals with chronic kidney disease (CKD) who are nearing dialysis are faced with a decision of great magnitude in choosing their future dialysis modality. Healthcare professionals' understanding of dialysis modality decision-making is based on existing epistemology and ontology, which emphasize neither the complexity nor explanatory causality of this phenomenon. A re-conceptualization is required to influence effective uptake of health services for this population. This is an important area of inquiry as the international burden of renal disease is large and growing (Just et al., 2008) and treatments that have economic and patient benefits such as home-dialysis are underutilized. Renal replacement therapies, such as kidney transplant and dialysis, can 'replace' some of the functions of the kidney but are expensive. For example, 1.2% of total health care expenditure in Canada is now spent on the care of dialysis and renal transplant patients (Manns, Mendelssohn, & Taub, 2007).

While kidney transplantation can improve renal failure, eligibility is restricted by age and health status, and the availability of donor kidneys (Courtney & Maxwell, 2009). In high-income countries, suitable individuals with CKD are likely to be offered a choice between transplantation and dialysis. Kidney dialysis is an effective and efficient ongoing treatment with few absolute contraindications (Courtney & Maxwell, 2009). Hemodialysis is a process in which substances in the blood transfer across the semipermeable membrane (commonly referred to as an artificial kidney) removing solutes and fluid

(Latham, 2006). Peritoneal dialysis (PD) uses the peritoneal membrane as the semipermeable membrane for fluid and solute removal (Kelman & Watson, 2006). Hemodialysis is predominantly performed in an in-center setting but can be performed at home, while PD is almost exclusively a home-based modality.

Advances in the hemodialysis technology in the 1960's secured the long-term viability of hemodialysis as a cost-effective and efficient option for kidney disease, which resulted in growth of home hemodialysis. In the late 1970s, the prevalence of home hemodialysis began to decrease (Blagg, 2007). This has been attributed to many factors. The introduction of the Medicare ESRD Programme in the United States of America for hemodialysis began and provided universal entitlement for dialysis and renal transplantation. This approach was much different than the previous system with dialysis eligibility decided upon by a hospital committee (Blagg, 2007); those accepted consisted largely of individuals deemed capable of doing home hemodialysis. Reimbursement was also higher for in-center dialysis compared with home, and the number of profit dialysis units outside of the hospital setting expanded (Blagg, 2007). The changing socio-demographics of the family with more women entering the workforce lessened the availability of lay care-giving for performing dialysis in the home and also contributed to the decline of home hemodialysis (Blagg, 2007). In 1976, the technology advanced with continuous ambulatory PD, and PD was accepted as a home-based therapy (Blagg, 2007), which was less costly with more user-friendly technology.

Home-dialysis services are widely available in high income countries including Canada, United States, France, Spain, Italy, United Kingdom, Sweden, the Netherlands, and Australia (USRDS, 2007). However, even in the context of more ‘user-friendly’ available technology, home-dialysis has not experienced growth, and the prevalence of PD is decreasing in North America (CIHI, 2008; USRDS, 2010). For example, approximately 21% of individuals on dialysis are on home-dialysis in Canada; this compares to 7% in the United States with the annual proportion of patients who receive home-dialysis declining (USRDS, 2010). The prevalence of home hemodialysis in the United States continues to be low (1%) (USRDS, 2010). Peritoneal dialysis is decreasing in North America, and many western European countries as well as New Zealand and Australia (Lo, 2007) with only 10–15% of individuals on dialysis worldwide are on PD (Oreopoulos, Ossareh, & Thodis, 2008). The decrease in PD is complex and has been attributed to many factors such as financial reimbursement issues with differing medical insurers, healthcare professionals biases and lack of experience (Lameire, Pellters, Vanholder, & vanBiesen, 2006), and social concerns such as suitable housing, non-adherence with complex regimens, late referral for pre-dialysis care, and creation of satellite hemodialysis units in local communities

(Mendelssohn, Langlois, & Blake, 2004) as well as an aging population with increased medical co-morbidity and support required (Nesrallah, 2006).

There are potential benefits for home-dialysis, but under-usage raises important issues for ethics and health services research. Home-dialysis does require the patient and/or family to have the cognitive ability to perform dialysis and to have adequate housing requirements such as space for supplies, and in the case of hemodialysis, an adequate supply of potable water. However, the likely benefits for patients on home-dialysis include more flexible dialysis schedules, greater opportunity for adequate dialysis, higher convenience, less reliance on and time devoted to travelling to hospital, more time with family, and greater independence and control over treatment. There is also strong evidence that home hemodialysis is cost-effective (Mowatt et al., 2003). In-centre hemodialysis is more costly (around US $51 252 per year of therapy per patient) compared with both home and self-care hemodialysis ($42 057) and PD ($29 961) (Lee et al., 2002). Other favourable factors supporting home-dialysis include higher reimbursement in some countries and resource availability (Just et al., 2008).

Practice variations exist regarding who is offered home-dialysis (O'Hare, Johansen, & Rodriguez, 2006) with no consensus on eligibility for home-dialysis (Mendelssohn et al., 2009). High levels of medical (83%) and psychosocial (88%) eligibility for home-dialysis (PD) have been reported

(Mendelssohn, Mullaney, Jung, Blake, & Mehta, 2001; Oliver et al., 2010). The low uptake of home-dialysis suggests that those who are offered the therapy are not choosing it in great numbers. This leads us to the question what can then be performed to promote the use of home-dialysis and increase our knowledge on who chooses home-dialysis and why?

Low Use of Home-Dialysis

Given the potential cost savings and patient benefits of home-based dialysis, it is important that patients are not only offered home-dialysis but are also given good support when choosing their dialysis modality. How then can patients be supported to choose the right mode of dialysis to balance possible risk, benefit, and cost?

Guidelines state that patients with CKD should be given education and support for dialysis modality selection. The Canadian guidelines for CKD management, Caring for Australians with Renal Impairment guideline and the European Best Practice Guidelines all recommend educational programmes to support patient's understanding of renal replacement options and to help them make reasoned choices regarding dialysis location. Indeed, education has been consistently proposed as the most significant intervention allowing patients to make informed decisions about modality selection. Despite these guidelines and subsequent re-alignment of health services to provide this education, the question remains – Why is the usage of home-dialysis low and declining? We suggest that more needs to be understood about the process of dialysis decision-making, and that this is a vital prerequisite of interventions designed to support patient decision-making.

To examine dialysis decision-making, this paper will draw on critical realism to interpret existing research findings and support a more fundamental re-conceptualization of decision-making around dialysis modality. We will argue that existing knowledge about dialysis modality decision-making should be examined more critically as the current body of knowledge is at risk of being superficial, atomistic, and based on an impoverished ‘successionist’ view of causation that is insufficient to adequately understand the complexities of these decision-making processes. The authors of this paper are not suggesting that other ways of knowing are not legitimate but rather, as a means for improving the design of future inquiry, we propose an alternative ‘generative’ conception of decision-making guided by critical realism, which we believe can make a great contribution to this area of research. Firstly, we will reprise briefly the tenets of critical realism and consider how these relate to human decision-making.

The Tenets of Critical Realism

Critical realism is a meta-theory that is an alternative to variations of positivism and constructivism (Wainwright, 1997). Originally developed in philosophy, critical realism has been used for theory and research in a range of disciplines, including economics (Lawson, 2003), social science (Sayer, 2000), management (Ackroyd & Fleetwood, 2000), evaluation (Pawson & Tilley, 1997), health (Connelly, 2001), and nursing (Clark, Lissell, & Davis, 2008). We describe critical realism briefly here in terms of the following elements: (i) truth, (ii) ontology, (iii) causality, (iv) open systems, and (v) agency and structure, and consider the implications of each for healthcare decision-making.

Truth

Critical realism posits that objective truth exists, but claims to knowledge can only be examined via reason (Bhaskar, 1975). Hence, all beliefs and the scientific processes are seen to be socially produced ('epistemic relativism'), but all beliefs about objective reality are not of equal value ('judgmental relativism') (Bhaskar, 1998). Science (and its associated findings, theories, and discourse) and beliefs are not equated with objective knowledge but make fallible claims to knowledge (Sayer, 2000). Discussion or debate occurs to reconcile competing claims to knowledge about the objective world.

In relation to healthcare decision-making, this means that the research represents decision-making – it cannot claim to fully understand or capture decision-making objectively. The truth value of competing approaches to understanding health decisions can be debated by comparing and contrasting their competing claims in the light of new data and approaches. For example, how effectively can an approach that assumes decisions are based on knowledge and rational choice explain the ongoing low usage of home dialysis?

Ontology

Critical realism posits that reality is stratified. The various objects, structures, and practices that make up reality are present independently of their perceived existence, nature, or observable effects, known or unknown (Bhaskar, 1975). Thus, ontology is stratified into three categories: (1) the empirical – that which is experienced and perceived, (2) the actual events or outcomes that occur (whether perceived or not), and (3) the real underlying structures and powers that can cause changes in events or outcomes (Bhaskar, 1975).

Hence, the outcomes of health decisions (as indicated by service usage patterns) can be influenced by various underlying factors and powers in the domain of the real. These exert an influence on health behaviours irrespective of whether this is recognized by the patient (in the domain of the empirical), because human accounts are always potentially fallible representations of what is occurring in the actual and real domains. Hence, the influence of wider social factors on decision-making can be said to occur irrespective of whether those who are making decisions recognize this. For example, the influence of societal factors that perpetuate income inequalities can exist whether people on low incomes affected by such factors recognize the existence and effects of these factors

(Blaxter, 1997). The existence and influence of these underlying factors does not disappear simply because those affected do not perceive them (Williams, 2003).

Causality

Causation in critical realism is viewed as being generative. This view of causality is in contrast to ‘successionist’ conceptions that are based on the number of times an event is perceived to precede another (Bhaskar, 1975), so-called frequentist approaches (Wainwright & Forbes, 2000). Rather, factors are viewed as causing or ‘generating’ outcomes with emphasis on the number of factors required to cause an outcome and the necessity of these factors being present in the right combination. To illustrate the generative nature of causation, Clark, MacIntyre and Cruickshank, (2007) used the metaphor of a candle to illustrate that to light a candle successfully (i.e. to cause the outcome of a flame) requires a range of factors to come together under the right circumstances, such as: dry match and wick, presence of oxygen, lack of high wind force, and appropriate wick. To achieve the outcome of lighting the candle, all of these factors must be present and a different outcome will be observed with even a small change in some.

The factors that combine to generate outcomes are in the real domain and are not often directly observable, although their causative influence can be inferred through their effects (Pawson & Tilley, 1997). Hence, outcomes are viewed as the consequences of unobservable powers that are enacted under different circumstances (Clark et al., 2007).

A frequent purpose of research based on critical realism is to explain events or outcomes in the actual domain through recourse to underlying factors in the real domain that combine to influence this outcome (Pawson & Tilley, 1997; Lawson, 2003). This means that accounts of decision-making using critical realism invoke the influence of a wider range of factors both in the individual and in elements of their context. This responds to new evidence that indicates that health decisions are strongly influenced by elements of context, such as neighborhood and place (Frohlich, Bodnarchuk, Chateau, Roos, & Forsyth, 2007; Macintyre, Ellaway, & Cummins, 2002). Moreover, these contextual factors may be intertwined with beliefs, practices, and approaches of the individual to their health decision-making (Freydberg, Strain, Tsuyuki, McAlister, & Clark, 2010). This interplay between individual and contextual factors may be difficult to attribute to one particular domain.

Open Systems

Critical realism views reality as a dynamic open system in which there are many interacting underlying structures and mechanisms that come together to cause events in the natural world (Sayer, 2000). The level of controllability in open systems is in contrast to closed systems – such as occur in experiments – which necessarily involve artificial abstraction, control, and manipulation. It is rarely possible to set up controlled experiments in a closed system in the social world in which we live and interact (Sayer, 2000). Factors in open systems include geographical, historical, social, cultural, environment, and physical phenomena (Sayer, 2000).

This means that health decisions are best researched in naturalistic or ‘real-world’ settings rather than contrived experimental or similar randomized control trial settings, because these constitute closed systems that do not sufficiently mirror the complexity of open systems (Pawson & Tilley, 1997). This follows because it is only in open systems that the full complexity and range of the factors influencing health behaviours comes about. Indeed, research on health decisions carried out in artificial situations can be seen as actively contributing to poor understanding of decision-making because of the dissimilarity of these decisions to those made outside of research studies by actual patients. This focus on complexity, open systems, and natural settings means that research into health decisions guided by critical realism is more likely to be qualitative (Sayer, 2000), because qualitative research tends to include first-hand data from participants who have actually made decisions in natural settings. However, other methods such as theory-driven quantitative (Olsen & Morgan, 2005; Pratschke, 2003) and mixed methods research (Lipscomb, 2008) are also consistent with critical realism.

Agency and Structure

Critical realists conceive that individuals have the power or agency to make decisions and change, but that decisions are also constrained by structural factors, and that each are given equal weight (Wainwright & Forbes, 2000). To understand determinants of health, critical realism suggests that the interaction of underlying agency and structural factors must be understood. This conceptualization of the agent–structure relationship assists in our understanding of individual's fate and experiences in society, (Angus, Miller, Pulfer, & McKeever, 2006) as it reveals influences that are socially created in which the individual may or may not be aware of. Some of these structures such as financial burden and lack of social support can predispose the individual to a great likelihood of poor health behaviours (Clark et al., 2007). A person's successes or failures may have little to do with their own reasons and intentions, but may have everything to do with the structure–agent interaction over which they have limited control or awareness (Sayer, 2000). Therefore, in order for health care professionals to understand health behaviours and decisions, both the person and the context must be explored (Sayer, 2000) as health outcomes and behaviour may be changed by interactions between the person and the programme-related social–cultural and organizational factors (Clark et al., 2007). In summary, critical realism is a meta-theory that was founded on the existence of an objective reality, but posits that this is always distinct from science, human perspectives, and beliefs. Events and outcomes in this reality are generated by real underlying powers, the existence and influence of which may not be known to humans. These events occur in open systems and are patterned, because they are caused by a complex interplay of underlying individual and structural factors.

We now move to use critical realism as a conceptual lens through which to interpret the strengths and weaknesses of existing understanding on dialysis decision-making. Critical realism has been used in this way previously to critique health research using methods such as randomized trials (Connelly, 2004) and meta-analysis (Clark et al., 2007), and substantively in research on health inequalities (Wainwright, 1997) and health services (Angus et al., 2006; Clark et al., 2007). While the discussion focuses on dialysis decision-making, implications for understanding decision-making more generally will be noted.

Research on Factors Associated with Home-Dialysis Decision-Making

Research on Links Between Knowledge and Education

Education for patients and their significant others about options for dialysis modality and the self-care implications arising from the different options are key components of CKD programmes. There is some evidence that patients do not receive the right kind of support. For example, people who do not choose a home-based and/or in-hospital self-care hemodialysis often have poor understanding of the various home and self-care techniques (McLaughlin, Manns, Mortis, Hons, & Taub, 2003; Mehrotra et al., 2005). They believe that they should not dialyse without adequate supervision and had a fear for needles and of being unsuccessful as well as a lack of space in the home (McLaughlin et al., 2003). These findings suggest that better education for patients and their significant others, as suggested by current guidelines, should promote increased use of home-dialysis.

Indeed, research on education programmes indicates that patient knowledge of the various methods of dialysis influences the modality they select. Education regarding dialysis modalities has been found to improve patient knowledge (Gomez et al., 1999; Klang et al., 1999), heighten patients' intentions to commence a self-care and home-dialysis modality (Manns et al., 2005), and increase the proportion of patients who actually start a self-care and home modality (Goovaerts et al., 2005; Pagels et al., 2008). In further examination of these studies, the format and content of the education programmes delivered varied. In this context, the educational programme is determined, albeit simplistically, to be the sole catalyst for the decision-making. The intent of these studies was not to explore how factors such as socio-demographic, culture, life experiences, agency, and structure influence modality selection. It cannot be denied that knowledge is an important factor in dialysis decision-making. However, it is plausible that knowledge of dialysis modalities contributes to home-dialysis selection but it is not, as these findings would suggest, the principal and exclusive determinant of dialysis choice.

These prevailing attitudes assume that in dialysis modality selection, it is the educational programme that has the exclusive or dominant power to influence the outcome regardless of the characteristics of either the individual or any elements of context. Critical realism would caution against such a narrow range of factors being seen as being important, because this simplifies decision-making too much (Clark et al., 2007). It assumes a 'rational-choices' model of decision-making that negates the influence on decision-making of other individual and contextual factors including, past patient experiences, and the values and beliefs of the individual, the influence of caregivers, family, and environmental context.

Critical realists would also question the underlying successionist view of causation that underpins the reasoning that 'education' leads to 'knowledge' that leads to 'empowerment'. The successionist view interprets causation as a series of chain-like events with causation being attributed to factors occurring in sequence with sufficient frequency. This approach fails, in critical realist terms, to understand how the intervention affects knowledge and empowerment – that is, the mechanism of the education intervention (Pawson & Tilley, 1997). More fundamentally, critical realists view causation as 'generative' – with events being caused only when numerous factors come together in the right combinations to generate a particular outcome of interest (Bryne, 2004). Using the previous analogy of lighting a candle, to the successionist, it may appear like a simple chain of causality (flame + wick = fire); a generative perspective would counter that fire will only occur when a range of localized and environmental factors are in place to generate the flame, such as the presence of oxygen, the correct chemical composition of the wick, the absence of a strong wind, the dryness of the wick, and so on. Dialysis selection is also most likely not generated by a single factor but rather by a myriad of factors internal and external to the individual. Current research does not examine the nature and influence of these factors, such as why education may cause changes in decision-making, how individuals experience CKD education programmes, or how the dimensions of the education programmes appear to generate change.

Research into Factors Correlated with Modality Selection

With this generative perspective in mind, what indications are there that other factors may be important? Research has examined factors correlated with modality selection or predictors of modality selection, which has influenced our current practices. This research tends to use methods of multivariate analysis of retrospective data to identify the association of a relatively small number of a priori demographic variables with decision-making outcomes. For example, older age is frequently associated with greater likelihood of in-hospital hemodialysis utilization (Goovaerts et al., 2005; Jager, Korevaar, Dekker, Krediet, & Boeschoten, 2004; Stack, 2002). Individuals who select PD are more likely to be employed (Stack, 2002), married or living with someone (Little, Irwin, Marshall, Rayner, & Smith, 2001; Stack, 2002) educated, have fewer co-morbidities, more frequent and earlier nephrological care (Stack, 2002), greater social support (Jager et al., 2004), and live increased distances from the dialysis center (Little et al., 2001).

These findings suggest that a variety of other factors may also influence modality decision-making. In critical realist terms, as these studies focus on predictors, they are best understood as providing clues to the mechanisms that causally affect decision-making (Ron, 2002). As predictors are not the same as causal factors, although the findings speak to trends emerging from the influence of underlying causal factors, the findings do not themselves reveal these causal factors. For example, while older adults may be less likely to select home-dialysis, it is not old age itself that determines causally the decision outcome, but factors associated with being older. These may include how health systems and professionals treat older adults or a myriad of different social and personal factors associated with old age that may affect the need for social support, ability to travel, and other life commitments. Hence, studies that focus on the predictive power of a single non-modifiable or similar demographic factors (such as age, sex, co-morbid conditions, medical diagnosis), in critical realist terms, do not adequately explain deeper causal reasons why any such associations exist. These studies do not enhance our understanding of the complexity, interactions, and processes that explain why age, sex, or other factors influence selection (Clark, Sharp, & MacIntyre, 2002). The results of the studies identify predictors of home-dialysis selection using multivariate analysis techniques that can be useful, applied to screening criteria for potential home-dialysis candidates, and can identify those at risk such as an elderly person living alone on home-dialysis. However, these methods do not explore what is causing the trends and under what circumstances these influence outcomes. Hence, from a critical realist perspective, while multivariate analysis can provide clues as to possible underlying factors that causally affect decision-making, when conducted in isolation of a theoretical base, it is insufficient to provide an understanding what individual and contextual factors influence decision-making.

Individuals' Accounts of Modality Selection: The Qualitative Perspective

Our understanding in the area of CKD decision-making has also been impacted by research into the experience of dialysis selection and use of health services (Morton, Tong, Howard, Snelling, & Webster, 2010) achieved by qualitative research. Indeed, a number of qualitative studies have increased the understanding of how the individual approaches and experiences dialysis selection. When individuals choose a modality, they evaluate the perceived negative aspects and weigh the benefits of the various modalities to maintain some 'normalcy', or minimize the disruption of dialysis (Lee, Gudex, Povlsen, Bonnevie, & Nielsen, 2008; Morton et al., 2010; Tong et al., 2009; Visser et al., 2009). However, family, social support, impact on employment, the quality and timing of information, and their physician's opinion also influences their decision-making (Landreneau & Ward-Smith, 2007; Lee et al., 2008; Lin, Lee, & Hicks, 2005; Tong et al., 2009; Tweed & Ceaser, 2005). The individuals also value autonomy and control when making their modality decision, flexibility of schedule and convenience of home-dialysis (Tong et al., 2009; Visser et al., 2009).

Although these studies contribute to our understanding of individuals' perception, a critical realist would approach these findings cautiously as the phenomena are only viewed through the perspective of the individual (Sayer, 2000). Critical realists believe this does not address the risk of the individual being only aware of a portion of their reality (Connelly, 2001) or being wrong as reality also exists beyond what people think, reveal, and are aware of (Williams, 2003). While human perspectives have subjective importance (and are thus amenable and useful to research), these perspectives cannot be equated with and do not determine objective reality. Rather, human perspectives are always a fallible representation of objective reality. For example, if an individual with CKD states they don't want home-dialysis because there is nothing wrong with their kidney function, some variations of qualitative research would suggest that this reality should be accepted as true. However, using a critical realist framework, other data, such as blood work results, symptoms reports, urinalysis, would suggest that objectively their kidney is diseased. While the patients' perceptions have subjective importance, in this situation, it is deemed by others in the likelihood not to be the most plausible explanation of events. In addition, there is a risk of over-privileging individual accounts on the existence and effects of structural phenomena that are either situated ‘upstream’ in terms of causative effects or particularly subtle and insidious in terms of effects. For example, the accounts voiced in a qualitative study exploring patient perceptions of a CKD education programme may not be aware that adverse socioeconomic circumstances are likely to impinge on their capacity and willingness to make health decisions (Blaxter, 1997). Qualitative methods used by critical realists tend to include multiple sources such as the use of focus groups with patients and healthcare providers to uncover the tensions between respecting and recognizing the usefulness of patient perspectives and over-privileging these perspectives in terms of objective reality to understand the influence of socio-structural factors. This approach using critical realism addresses epistemological flaws of what can be known of phenomena that can exist independent of our knowledge. Bhaskar (1989) refers to this as the epistemic fallacy in the context of stratified ontology – the empirical, actual, and real.

Re-Conceptualizing Dialysis Decision-Making: Recognizing Agency and Structure in the Real World

Existing qualitative and quantitative research provides some knowledge regarding the determinants of dialysis modality, but does not sufficiently identify the deeper causal factors influencing decision-making. Drawing on both subjective and objective data, critical realism can be used as a viable framework to examine and contribute to the body of knowledge of these causal determinants. What would a critical realist approach intended to examine dialysis modality decision-making look like?

A critical realist approach to decision-making about dialysis modality, drawing on the tenets outlined, would seek to understand the complex and deep interplay of agency and structural factors influencing dialysis selection. Decision-making would then be viewed as an expression of human agency but one that is always influenced by structural factors. Hence, structure and agency:

> **…**are intertwined: individuals always act in some social context. Study of the social world, therefore, requires a methodological approach able to grasp analytically the distinction between agency and structure…(this) makes possible the study of how prior structures condition agents, and how agency modifies structures, although structures may resist reformation (Carter, 2003, p. 150).

This influences critical realism research methods by rejecting causation from a small number of factors linked to outcomes in preference for a deeper understanding of how a number of factors combine to generate differences.

Contextual and service-related factors influence health behaviours. Health programmes should be viewed as socially and organizationally embedded multi-layered entities. In this context, CKD educational programmes have organizational dimensions that affect the content and are generally conducted in healthcare centers inherent with social structures, norms, values, and interrelationships of this environment, which influence the success of the programme (Pawson & Tilley, 1997). When outcomes are achieved as a result of such programmes, the power of this change is often attributed less to the individual and their context, but to the programme (Clark et al., 2007). The reverse also holds. For example, if people are not prepared for dialysis or are not able to make modality decisions and the incidence of new patients choosing home-dialysis is low, it is concluded that there must be errors with health programmes. Patients who attend these programmes come with a history of past experiences and social contexts – not a 'blank slate' – which impacts on their decisions and behaviours. Just as patients who attend these programmes exist with wider societal and cultural influences, so do the healthcare providers, programmes, and healthcare systems. For example, administrative decisions may be under pressure to reach 'acceptable' numbers of patients on home-dialysis. All of these stratified levels, patterns, and systems interact in a complex manner to affect health decisions. Healthcare professionals may, albeit hidden, interject their own biases as to which modality is best suited for a patient or what would they, as individuals, choose if faced with the same situation. The context and structure of the individual developing the CKD programmes and those allocating resources, both human and financial to CKD programmes, may have an influence on the service usage of home-dialysis.

Using critical realism as a worldview to understand, CKD decision-making has clear implications for how complex health decisions are conceptualized and explained using research methodology. To summarize, CKD decision-making research conducted in the tradition of critical realism provides an explanation of the causal mechanisms that contribute to the decision-making process, irrespective of the individual's perception of it, acknowledging the underlying social factors and the context in which decisions are made as well as agency and structure in an open system.

Conclusion

Herein, we have thoroughly critiqued the prevailing attitudes and understanding of home-dialysis modality decision-making and the ontological and epistemological assumptions embedded in them. In doing so, we have articulated the need for a new approach using critical realism to theorize and research CKD decision-making for health services utilization. CKD educational programmes are very important to home-dialysis selection and should continue. However, they only partially impact on this decision-making process. Predictors of home-dialysis selection provide us with an understanding of who chooses the various modalities, yet lack in elucidation of why and under what circumstances. Studies limited to the subjective perspective only may ignore the objective reality and the influence of structural forces on decision-making. A re-conceptualization of CKD decision-making using critical realism is warranted as an alternative to current ways of knowing. Critical realism is well suited in examining the deeper mechanisms and wider determinants of CKD dialysis modality decision-making and can make a significant contribution to nursing and health services research in this area.

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Chapter 2: The Research on Dialysis Modality Decision-Making

Review of the Literature

The papers in this thesis contain similar yet distinct literature reviews of the quantitative literature on CKD modality decision-making. In summary, the quantitative research has examined factors associated with home-dialysis service usage which includes age, co-morbid conditions, living arrangements, employed status, race, functional status, levels of education, modality awareness, dialysis environment, interest to perform home-dialysis and self-management of CKD. The review of the quantitative research provides us with information regarding who is likely to select/use home-dialysis and possibly why however this research limits our understanding of the context of these decisions and the processes involved in the decision-making. The particular paper in this chapter is a publication of a systematic review and meta-synthesis of qualitative research on dialysis modality decision-making.[2] This knowledge synthesis was undertaken to understand how the qualitative studies on dialysis modality decision-making relate to each other, reveal gaps in this literature, make recommendations for future research and more generalized implications for practice.

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[2] A version of this chapter has been published. Harwood, L. & Clark, A.M. (2012). Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies. *International Journal of Nursing Studies, 50*, 109-120.

Knowledge Synthesis

In the current environment of evidence-based decision-making the method of knowledge synthesis is increasingly important in health care (Tricco, Tetzlaff, & Moher, 2011), nursing practice (Thorne, 2009) and policy (Britten et al., 2002). The findings from individual studies within the context of the global evidence bridges the gap between research and decision-making based on more generalized research findings (Tricco et al., 2011). The method of meta-ethnography was chosen because it is inductive, interpretive, the studies are commensurable and the meaning of the individual studies remain in the final analysis (Britten et al., 2002). Permission to use this publication in this thesis has been obtained (see Appendix C).

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Review

Understanding pre-dialysis modality decision-making: A meta-synthesis of qualitative studies

Lori Harwood [a,b,c,*], Alexander M. Clark [d]

[a] *London Health Sciences Centre, Canada*
[b] *University of Alberta, Canada*
[c] *University of Western Ontario, Canada*
[d] *Faculty of Nursing, University of Alberta, Canada*

Abstract

Objectives: This systematic review examined how people with chronic kidney disease make decisions about the type of dialysis modality to use. In particular, meta-synthesis was used to understand the process of patient decision-making and how aspects of context influenced these decisions. This topic is important because home-dialysis has economic and quality of life advantages for patients and society but is underutilized. To increase the use of home-based dialysis services a greater understanding is needed of how patients make dialysis modality decisions.

Design: Systematic review methods incorporating meta-synthesis were used.

Data sources: Seven databases were used for the search. Eligible studies were published qualitative research studies containing extractable data on decision-making about dialysis modality selection generated from patients with chronic kidney disease.

Review methods: A systematic review was conducted and the data were analyzed using meta-synthesis (also known as meta-ethnography) for qualitative research.

Results: Sixteen studies were included (410 patients at various stages of chronic kidney disease). Across all the studies, decisions drew on patients' values and in the context of their situation and life. Common elements across patients' decisions were: (1) the illusion of choice – a matter of life or death, (2) minimization of the intrusiveness of dialysis on quality of life, autonomy, values, sense of self, and (3) decision-making in the context of wider knowledge and support.

Conclusions: Modality decisions are highly personal and strongly influenced by patient and family values, the context of their life, and a desire for minimal intrusiveness. There is a clear need for planned and timely discussions about modalities in which home-based dialysis is presented as a viable option. Professional support should focus on patient and family preparation, knowledge of different modalities and the lifestyle implications of different modality choices.

What is already known about the topic?

- Home-dialysis has patient and economic benefits but in many high income countries it is underutilized.
- Education and awareness of home-dialysis modalities can increase home-based service usage but decisions are poorly understood.

What this paper adds.

- Dialysis modality decision-making is very personal and is strongly influenced by patient and family values, the context of their life, and a desire for minimal intrusiveness.
- Value responsive intervention may be effective in assisting individuals with dialysis modality decision-making.

Introduction

Chronic kidney disease (CKD) progressing to dialysis affects 386 people per million in low, middle and high income countries worldwide (USRDS, 2010). Pharmacological management is only effective for the early stages of CKD, for long term survival patients in high-income countries are offered transplant or dialysis. However, transplantation can improve life expectancy and quality (Johansen, 2011), eligibility for this surgery is constrained by the patient's health status and the low availability of donor kidneys (Courtney & Maxwell, 2009). As dialysis has few absolute contraindications, it is the most common and vital means to treat people with CKD (Courtney & Maxwell, 2009).

People with CKD in high income countries often have to make decisions about the location of dialysis. While hemodialysis is most often performed in-center, most often at a hospital, it can also be done at home; conversely peritoneal dialysis is almost exclusively done in the home. Home-dialysis requires the patient and/or family to have the cognitive ability to perform dialysis, support available and to have adequate housing requirements such as space for supplies and in the case of hemodialysis an adequate supply of potable water (Harwood & Leitch, 2006). There is consensus in clinical practice guidelines from the United

States of America, Canada, Australia, and Europe that individuals with advanced CKD who need renal replacement therapy should be offered different dialysis modalities and be given timely education to support them to choose the modality that best reflects their circumstances, needs and values (Covic et al., 2010; Kelly, Stanley, & Harris, 2005; Levin et al., 2008; NKF, 2006).

Compared to hospital based dialysis, home-based dialysis offers financial advantages (Mowatt et al., 2003) and for many patients improved quality of life due to the reduced need to travel for dialysis, higher autonomy and greater flexibility to fit around the recipient's occupational and social roles (Harwood & Leitch, 2006). Home-dialysis services are now widely available in high income countries including Canada, the United States, France, Spain, Italy, the United Kingdom, Sweden, Netherlands and Australia (USRDS, 2007). Yet, despite this commonality and the potential benefits, patient uptake of home-based dialysis is very low (Blake, 2000; Jiwakanon, Chiu, Kalantar-Zadeh, & Mehrotra, 2010; Mendelssohn et al., 2001) and in-center hemodialysis remains the most common type of dialysis (USRDS, 2010). For example, in the United States, the prevalence of peritoneal dialysis is declining (7%) while, the prevalence of home hemodialysis in eligible patients remains at 1% (USRDS, 2010). Australia and New Zealand have the highest prevalence of home hemodialysis with 9.4% and 15.6% prevalence among eligible patients respectively (USRDS, 2010). This has little do to with the higher prevalence of rural patients in these countries – in the

United States people in remote or rural areas are less likely to be offered home-based dialysis (O'Hare et al., 2006).

Utilization rates may relate to wider health system issues and may not reflect choice. However, until recently, little was known about why patients do and do not select home-based dialysis. Regression analyses have identified that patient knowledge, educational support and sociodemographics can predict modality choice. Lack of uptake of home-based dialysis is predicted by poor knowledge of dialysis, how to dialyze effectively (NKF, 2006; Kelly et al., 2005; Levin et al., 2008) and of the various home and self-care techniques (McLaughlin et al., 2003; Mehrotra et al., 2005). Conversely, better knowledge of dialysis modalities predicts increased uptake of home-based modalities (Gomez et al., 1999; Goovaerts et al., 2005; Klang et al., 1999; Manns et al., 2005; Marron et al., 2006; McLaughlin et al., 2003; Pagels et al., 2008; Prichard, 1996; Stack, 2002). Beyond knowledge, modality selection is also predicted by age, with older patients being less likely to select home-based dialysis (Goovaerts et al., 2005; Jager et al., 2004; Stack, 2002). Peritoneal dialysis is also more common in those who are employed, have higher education, fewer co-morbidities, early and frequent nephrologic care, are married or cohabitating (Little et al., 2001; Stack, 2002), have greater social support (Jager et al., 2004) and live further from dialysis centers (Little et al., 2001).

Knowledge of what predicts modality selection can be used to assess the likelihood of a patient selecting a particular modality. However, identifying the main predictors of modality selection conveys little of the personal experiences of the patient decision-making processes for modality selection and how these processes are influenced by other factors, including the patient's context. Understanding these key processes and factors is important because it can be used to develop interventions to increase uptake of home-based dialysis. Qualitative research is particularly helpful in proving a deeper understanding of the personal experience and the processes involved.

Two systematic reviews have been conducted examining the factors influencing decision-making for all forms of renal replacement therapies. Morton et al., (2010a), conducted a systematic review of qualitative research on all forms of renal replacement therapies. The objective of this review, using an aggregative design, was to synthesize the views of patients and caregivers in decision-making regarding CKD treatments including dialysis and transplantation. A second review has been conducted by Murray et al., (2009) with the aim of identifying factors influencing patient involvement in CKD decision-making and effective interventions to support this decision-making. This review included quantitative studies, and topics of conservative management and withdrawing from dialysis (Murray et al., 2009). Although these earlier reviews provide valuable information we feel there is merit examining the qualitative literature with an interpretive synthesis specific to dialysis modality decision-making.

From the authors clinical experience we question that decision-making for dialysis is different than the choice for transplantation and conservative management. Given the long waiting times for organs many patients who are eligible for transplantation (excluding pre-emptive) must first make a modality decision. In addition very little information is known about the uptake of conservative management (Morton, Turner, Howard, Snelling, & Webster, 2012). One Australian study documented one in seven (14%) people with CKD selected conservative management (Morton et al., 2012). However, a Canadian study demonstrated a very high (61%) percentage of people on dialysis regretted their decision to start on dialysis, stating it was their physician's decision (52%) with 90% of dialysis patients never having discussed advanced are planning with their nephrologists (Davison, 2010). This suggests that the frequency of conservative management may be less than documented by Morton et al., (2012). Discussions regarding conservative management are likely infrequent for people with CKD and practice variability exists in who is/is not offered dialysis.

Our aim in this review was to focus on the processes of dialysis modality decision-making in order to gain insight into home-dialysis decision making. The authors purposefully narrowed the focus of this systemic review from conservative management and transplant to dialysis modality. From a familiarity of the literature we also believed a systematic review on qualitative research with home-dialysis decision-making exclusively would be too narrow of a focus limiting the review to only a few studies. This review is the first to focus on dialysis modality decision-making and report the findings on how people with CKD make treatment decisions about the type of dialysis modality to use. The purpose of our review was to examine the patterns and themes of modality decision-making and synthesize these findings using meta-ethnography into more generalize knowledge claims which clinicians may better apply to CKD interventions and potentially impact on home-dialysis uptake.

Methods

A systematic review of qualitative studies was conducted using meta-ethnography to synthesize studies with an inductive and interpretive analysis (Noblit & Hare, 1988). The result of the synthesis is the translation of one study into another allowing for transferring ideas, concepts and metaphors across the reviewed studies (Britten et al., 2002). This method preserves the meaning in the text in the final synthesis as both the interpretations and explanations in the original studies are considered data (Britten et al., 2002). This approach has been used successfully to understand complex decisions related to health care (Britten et al., 2002).

Protocol and Eligibility Criteria

The review protocol was developed and agreed upon by the authors. The population in the qualitative studies selected for review was people aged 18 years of age or more with CKD. Studies that were neither qualitative nor pertaining directly to dialysis modality decision-making were excluded. If the samples also included people with transplant, caregivers or conservative management the studies were included in the review. However, if the purpose of focus of the study was exclusively on caregivers, transplantation or conservative management the study was excluded. The qualitative studies had to include face to-face data collection methods and have exemplars of texts in the publications. Studies were also excluded if the main method was quantitative such as those that included one supplementary open-ended question at the end of the study or structured surveys. Non-English publications and non-published literature were excluded. Mixed method studies were included if they had a specific qualitative component. The final protocol was shared with a health sciences librarian and search terms were developed in collaboration.

Information Sources and Search

The search was conducted in collaboration with a health sciences librarian and completed until September 30, 2009. Studies were identified by searching electronic databases and scanning reference lists of pertinent articles. Databases included were: Medline (1950–2009), Embase (1950–2009), CINAHL (1937–

2009), Web of Science (1956–2009) and Scopus (1960–2009). The Joanna Briggs Library of Systematic Reviews and the Cochrane database were also searched. Tables of contents for ‘Hemodialysis International’ were hand searched from the years 2003 to 2009. The full electronic search strategy terms were developed to identify qualitative studies (see Table 2.1). A focused updated search was performed from (September 30, 2009 to January 30, 2012) prior to submission of this paper as well as a supplemental search using PsycINFO database which was missed on the original search. All studies found outside of the original search were held to the same eligibility criteria and synthesis methods.

Study Selection and Data Collection

Assessments of eligibility were performed by reviewing the title and abstract of all citations independently in a standardized manner the authors. A data extraction form was developed by the authors based on an extraction form which had been previously successfully used by one of the authors (AC). The form included details regarding the study title and complete reference, main focus, country, population studied, type of study, sample (age, sex), type of CKD, qualitative approach, data collection methods and findings. The full text of all relevant articles was reviewed by one researcher (LH) using the standard data extraction form and checked for accuracy by AC. Study quality was determined based on the Critical Appraisal Skills Programme (CASP, 2007) tool of quality appraisal for qualitative research. Using the tool, the quality of each study was categorized as: low, moderate or high and the main reasons for categorization were recorded. A quality assessment for each paper was performed by the primary reviewer (LH) and confirmed by the secondary reviewer (AC). All discrepancies in this process were be resolved by consensus. At this stage in the process the authors did not exclude those studies with low quality.

Data Analysis

Meta-ethnography (Noblit & Hare, 1988) was the synthesis approach used. This approach involved the primary reviewer (LH) firstly reading each selected study to identify the main concepts in studies related to processes of modality decision-making. The details of each study in terms of setting and methodological quality were also extracted and taken into account at this stage. After this, stage two (2nd order coding) was conducted which involves the researchers examining emerging themes and relationships across the studies. Common or reoccurring concepts were identified. The main concepts identified were then used to re-review all the themes identified across the papers. The authors discussed the preliminary findings at each of the three stages and the supporting data. These lattermost findings are the results of this synthesis.

Results

Study Selection

The search yielded 989 potentially relevant studies for screening (Fig. 1). Duplicates (n = 302) and non-English (n = 64) articles were the first to be excluded. A more detailed evaluation was then conducted examining the entire abstract. The majority of the remaining studies (n = 623) were excluded for having unsuitable topic/population (n=577) or because they were not qualitative (n = 30). From 16 suitable studies, two further studies were excluded: one due to lack of relevant findings pertaining to the subject area (Wilkinson, 1998) and the second because the study contained a secondary analysis (Breckenridge, 1997a). Focused searches conducted to include eligible publications after the original search resulted in the addition of two studies (Morton et al., 2010b; Sondrup, Copland, Black, & Trask, 2011) with sixteen studies in total included in the meta-synthesis.

Characteristics of Included Studies

All studies (total n = 410 participants) included in the review (see Table 2.2) were published in English and between the years 1996–2011. The overall quality of the studies was moderate; two studies were rated low quality, ten were rated as medium and four were rated as high quality. Two of the studies were mixed methods (Courts, 2000; Jennette, Derebail, Baldwin, & Cameron, 2009). The studies were conducted in a variety of countries such as United States (n = 8), Australia (n = 2), United Kingdom (n = 2), and Canada, Denmark, Netherlands, and Taiwan. The most frequently reported qualitative method was interpretive descriptive (n = 8), grounded theory (n = 4), phenomenology (n = 3) and ethnography (n = 1).

Sample

The studies included samples of patients (n = 12) and their families (n = 3) as well as one study where health care professionals were also included. The total sample included 477 persons, with 410 patients, 29 family members and 38 health care providers. The samples were varied and included: people with CKD not on dialysis (Andrew, 2001; Tweed & Ceaser, 2005), retrospective to starting dialysis (Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kaufman, Shim & Russ, 2006; Kelly-Powell, 1997; Landreneau & Ward-Smith, 2006, 2007; Lin et al., 2005; Morton et al., 2010b; Sondrup, Copland, Black & Trask, 2011; Whittaker & Albee, 1996), and both on dialysis and not yet on dialysis (Lee, et al., 2008; Tong et al., 2009; Visser et al., 2009). Four of the above mentioned studies also included renal transplant recipients (Jennette et al., 2009; Landreneau & Ward-Smith, 2006; Morton et al., 2010b; Tong et al., 2009). The mean age of the sample was reported in eight studies and this result varied from 50.7 to 72.6 years. The age range of the sample was reported in ten studies and collectively spanned 20–87 years of age. The sex of the sample was reported in twelve studies; overall the review contained 55% males and 45% females, excluding the sex of the caregivers.

Synthesis of Findings

Across the studies, decisions about dialysis modality were firmly embedded within the context of the patient's life and values. There were three dominant themes (see Table 2.3) present across the studies: (1) the illusion of choice – a matter of life and death, (2) personal factors and the minimization of the intrusiveness of dialysis, and (3) the imperative of knowledge and support for decision-making. A summary of the supporting studies to the concepts is listed (Table 2.4) with specific exemplars of the various themes (Table 2.5).

The illusion of choice – a matter of life or death.

Despite existing guidelines assuming that patients should and do make choices on modality selection, perspectives on decisions varied widely across the studies. Across many studies, patients perceived that they were provided with choice over modality selection (Andrew, 2001; Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kaufman, Shim, & Russ, 2006; Kelly-Powell, 1997; Landreneau & Ward-Smith, 2006; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Visser et al., 2009; Whittaker & Albee, 1996). However, unforeseen medical considerations also forced dialysis choices to be made by the family or physicians at a very late juncture or on a short timescale (Breckenridge, 1997b; Courts, 2000; Kaufman et al., 2006; Landreneau & Ward-Smith, 2006; Lee et al., 2008) for example, ‘‘the doctors pretty much made the decision and my son agreed (Kaufman et al., 2006, p. 181).

Patients viewed choices about commencing dialysis and dialysis modality as being decisions of great magnitude and personal significance. Across many studies, dialysis decisions were perceived as constituting a choice between receiving life saving dialysis or dying (Andrew, 2001; Jennette et al., 2009; Kaufman et al., 2006; Kelly-Powell, 1997; Lin et al., 2005; Tong et al., 2009; Visser et al., 2009). This reduced the sense of ‘real choice’ or the illusion of choice patients perceived, for example, patients expressed ‘‘I had no choice, or I would be dying slowly’’ (Visser et al., 2009, p. 796). Hence, even when a choice was reportedly offered, it could be perceived that there was not a true choice in the situation if the patient wanted to live, ‘‘I have no choice. . .I wanted to live’’ (Kaufman et al., 2006, p. 981).

Unsurprisingly, given this perceived importance, facing and making decisions about dialysis was stressful for patients (Andrew, 2001; Breckenridge, 1997b; Jennette et al., 2009; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Whittaker & Albee, 1996) and was done with considerable reflection on their current life, values and anticipated future life when on dialysis (Andrew, 2001; Jennette et al., 2009; Kaufman et al., 2006; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b; Tong et al., 2009). The patients reported being ‘‘shocked, fearful and bewildered at the prospect of dialysis’’ (Andrew, 2001, p. 73), ‘‘I was so frightened when I was in the ER. I kept thinking what is the treatment all about’’ (Lin et al., 2005, p. 921).

Personal factors and the minimization of the intrusiveness of dialysis.

There was no single ideal or best dialysis modality as the decision was dependent on personal preferences, values and a belief that dialysis should not only prolong life but also allow the patient to have a good quality of life. Hence, minimizing the intrusiveness of dialysis was the central element guiding decisions over preferred modalities and was the theme that most influenced this decision-making. This decision-making was strongly influenced by which type of dialysis patients believed to be least disruptive or intrusive for their quality of life (Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kaufman et al., 2006; Kelly-Powell, 1997; Lin et al., 2005; Morton et al., 2010b; Tong et al., 2009; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996) and maintaining ‘‘normal’’ life routines (Andrew, 2001; Courts, 2000; Jennette et al., 2009; Kelly-Powell, 1997; Lin et al., 2005; Tong et al., 2009; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996). Findings, for example, consistently made reference to the importance of maintaining normalcy and a routine. For example, ‘‘If I can’t have a semblance of a normal life, then why would I want to live’’ (Tweed & Ceaser, 2005, p. 661).

Other factors perceived to affect intrusiveness.

A long travel distance to the dialysis center (Breckenridge, 1997b; Courts, 2000; Morton et al., 2010b; Visser et al., 2009) was a prominent a factor in selecting home-based dialysis over hospital-based dialysis. Patients consistently sought to maintain autonomy (Andrew, 2001; Courts, 2000; Jennette et al., 2009; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996) and sought to select a modality that accorded with their values (Courts, 2000; Kelly-Powell, 1997; Lin et al., 2005; Morton et al., 2010b; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996) and identity (Courts, 2000; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996). The patients' choices reflected their values and beliefs and were informed by personal experiences (Andrew, 2001; Kelly-Powell, 1997; Lin et al., 2005; Tong et al., 2009; Tweed & Ceaser, 2005; Whittaker & Albee, 1996). Many drew on past experiences of themselves and their family members to make decisions regarding modality (Andrew, 2001; Breckenridge, 1997b; Kelly-Powell, 1997; Lin et al., 2005; Morton et al., 2010b; Tweed & Ceaser, 2005; Visser et al., 2009; Whittaker & Albee, 1996) such as ‘‘I decided to take it (dialysis) with the machine because I already knew what it was like’’ (Whittaker & Albee, 1996, p. 373). Self care was also valued for example, ‘‘I think I like the idea of caring for myself rather than having someone else totally in control of whats happening to me’’ (Whittaker & Albee, 1996, p. 373). The individuals who were already on dialysis and were interviewed retrospectively about their choice made comments regarding how dialysis had changed their sense of identity.

Knowledge and social support: essential and context bound.

In addition to personal values, preferences and elements of identity, knowledge of the various modalities was used to assess how particular dialysis modalities would impact their future life. Patients derived knowledge about dialysis mostly from family, health care professionals, and other patients on dialysis (Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kaufman et al., 2006; Kelly-Powell, 1997; Landreneau & Ward-Smith, 2007; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Tweed & Ceaser, 2005; Whittaker & Albee, 1996). Acquiring more knowledge about dialysis was seen by patients as being essential to decrease misunderstandings. For example, patients wanted to hear all the options available to them: ‘‘When I went on dialysis, I was automatically put on hemodialysis. I was not even told about CAPD. . .if I had been told about something like that, I would have wanted to go with it’’ (Breckenridge, 1997b, p. 317). In addition to dialysis options other information, consistently deemed important, were the requirements of each modality such as frequency, location, risks, use of needles, who performs the dialysis and time requirements (Andrew, 2001; Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kelly-Powell, 1997; Landreneau & Ward-Smith, 2006, 2007; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b; Tweed & Ceaser, 2005; Whittaker & Albee, 1996). Acceptance of the medical advice/information was aided by a trusting relationship with the health care providers which facilitated the acceptance of the medical advice and support (Landreneau & Ward-Smith, 2007; Morton et al., 2010b; Tweed and Ceaser, 2005; Whittaker & Albee, 1996).

Across many studies, education was important not only for the patient but also for the family because decision-making was collaborative (Andrew, 2001; Breckenridge, 1997b; Courts, 2000; Kaufman et al., 2006; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Whittaker & Albee, 1996). When making decisions regarding dialysis modality the individuals also relied on information from lay persons and social acquaintances such as, ‘‘My mother asked a 70-year old neighbor about the treatment. She was told that there was nothing to fear. Gradually I accept it’’ (Lin et al., 2005, p. 924).

Social support was an important factor that affected decision-making (Andrew, 2001; Courts, 2000; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Tweed & Ceaser, 2005; Whittaker & Albee, 1996) particularly from their families for example ‘‘My nephew, also on CAPD, told me about CAPD, which I am now on’’ (Breckenridge, 1997b, p. 318). Patients relied on their families for support however, they were mindful that their choice about dialysis would also affect their families and possibly the levels of support they would require (Andrew, 2001; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009). For those already on dialysis, dialysis was seen to affect the whole family (Courts, 2000).

Discussion

This review, the first qualitative systematic review to focus specifically on dialysis decision-making, identified that decisions about dialysis are made in the context of the patient’s life, family and values. Despite medical reasons for ineligibility of some modalities patients who were offered a choice often perceived that they were not provided with a truly informed choice over modality selection despite this being a decision viewed by them as stressful, important as it was a means to survival. The main priorities guiding decision-making were the importance of minimizing the intrusiveness of dialysis on daily life and selecting a modality that accorded with their values and identity. Although home-dialysis has many benefits there was no one single inherently superior modality type as decision-making was very personalized. Decisions were made individually but with reference to wider social factors, including other patients and family members. These findings demonstrate that people with CKD understand dialysis is a life sustaining therapy, require information regarding the options in order to make an informed personal choice; but that these choices are influences beyond health care professionals advice and support, including peers, family and friends with quality of life concerns.

In this systematic review no studies were published before the year 1996. This is likely reflective of the relatively recent emphasis on CKD prior to dialysis. Only two (Andrew, 2001; Tweed & Ceaser, 2005) of the samples in the studies were exclusively in the active stage of modality decision-making and prospective to dialysis. None of the studies with a sample in the CKD stage not on dialysis focused on home-dialysis decision-making. Given the complexity in this decision-making process further qualitative studies are needed during the CKD stage when active decision-making occurs to more fully understand the nuances specific to home-dialysis.

These findings provide further research evidence for clinical practice guidelines (NKF, 2006; Kelly et al., 2005; Levin et al., 2008) and the new U.S. CKD Medicare initiative that policy, programs, and health services be designed to support informed patient choices about dialysis modality without undue coercion and based on comprehensive information. These services should include people with CKD and their caregivers and respond to patients' knowledge needs, values and preferences and address the advantages and disadvantages of each modality yet, acknowledge the patient's lifestyle, values and desire for minimal disruption. Opportunities to discuss the dialysis experience with people already on dialysis also is important in modality decision-making (Winterbottom, Bekker, Conner, & Mooney, 2012) and consideration given to providing these peer educational services is needed.

Research on dialysis modality education programs indicates that patient knowledge of the various dialysis modalities influences the type of dialysis they select. Education regarding dialysis modalities improves patient knowledge

(Gomez et al., 1999; Klang et al., 1999), increases the intention (Manns et al., 2005) and likelihood of starting on a self-care or home modality (Goovaerts et al., 2005; Pagels et al., 2008). In the setting of early nephrologic care and planned dialysis starts it is the responsibility of health professionals to elicit patient and family values and beliefs in the context of dialysis modality decision-making in shared decision-making models. When offering any treatments or options to patients, there is a persistent risk for 'framing' problems to occur. This is in regards to how the options are constructed and delivered (i.e. framed) to patients. This process is often neglected and patients may not be offered a range of treatment options (Wirtz, Cribb, & Barber, 2006).

The format and content of the education programs reported in these studies varied greatly. This systematic review suggests education is necessary but also insufficient for decision-making. Our findings demonstrate modality decision-making is complex, value laden and contextually bound. Health care professionals may not be aware of the level of education, values, and goals of the patient and family therefore population based interventions may be unsuccessful. Current systematic review and meta-analysis level of evidence on the effectiveness of value based decision aids shows promise as demonstrated in other populations that these aids can significantly improve patient knowledge, lower decisional conflict regarding feeling uninformed or unclear about personal values and reduce the proportion of individuals who are undecided or passive in decision-making (O’Connor et al., 2009; O’Conner et al., 1999). Value based care has recently been recommended for CKD decisions in nursing clinical practice guidelines (RNAO, 2009). Unfortunately, no specific value based decision support intervention exists for people with CKD (Loiselle, O'Connor, & Mechaud, 2011). The implementation of value based interventions with CKD decision-making and the effect it will have on home-dialysis decision-making is a growing area of practice and research.

Two other systematic reviews have been conducted on similar topics: CKD decision-making including transplantation and withdraw/with-holding of dialysis decisions (Morton et al., 2010a; Murray et al., 2009). Similarities are evident between dialysis decisions and decisions for other renal replacement therapies which were explored in these reviews. For example concepts such as confronting mortality, a perceived lack of choice, the importance of weighing alternatives (Morton et al., 2010a) and the high importance given to information and the magnitude of the decision (Murray et al., 2009) were common. This suggests that similar weaknesses in health care practices exist in other decisions related to CKD. CKD health care teams providing patient education and support would benefit from additional training around communication and incorporation of patient values in decision-making. These results also suggest that more commonalities than differences exist than we had anticipated in the decision-making processes for CKD treatments. The processes of renal replacement therapy decision-making are similar and likely transferable to other health decisions which are contextually based, life sustaining and reflective of rational decision-making theory.

The current hegemony of modality selection is based upon choice being the primary determinant of modality selection (Jassal, Krishna, Mallick, & Mendelssohn, 2002; Jung, Blake, Mehrotra, & Mendelssohn, 1999; Mendelssohn et al., 2001; Thammer, Hwang, & Fink, 2000). The results of our review and Morton's et al. (2010a) review demonstrates that CKD decision-making is very individual and contextually driven. This represents challenges for health care providers and service delivery as value-based approaches to increase home-dialysis uptake have ethical, economic and policy implications. How do we as health care professionals influence values which are generally firmly embedded? For example if an individual does not value autonomy with their health care it seems unlikely that person would choose a home-based therapy. Interventions could then focus on having people with CKD clarify their values and find a modality which is suited to their lifestyles. In informed decision-making models people are given the autonomy to make their own decisions based on the information that not only health care professionals have provided but also family and peers (Wirtz et al., 2006). This implies that health care professionals must accept the decision and set aside our own personal biases toward which we feel would be the ‘‘best’’ decision for that person. The results of a few studies with people with kidney disease have demonstrated that patient decision-making does not appear to be heavily influenced by factors that health care professionals value such as ‘‘clinical targets’’ (Tong et al., 2009), blood pressure management (Jennette et al., 2009), and optimal vascular access (Xi et al., 2011). In a health care environment with practice variations in offering home-dialysis therapies (Mehrotra et al., 2009; O'Hare et al., 2006), lack of consensus regarding modality eligibility and valuing patient choice, further emphasis is needed on implementation and sustainability at the system level to offer all people with CKD a wide array of renal replacement therapy options at each center along with timely interdiscpinary education and decision support. Health care systems therefore need to have health care policy to enable interdisciplinary teams to provide these services.

Study Limitations

Some limitations were noted with this systematic review. This review relied only on published studies or data and exclusively English publication and thus this bias must be acknowledged. The method of meta-ethnography does not provide guidelines for the quality of studies to be included in the synthesis leaving the judgment to the researchers. In this study two of the studies included were rated as low quality which may have an effect on the results. Overall, age, sex and socio-demographic descriptors were poorly reported in some studies and we did not find any influences of these factors on decision-making despite dialysis modality decision-making being highly personal and contextual. The quality of reporting qualitative findings, in this area, could be improved with the use of consolidated criteria (Greenhalgh, Wong, Westhorp, & Pawson, 2011; Tong et al., 2007). Positively, a wide range of countries and cultural groups were represented in this meta-ethnography. Unlike aggregative qualitative systematic reviews, meta-ethnography is a holistic interpretive method (Noblit & Hare, 1988) which preserves the uniqueness and cultural variations of the various studies by translating the studies into one another to produce synthesis results. Despite the fact that many countries and cultural groups were represented there were commonalities across the cultural groups.

The studies included in our review were both prospective and retrospective relative to dialysis initiation with only two studies conducted prior to initiation of dialysis (Andrew, 2001; Tweed & Ceaser, 2005). Retrospective accounts of dialysis (hospital based and home-based) decision-making may have been influenced by experiences after starting dialysis. Details of time since starting dialysis was not included in all the studies but when it was included the time period ranged zero to 19 years which certainly could have influenced recall of events and the results further emphasizing the need for studies prior to initiating dialysis. Five of the studies (Andrew, 2001; Breckenridge, 1997b; Courts, 2000; Kelly-Powell, 1997; Whittaker & Albee, 1996) were published more than ten years ago and the clinical approach to CKD, burden of kidney disease and beliefs about dialysis service usage has changed in this period which may have influenced the results. As dialysis modality decisions were made in reference to wider social factors further health services research is needed in order to understand the full complexity of this issue.

Conclusions

Decisions about dialysis modality are very significant to patients and their families. They are seen to relate to both, survival and quality of life, are very personal and strongly influenced by the values of patients and their families, the context of their life and an over-riding desire to create minimal disruption to the lives of the patient and their family. These findings emphasize the need for planned and timely discussions about dialysis modality that incorporate patient and caregiver values in decision-making and whereby home-based dialysis is presented as a viable option. Support from health professionals should focus on preparation for decisions, providing knowledge of different modalities and explaining the individual implications of different modality choices on disruption to the patient and their family.

Table 2.1

Search Terms

The following search terms were used: action, analys, audio, audiorecord, category, choice*, choose, chosen, colaizzi, compare, constant, content, continuous ambulatory peritoneal dialysis, continuous renal replacement therapy, critical, decide*, decision making, decision support system, decision*, dialysis, emic, ethnog, ethnol, ethnonurs, etic, experience, extended daily dialysis, field, fieldnote, focus, giorgi, glaser, grounded, groups, hare, heidegger, hemodiafiltration, hemodialysis, hermeneutic, home dialysis, Husserl, interview, kaam, leiniger, lived, manen, maximum, merleau-pont, meta-analy, Meta-ethnog, meta-interpret, meta-narrat, meta-stud, meta-summar, meta-synthes, metaanaly, metaethnog, metainterpre, matanarat, metastud, metasummar, metasynthes, narrative, noblit, non, nonparticipants, note, observ, option*, participant, peritoneal dialysis, phenomenology, prefer*, purpose, qualitative, realism, record, renal, renal replacement therapy, research, ricoer, sampl, select*, semi-structured, semistructured, snowball, spiegelberg, strauss, structured, stud, tape, tape, taperecord, thematic, theor, theoretical, triangulat, unstructured, van, variation, video, videorecord, videotap.

Table 2.2

Summary of Studies in Systematic Review

Authors/Country	Population	Sample Size	Focus/Approach	Conclusions
Andrew, J (Andrew, 2001) United Kingdom	CKD Patients and family	n=10	The pre-dialysis experience. Grounded Theory	Patients and families accepted a different life view necessary to make modality decisions.
Breckenridge, D (Breckenridge, 1997b) United States	HD PD	n=22	Why, how and by whom dialysis was chosen. Grounded Theory	Patients and/or others selected the modality. Modality was selected based on practical or clinical circumstances.
Courts, N.F (Courts, 2000) United States	Home HD Patients and partners	n=14 Patients n=11 Partners	How decisions were made to choose home HD. Interpretive Descriptive	Patient or family made the decision based on distance, lifestyle, negative in-centre experience and control over daily routine.
Jennette, C et al. (Jennette et al., 2009) United States	HD PD Transplant	n=35 n=12 n=1	Barriers to choice for renal replacement therapy. Interpretive Descriptive	Fear was a predominant theme. Distrust of medical system, denial and previous experience with modalities were barriers to care. Pre-dialysis education was needed.
Kaufman, R et al. (Kaufman et al., 2006) United States	HD Patients and HCP*	n=43 Patients n=38 HCP	Old age, life extension and medical choice. Ethnography	Dialysis extended life but not what was considered a good or full life. Choice reflected adaptation to dialysis and acceptance of a diminished life.
Kelly-Powell, M.L (Kelly-Powell, 1997)	HD	n=9	Patients' experiences making treatment	Decisions were very personalized consistent with self-identity in the

United States			decisions. Grounded Theory	context of their life.
Landreneau, K & Ward-Smith, P (Landreneau & Ward-Smith, 2006) United States	HD PD Transplant	n=2 n=2 n=2	Perceptions concerning choice among renal replacement therapies. Phenomenology	No one remember making their own choice. There was uncertainty of future health and lack of information regarding renal replacement therapies.
Landreneau, K & Ward-Smith, P (Landreneau & Ward-Smith, 2007) United States	HD	n=12	Perceptions of patients on HD concerning choice. Phenomenology	Patients perceived they had a choice. Education impacted choice.
Lee, A et al., (Lee et al., 2008) Denmark	CKD HD Self care-HD Home HD PD CKD Family	n=3 n=5 n=5 n=5 n=9 n=18	Patient views regarding choice of dialysis modality. Interpretive Descriptive	There was no ideal therapy. Flexibility, independence and security influenced decision-making. Maintenance of a ‘normal’ life was the goal. Patient and family participated in the choice. Education and support were required to enable decision-making.
Lin, C et al., (Lin et al., 2005) Taiwan	HD	n=12	Deciding about HD among Taiwanese. Phenomenology	Three themes emerged representing decision-making; fear caused by false beliefs, seeking further information and living with dialysis.
Morton, R et al., (Morton et al., 2010b) Australia	HD Satellite -HD PD Home HD Transplant	n=8 n=52 n=13 n=4 n=18	Patient views about treatment of stage 5 CKD. Interpretive Descriptive	Therapies were chosen to enhance freedom and autonomy and with methods that were convenient, effective and simple. They chose a therapy which most embodied characteristics that minimized the impact on their life.
Sondrup, B et al., (Sondrup, Copland, Black, & Trask, 2011)	HHD PD	n=3 n=3	Patient perceptions and possible barriers related	Hardship was experienced due to loss of kidney function. There was need for

Canada			to choosing home-dialysis therapies. Interpretive Descriptive	support from HCPs, educational materials, recruitment strategies which focused on independent dialysis and technical support.
Tong, A et al., (Tong et al., 2009) Australia	CKD Dialysis Transplant	n=21 n=18 n=24	Patients' experiences and perspectives living with CKD. Interpretive Descriptive	Adjustment to the many disruptions and implications of CKD were required. Choice of modality was influenced by lifestyle, family impact and physical comfort rather than clinical outcomes. Time, information and support were required.
Tweed, A & Ceaser, K (Tweed & Ceaser, 2005) United Kingdom	CKD	n=9	Renal replacement therapy choices. Interpretive Descriptive	Decision-making was individualized and contextualized within participants' illness experience. Four themes emerged; maintaining integrity, forced adaptation, information, support and illness experience.
Visser, A et al., (Visser et al., 2009) Netherlands	CKD HD	n=6 n=8	Accepting or declining dialysis in elderly patients with CKD. Interpretive Descriptive	Decisions to accept dialysis were not based on treatment effectiveness but personal values, beliefs, feelings toward life, suffering and death and incorporating dialysis in their lives.
Whittaker, A & Albee, B (Whittaker & Albee, 1996) United States	HD PD	n=10 n=10	Factors influencing dialysis selection. Grounded Theory	Dialysis selection was influenced by basic resources of quality and timing of information, prior placement of vascular access and social and family support systems.

*Health Care Professionals

Table 2.3

CKD Dialysis Modality Decision-Making Meta-Synthesis

Dialysis modality choice Illusion of choice-A matter of life or death Perceived intrusiveness-personal and other Knowledge and social support-Essential and context bound

Table 2.4

Summary of Concepts Supporting Studies

Author	Illusion of choice-genuine or none	A matter of life or death	Minimization of perceived intrusiveness	Knowledge and support
Andrew (2001)	•	•	•	•
Breckenridge (1997b)	•	•	•	•
Courts (2000)	•		•	•
Jennette et al., (2009)	•	•	•	•
Kaufman et al., (2006)	•	•	•	•
Kelly-Powell (1997)	•	•	•	•
Landreneau & Ward-Smith (2006)	•			
Landreneau & Ward-Smith (2007)				•
Lee et al., (2008)	•			•

Lin et al., (2005)	•	•	•	•
Morton et al., (2010b)			•	•
Sondrup et al., (2011)		•	•	•
Tong et al., (2009)	•	•	•	•
Tweed & Ceaser (2005)			•	•
Visser et al., (2009)	•	•	•	
Whittaker & Albee (1996)	•	•	•	•

Table 2.5

CKD Decision-Making Concepts and Exemplars

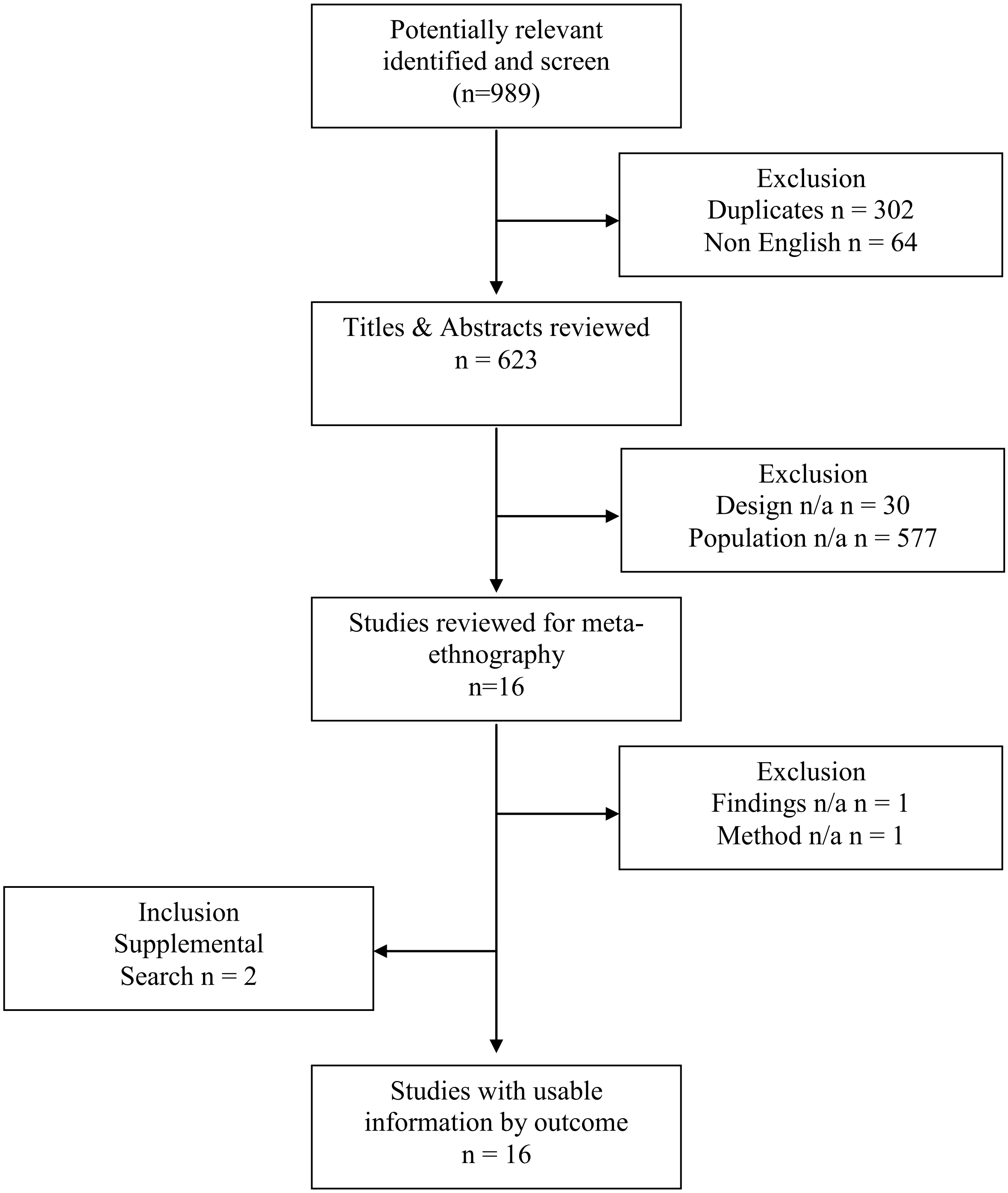
Concepts	Exemplars
The illusion of choice-A matter of life and death	"The only thing the doctor said was that I was going to be on dialysis… I didn't have a choice" (Breckenridge, 1997b, pp. 318). "I was really scared when the doctor told me that the machine is the only way to keep me alive. This is the only option" (Lin et al., pp. 921). "I was thankful for dialysis and that gave me a second chance at life" (Breckenridge, 1997b, pp. 317). "You all ask us like we took this by choice. We didn't have any control over this…I was afraid but I wanted to live. That's what it comes down too" (Jennette et al., 2009, pp. 22). "No, your life is not over. No, you are not going to die. We can make you better, and this is how you can do it" (Sondrup et al., pp. 494).
Personal factors and the minimization of intrusiveness of dialysis	"I'd like to stay as normal as I possibly can, …(hemodialysis) would be less disruptive of our life" (Kelly-Powell, 1997, pp. 223).

	"I don't want it at home. I don't want to be reminded of having an illness. When I come here (dialysis centre), when I enter that door I am ill—at home I am not ill" (Lee et al., pp. 3956). "I planned on going back to work, and I couldn't see carrying around those bags with me and doing it four times a day. With the hemo treatment, it's three hours, three times a week. I'm working and this seemed like it would be much better for my schedule" (Whittaker Albee, 1996, pp. 372).
Other factors perceived to affect intrusiveness	*Travel* Peritoneal dialysis is better because I can work all day and my husband can stay at home whereas with hemodialysis you would have to go every other day…" (Breckenridge, 1997b, pp. 16). *Autonomy, values and control* "You know that background I talked about before? I think that it makes a difference. In the environment that we grew up in and how the families thought and…you pick a lot of that up and you carry it through life…and so it taught me to ask questions. And I guess that's one reason I could make that kind of decision" (Kelly-Powell, 1997, pp. 222). "Mainly because it (home dialysis) gives me a bit more freedom…it would allow me if I wanted to take a trip, to go somewhere and basically do it myself" (Breckenridge, 1997b, pp. 317).

	Sense of identity "I just didn't want to live with a machine attached to me…I'm never sick-just doesn't fit my vision of me" (Whittaker & Albee, 1996, pp. 374).
Knowledge and social support: Essential and context bound	"When I went on dialysis, I was automatically put on hemodialysis. I was not even told about CAPD. The doctor might have mentioned it, but I was so sick at the time I didn't catch on to it. My response was that if I had been told about something like that, I would have wanted to go with it" (Breckenridge, 1997b, pp. 317). "You think you're the only one in the world and I found there were lots of other people and people that were younger than me. I know it sounds awful, but it helped me, you know they've got a longer period to do this kinda thing (dialysis)" (Tweed & Ceaser, 2005, pp. 662). "So between those members of my extended family…and between what I believe in the word of God, the two coming together made me decide that I could take the CAPD" (Kelly-Powell, 1997, pp. 221). "That part of your brochure that comes with this that says, if you are considering home-based dialysis, there is this group of people that will take care of you—the medical team, the technical team, the supply people team, even the peer group support" (Sondrup et al., 2011, pp. 496).

Figure 1

Quorum Flow Diagram for Meta-Ethnography of Qualitative Studies



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Chapter 3: Chronic Kidney Disease Stressors Influence Choice of Dialysis Modality

This chapter contains the results of study that examined the determinants of stress and coping and the relationship to home-dialysis service usage.[3] In critical realism the object of study is often the agent-structure relationship (Connelly, 2001) as the explanation of the actions of individuals requires both their inner constitution and the social structures in which they are located (Sayer, 2000). Agency refers to individual factors such as beliefs, attitudes and personal meaning while contextual or structural factors refer to social norms, culture, geography and environment (Archer, 1995; Clark et al., 2008). This study is based on the hypothesis that the influence of personal agency and social structure may affect dialysis modality service usage. The stressors listed in this study cannot all be easily categorized as being attributed to personal or structural stressors. Stressors such as; feeling unsure about life with dialysis, changes in mood, knowing when to call the health care team and not knowing enough about dialysis could be considered stressors of a more personal nature. CKD stressors such as; having to rely on health care team, waiting for dialysis closer to home, rides/driving to the clinic visits and changes in social life are more constructs structural in nature. The physiological stressors such as restless legs and neuropathy in hands and feet are not as easily categorized.

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Research informed by critical realism is predominately qualitative (Sayer, 2000) however, quantitative study designs such as mixed method designs (Lipscomb, 2008) and theoretically driven quantitative analysis (Pratschke, 2003) are cohesive with critical realism. Some skepticism exists amongst critical realists on the use of statistics. This is based on the assumption that statistics are constructed of regularities between independent and dependent variables in a closed system (Olsen & Morgan, 2005). However, more important to critical realists then the method is the methodology and interpretation of the meaning of the results i.e. open ontology (Olsen & Morgan, 2005; Pratschke, 2003). Critical realists believe that the construction of regularities of variables are not law-like but patterns do occurs in some regularity/relationship which they refer to as demi-regularity (Lawson, 1998). Therefore, in this study critical realism was used to hypothesize that the personal and structural variables of stress and coping may impact on home-dialysis service usage. The results suggest that physiological stressors influence in-centre HD selection but dialysis modality decision-making is complex and is more likely to be influenced by a myriad of factors that occur with/influence physiological stressors (Harwood & Clark, 2012a). This study was conducted to help in our understanding of some predictors of modality decision-making whereby providing cues that physiological stressors on some level influences CKD decision-making. How and under what circumstance these physiological stressors impact home-dialysis decision-making remains unknown.

The Peer Reviewed Publication

The ethical approval for this study is included in (see Appendix D) and permission to use this publication in the thesis has been granted (see Appendix E).

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ORIGINAL RESEARCH

Chronic kidney disease stressors influence choice of dialysis modality

Lori Harwood, Barbara Wilson, Jessica Sontrop & Alexander M. Clark

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Abstract

Aim. This article is a report of a study examining the relationships between chronic kidney disease stressors and coping strategies with dialysis modality.
Background. People with chronic kidney disease are given information to enable dialysis modality choice. This education increases awareness and may alleviate concerns and stress. Disease-related stressors and coping may affect dialysis selection. Understanding the influence of stress and coping on dialysis choices will assist in providing responsive programmes. Reducing stress and encouraging coping may increase home dialysis which, despite economic and patient benefits, remains underused.
Design. A prospective correlational design was used.
Methods. Information was obtained from the Chronic Kidney Disease Stress Inventory and the Jalowiec Coping Scale in 223 individuals not on dialysis between the years 2005–2007. Data were recorded with respect to modality at dialysis initiation (n = 76) from 2005–2010. The effects of stress, coping and patient parameters on modality selection were compared using bivariate and multivariate analyses.
Results. Individuals on home dialysis vs. in-centre haemodialysis reported significantly fewer pre-dialysis stressors. Coping was not associated with dialysis modality. Individuals on in-centre haemodialysis had a lower serum creatinine, less advanced kidney disease and weighed more than those who started on a home therapy. Physiological stressors were most common and are amenable to interventions.
Conclusion. Pre-dialysis stress levels predicted dialysis modality. Interventional studies are recommended to address chronic kidney disease stressors with the outcome of improving home-dialysis usage.

CKD Stressors Influence Choice of Dialysis Modality

There is a current focus on home-dialysis therapies due to favourable economic outcomes and patient benefits. Despite these benefits, experts believe service usage of home dialysis is underused (Jiwakanon et al., 2010; Jung et al., 1999; Mendelssohn et al., 2001). The prevalence of home haemodialysis (HD) in the US remains low at only 1% (USRDS, 2010) although peritoneal dialysis (PD) is higher at 7% but the prevalence of this is decreasing (USRDS 2010). In the UK between 2005–2008, there was 6.3% per million population fall in PD prevalence rates and by 2008 home therapies accounted for approximately 10% of treatment therapies (PD 9%; home HD 1%) (Byrne, Steenkamp, Castledine, Ansell, & Feehally, 2010) Numerous clinical practice guidelines recommend that individuals with chronic kidney disease (CKD) receive education (Covic et al., 2010; Kelly et al., 2005; Levin et al., 2008; NKF, 2006) specific to renal replacement therapy options as a means to help people make informed choices about dialysis modality selection. However, practice variations exist about home-dialysis eligibility (Mendelssohn et al., 2009) and geographical differences persist about who is offered home dialysis. Personal factors such as age (Jager et al., 2004; Mehrotra et al., 2009; Stack, 2002), employment status, level of education, comorbid status, early and frequent nephrological care, marital status (Stack, 2002), social support (Jager et al., 2004; Oliver et al., 2007) and distance from a dialysis centre (Little et al., 2001) have all been demonstrated to impact on home-dialysis utilization.

Regardless of the mode of the educational programme delivered or the evaluative study design, patient awareness and knowledge of home-dialysis therapies are repeatedly associated with home-dialysis selection (Agraharkar, Patlovany, Henry, & Bonds, 2003; Gomez et al., 1999; Goovaerts et al., 2005; Hyphantis, Katsoudas, & Voudiclari, 2010; Klang et al., 1999; Manns et al., 2005; Marron et al., 2006; McLaughlin et al., 2003; Mehrotra et al., 2005; Pagels et al., 2008; Prichard, 1996; Stack, 2002; Wuerth et al., 2002). Why does education have such a strong effect on home-dialysis selection? Educative interventions may increase patients' awareness of the different modalities available and how dialysis can be incorporated into their lifestyles, values and beliefs. Does this education/information alleviate concerns and stressors which impact on modality decision making? At this point it is unknown whether stressors associated with CKD and coping strategies used contribute to dialysis modality choices.

Stress is a common occurrence for individuals with an enduring illness, including those with CKD (Harwood, Wilson, Locking-Cusolito, Spittal, & Sontrop, 2009). High levels of stress may have an impact on psychological and medical outcomes (Cukor, Cohen, Peterson, & Kimmel, 2007). Variability in how one perceives stress and is able to cope may be influenced by a number of factors including personality, psychological functioning, resources available and the cultural beliefs of the individual (Cukor et al. 2007). There is much more to be known about how the wider social, economic and psychosocial factors interact in CKD (Bruce et al., 2009) and in particular, with respect to home-dialysis selection. Stressors and coping responses associated with CKD may contribute to health behaviours such as dialysis modality preferences.

Background

CKD Stressors and Coping

To date, only one study has been reported specific to stressors in patients with CKD. Harwood et al. (2009) reported on the development of the CKD Stress Inventory (CKDSI); a self-administered instrument for the purpose of identifying the presence and severity of stressors associated with CKD. Results demonstrated that the top six stressors with highest intensity all pertained to physical symptoms; fatigue, sleep problems, peripheral neuropathy (numbness/pins and needles), muscle cramps, restless legs and shortness of breath. Furthermore, principal components analysis of the CKDSI demonstrated that three factors accounted for much of the variation among items and the authors categorized the stressors experienced into three subscales: physiological, psychosocial, and logistical. In terms of relationships between variables, CKD stress was inversely associated with CKD severity and age, speculating that those in the later stages of CKD have had more opportunities for educational and supportive interventions and established therapeutic relationships with nephrology healthcare professionals. In a secondary analysis of data, gender differences were noted with respect to coping such that women with CKD used more coping strategies and were more likely to seek out and use supportive interventions and services than men (Harwood et al., 2011). This has important implications for CKD health promotion programmes as approximately 60% of individuals on dialysis are men

(CIHI, 2010). Those who had higher levels of formal education had higher coping scores which may directly relate to their ability for chronic disease management.

Maladaptive coping styles such as ‘blunting’ or avoidance are associated with faster progression of disease and early initiation of dialysis, as these individuals may be less likely to have medical follow-up and delay seeking medical treatment (Devins, Mendelssohn, Barre, & Binik, 2003). Ego mechanisms of defence are associated with patients’ dialysis modality preferences (Hyphantis et al. 2010) with those selecting HD as having a tendency towards higher symptom distress scores compared to those who selected PD. Furthermore, individuals who selected PD were twice as likely to adopt an adaptive defensive style in opposition to those who selected HD had an image distorting defensive style (Hyphantis et al. 2010).

We hypothesized that increased stressors and poor coping strategies associated with CKD would influence dialysis modality selection, particularly home and self care modalities. Furthering knowledge of factors that may influence modality service usage will form the foundation for quality interventions for individuals with CKD. This, in turn, may reduce stressful perceptions and encourage adaptive coping behaviours and home-dialysis selection.

The Study

Aim

The aim of this study was to evaluate whether CKD stress levels and coping strategies influenced the decision to initiate treatment with HD vs. PD.

Design, setting and participants

Participants in this prospective cohort study were recruited between 2005–2007 from one CKD clinic at an urban academic teaching hospital in Canada. Eligible patients included those diagnosed with CKD by a nephrologist, but not receiving dialysis. Additional eligibility criteria included serum creatinine >250 μmol/L (2.84 mg/dL) and/or eGFR <60 mL/min/1.73 m^2, age ≥18 years, and the ability to speak and understand English. A serum creatinine >250 μmol/L was chosen as it is the current practice indicator at the study centre to begin multi-disciplinary CKD care for teaching and support. An eGFR <60 mL/min/1.73 m^2 was chosen as this is consistent with accepted CKD staging and represents loss of more than half of normal adult kidney function and the point which the prevalence of disease-related complications increase (Levey et al., 2003). The participants all received standard CKD care given by a multi-disciplinary team (nephrologist, nurse, social worker, dietitian) with a consistent and organized CKD educational programme. A variety of renal replacement therapies were available to the participants such as transplantation, HD (in-centre, self care and home) and PD. Unless medically or socially contraindicated, individuals were given their choice of modality. Records are kept in the renal programme upon initiation of all renal replacement therapies. Between 2005 and 2010, these records were reviewed every 6 months to determine which patients in the original sample had initiated renal replacement therapy. The researcher recorded the date of renal replacement therapy initiation, the modality at initiation and again at 6 months.

Data Collection

At study entry, participants completed a survey including questions on sociodemographic and clinical factors, the CKDSI (Harwood et al. 2009) and the Jalowiec Coping Scale (JCS) (Jalowiec, 2003a; Jalowiec, Murphy, & Powers, 1984). Information on the number of months seeing a nephrologist and participants' most recent pre-dialysis serum creatinine, urea, albumin, haemoglobin, and weight were obtained from medical records. The Charlson Co-morbidity Index (Hemmelgarn, Manns, Quan, & Ghali, 2003) was used to assess co-morbid risk. The eGFR was calculated using the Cockcroft–Gault equation (Cockcroft & Gault, 1976) and CKD staging was done using the National Kidney Foundation/Kidney Disease Outcome Quality Initiative guideline (NKF, 2006).

For the purpose of this study, Lazarus and Folkman's (1984) definition of stress was used. They defined psychological stress as a relationship between the environment and person when appraised as taxing or exceeding resources and/ or endangering the well-being of the individual (Lazarus & Folkman, 1984). In this case there is an identifiable stressor or a stimulus. This is in contrast to anxiety which is a behavioural response to thought patterns, feelings and situations which persist after the threat has ceased (Lazarus & Folkman 1984).

Validity and Reliability

The chronic kidney disease stress inventory.

The CKDSI is a new 34-item stressor inventory designed to evaluate stressful experience among adults with CKD not on renal replacement therapy

(Harwood et al. 2009). The inventory was conceptually based upon Lazarus and Folkman's (1984) theory of stress, appraisal and coping. The 34-item scale can be grouped into three stressor sub-scales: logistical (14-items), psychosocial (9-items) and physiological (11-items). Participants rate their level of stress for each item on a 4-point Likert scale (0–3) with higher scores indicating the greater severity of stress experienced. Information on the preliminary validation of this inventory is available elsewhere (Harwood et al. 2009). Briefly, varimax rotation indicated that 44.1% of the total variance was predicted by the three sub-scales (Harwood et al. 2009). Internal consistency, how well the items fit together conceptually (DeVon et al., 2007), was measured by Cronbach's alpha for each subscale, respectively, and were 0.88, 0.84 and 0.80, with 0.91 for the entire 34-item scale (Harwood et al. 2009). Content validity was established (Harwood et al. 2009), however, criterion validity and test re-test reliability were not conducted.

The jalowiec coping scale.

The JCS is a generic, self-administered questionnaire to assess coping strategies used and the effectiveness. It assesses a wide range of coping behaviours and methods. Psychometric testing of the JCS has demonstrated good reliability and validity (Jalowiec et al. 1984, Jalowiec 2003) with reliability for total coping use (0.88), total coping effectiveness (0.91) and coping use subscale mean (0.71) and coping effectiveness subscale mean (0.73) (Jalowiec, 2003b).

Ethical Considerations

Research Ethic Committee approval was obtained from the local research ethics board.

Data Analysis

Proportions were compared using the chi-squared test and continuous variables compared using the independent t-test or the Mann–Whitney U-test as appropriate. Variables significantly associated with dialysis modality were considered potential confounders and included in the multivariable analysis. Odds ratios (OR) and 95% confidence intervals were estimated using logistic regression to assess whether predialysis stress predicted subsequent dialysis modality while controlling for potential confounders. Although CKD stage was significantly associated with dialysis modality it was not included in the multivariable models due to collinearity with serum creatinine. Age and gender were included in all models. Means and standard deviations (SD) are reported. A p-value of 0.05 was considered statistically significant.

Results

The original questionnaires were completed for the period from September 2005–July 2007. Of the 223 participants who completed the baseline assessment, two underwent preemptive kidney transplants and 76 initiated dialysis during the follow-up period between September 2005–June 2010. Of those who initiated dialysis, 49 (64.5%) opted for in-centre HD and 27 (35.5%) opted for PD. None of the participants started on home HD. Participant characteristics at baseline are shown in Table 3.1. The average age was 62 years (SD 15) and 70% were men.

Mean serum creatinine was 447.5 µmol/L (SD 155.0) and 39.5% had reached Stage 5 CKD but were not yet on dialysis. Dialysis modality groups were similar with respect to age, gender, education, years seeing a nephrologist, cause of CKD, and comorbidities. However, participants who initiated HD vs. PD had significantly lower serum creatinine (mean 421 µmol/L vs. 496 µmol/L; p = 0.04), less advanced CKD (p = 0.04), and were significantly heavier (mean 90.2 kg vs. 76.6 kg; p = 0.002). Preliminary analysis showed no important associations between coping and any variable and therefore no further analysis was conducted with coping.

Pre-Dialysis Stressors Experienced

The five stressors with the greatest intensity all pertained to physical symptoms (fatigue, sleep problems, restless legs, muscle cramps and peripheral neuropathy (numbness/pins and needles) (Figure 2). Accordingly, participants scored higher on the physiological subscale of the CKDSI (mean 0.96, SD 0.6) followed by psychosocial and logistic CKDSI subscales: 0.62 (SD 0.6) and 0.41 (SD 0.5), respectively.

Pre-Dialysis Stressors and Dialysis Modality

Participants who initiated HD reported significantly higher levels of pre-dialysis stress than participants who initiated PD (mean CKDSI score: 0.72 vs. 0.42, p = 0.004) (Figure 3a,b,c). More specifically, participants who initiated HD reported higher levels of physical, psychosocial and logistical stress at baseline than those who initiated PD; however, only psychosocial stress levels were significantly different between modality groups (p = 0.02). After controlling for age, gender, weight, and serum creatinine, the likelihood of initiating HD vs. PD increased 1.16 times for each unit increase in the 34-item CKDSI ($p = 0.03$) (Table 2). None of the CKDSI subscales were important predictors of modality choice after controlling for confounders.

Discussion

In this study of Canadian CKD patients, pre-dialysis stress levels predicted future dialysis modality such that the likelihood of initiating HD vs. PD increased 16% for each unit increase in the 34-item CKDSI. This association remained statistically significant after controlling for age, gender, weight and serum creatinine and had no relation to coping. From a clinical standpoint, these results suggest that individuals with CKD reporting higher pre-dialysis stress levels are less likely to choose a home-dialysis modality. These individuals may feel ill-equipped to take on the added responsibilities associated with a home therapy; while knowing that HD is provided in a hospital setting with treatments carried out by professional staff. Furthermore, our facility provides an on-site team of professionals for individuals on HD (i.e. nephrologists, nursing, social worker, and dietitian) that can be easily accessed as needed. By contrast, individuals with lower levels of stress in CKD may feel better able to manage the demands of therapy at home.

CKD Stressors and Symptom Burden

It is becoming increasingly recognized that symptom burden is high among individuals with CKD. Our results demonstrate that individuals with CKD experience a clinically significant number of physical symptoms as part of their long-standing illness. Furthermore, beyond the identification of a number of physical symptoms and their severity, the results of this study highlights that these physical symptoms are an important source of stress. In this sample, the five stressors with the greatest intensity all pertained to physical symptoms; fatigue, sleep problems, restless legs, muscle cramps, peripheral neuropathy (numbness/pins and needles). Assessment of symptoms among CKD patients has been recently investigated with the subsequent development of a CKD Symptom Assessment Instrument for use with patients in an effort to measure the presence and severity of symptoms in those with CKD (Agarwal, 2010). Similar to our results, Agarwal (2010) reported a number of CKD symptoms including: 'stop and rest often', joint pain, nocturia, limited physical activity and 'tire easily'. Presumably, these physical symptoms, like the physical stressors we identified, may be highly amenable to a variety of multidisciplinary interventions. It is important for renal team members to assess for the presence and severity of physical symptoms as part of ongoing care. It is also important to acknowledge that Agarwal's (2010) instrument is limited to measuring the presence of a symptom and does not take into consideration the extent to which the individual appraises the symptom as stressful.

CKD Stress and Decisional Conflict

Individuals who feel overwhelmed with the stressors associated with their CKD may also find it difficult to make a modality decision. In the clinical setting, in-centre HD is always the default for those who are unable to decide, or delay their modality decision leaving insufficient time to organize and train to do home dialysis. Decisional conflict may be present with CKD modality decision-making especially in those with high stress levels. The Registered Nurses Association of Ontario (RNAO) Clinical Practice Guidelines on CKD Decision Support recommend an approach to CKD care which includes decision support and value based interventions (RNAO, 2009). Value based decision aids can significantly improve patient knowledge, reduce decisional conflict in those feeling uninformed or unclear about personal values, and reduce the proportion of individuals who are undecided or passive in decision-making (O'Connor et al., 2009; O'Connor et al., 1999). Further study in the area of CKD modality decision-making, the presence of decisional conflict and the role of decision aids is warranted.

Psychological Stressors and Uncertainty

Although individuals with CKD who initiated HD reported higher levels of stress in all three subscales of the CKDSI, only psychosocial stress levels were significantly higher at baseline in the group choosing HD (Figure 3b). In fact, individuals who chose HD scored higher on average intensity for each item on that subscale. The top three items – 'limits on vacation', 'changes to social life' and 'limits on trips', are all specific to perceived changes in lifestyle (i.e. travelling). These results are similar to a systematic review of qualitative research on patient and caregivers views of CKD treatment decision-making whereby these decisions were personal and influenced by their knowledge of the treatment and the subsequent impact to their lifestyle (Morton et al., 2010).

Items such as ‘feeling alone’, ‘fear of being alone’ may be perceived as pertaining to one’s perception of social support. Social support has a strong influence on home-dialysis usage (Andrew, 2001; Courts, 2000; Jager et al., 2004; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Oliver et al., 2007; Stack, 2002; Tong et al., 2009; Tweed & Ceaser, 2005; Whittaker & Albee, 1996). Current studies on social support which measured the concept from the perspective of the healthcare professional (Jager et al., 2004; Oliver et al., 2010; Stack, 2002) concluded that social support was a predictor of modality service usage. However, when individuals new to dialysis completed social support surveys no difference was found between the in-centre and home-based groups about social support. This suggests that social support exerts a greater influence in the pre-dialysis stage of modality selection but does not affect outcomes once dialysis has been initiated (Plantinga et al., 2010). To date, the study of social support on individuals with CKD, not yet on dialysis, specific to the individual’s perspective is limited to qualitative studies which were not specifically designed to explore social support. As social support appears to have such a strong relationship to home-dialysis selection, it is worthy of a detailed inquiry to further explain why and how social support exerts this influence.

It is difficult to determine whether patients responded the way they did based on how they felt at the time the questionnaires were completed, or whether responses reflected their knowledge of the dialysis modalities available to them (i.e. in-centre vs. home). In terms of ‘driving for dialysis’, which was deemed a higher intensity stressor for those who chose PD, perhaps thinking about future drives to haemodialysis creates stress early on. It may also be that individuals stressed and worried about travelling to haemodialysis are more likely to consider PD as a treatment modality. Further understanding of these potential sources of psychosocial stress and efforts to reduce these barriers through further education, peer support programmes, and/or counseling specific to changes in lifestyle may be of benefit in improving future utilization of home dialysis.

Although not statistically significant, it is interesting to note that logistical stressors were an important source of stress for both groups as well. The top two items for both groups ‘unsure about life with dialysis’ and ‘not knowing when dialysis will be needed’ would appear to demonstrate that patients found uncertainty stressful. Uncertainty has been previously documented with CKD (Harwood et al., 2005; Tong et al., 2009), however it has not been studied in any great detail and is an area requiring further study. Uncertainty has been recently studied in individuals on PD where stress, among all the variables studied, was most associated with uncertainty (Madar & Bar-Tal, 2009). The authors suggest that interventions aimed at decreasing stress may reduce the uncertainty associated with their PD.

Dialysis Initiation and Other Stressors

Dialysis modality groups were similar with respect to a number of demographic characteristics including age, gender, education, years seeing a nephrologist, cause of CKD, and comorbidities. Individuals who initiated HD had a significantly lower serum creatinine and less advanced CKD than their PD counterparts. Perhaps this can be partly explained by the fact that PD requires more planning in terms of arranging catheter assessment, placement and training. Haemodialysis, on the other hand, can be initiated at short notice in the absence of a usable arteriovenous fistula by insertion of a central venous catheter. Starting PD at a more advanced stage of renal impairment – a home therapy which requires more patient participation, self-management skills, physical and cognitive functioning, may be less likely to be successful if patients need to be taught at a time when CKD symptoms (uraemia) deters learning. These results would suggest the need to further examine and improve processes associated with practices that ensure that PD is initiated in a timely manner and patients are well enough to learn the necessary skills to be successful at home.

In this study stressors were associated with an increased propensity to start on an in-centre dialysis modality. What coping strategies they used, and demographics such as age, gender, level of education, length of time seeing a nephrologist and CKD severity were not found to have an influence on modality selection. There is no simplistic answer to the question of what influences dialysis modality selection, however, this study has contributed to our understanding of the role that stressors play. This area of inquiry remains complex and largely poorly understood. Investigation into other factors which intertwine with stressors and education, such as, uncertainty, social support and decisional conflict are worthy of further examination.

Coping Strategies

In this study we examined the association of coping strategies in individuals with CKD and dialysis modality. Coping was not found to be associated with modality service usage. Intuitively coping should mediate disease-related stressors, favouring home-dialysis, however, our findings did not support this. This is an important area of research as repeated stressors over a lifetime can accumulate predisposing an individual to health inequalities (Denton, Prus, & Walters, 2004). Stressors can be moderated by psychological attributes such as self esteem, mastery or coherence (Denton et al. 2004). Perhaps these attributes are more at play here and form the foundation for coping in assisting individuals with their CKD stressors and dialysis modality decision-making.

Study Limitations

Several limitations must be considered when interpreting the results of this study. First, the sample was non-randomized and subjects chosen from one CKD clinic in an urban academic health sciences centre in Canada. Second, the end point of this study was dialysis initiation, meaning patients were not tracked from the CKD clinic, thus the number of deaths, lost to follow-up and those still in CKD is unknown. Third, details of how much of the modality education provided to this group that was used or comprehended by patients is also unknown in this study. At our centre, patients and families are offered standard multidisciplinary CKD care including written material and three voluntary group education classes specific to chronic disease management (class #1), modality choices (class #2) and living with end stage renal disease (class #3). It is unknown if they read the material provided or attended the teaching sessions offered outside of the clinic visits. Thus, the amount and type of education uptake or individual learning styles that may have had an influence on the dialysis modality selected are not known.

Lastly, the effect of time is unknown. Despite a previous study demonstrating an inverse relationship between stress and CKD stage (Harwood et al. 2009), it is not known if and how much stressors change over the course of progression with CKD. We also did not collect information on the individual's modality choice and we are making the assumption that usage equals choice. Future studies specific to methods of delivery of CKD education, patient preparation, and how they impact on patient stressors and/or future modality choice would be of value to renal programmes.

Implications for Nursing Practice

This study adds valuable information to what is known about stressors experienced by individuals with CKD and reinforces the variety and relative intensity of stressors experienced by this group of patients. Furthermore, results of this study suggest the possible link between stressors experienced and dialysis modality selection. As efforts to increase numbers on home modalities continue, renal teams need to assess for stressors in all three categories (physiological, psychosocial, logistical). In terms of patients' modality decision-making, the use of decision support tools may be helpful, in particular instances when decisional conflict is apparent. Opportunities to reduce uncertainty should be considered through provision of information in a timely manner.

Conclusion

In summary, this study is the first to identify that CKD stress levels influence dialysis modality usage. Our results lay the foundation and identify the need to develop consistent clinical approaches, and/or algorithms based on evidence in an effort to address common physiological stressors in this patient population. In addition, efforts aimed at assisting patients to deal with psychosocial and logistical stressors and uncertainty associated with CKD would also be of tremendous benefit to altering health behaviours and ultimately increase home-dialysis service usage.

What is already known about this topic

- Living with chronic kidney disease is a stressful experience and is becoming more common worldwide.
- Clinical practice guidelines consistently propose education and support to assist individuals with late stage chronic kidney disease with the important task of choosing a dialysis modality.
- Stress can affect health outcomes.

What this paper adds

- Stress associated with chronic kidney disease affects dialysis modality service usage.
- Physiological stressors are of greatest concern for individuals with chronic kidney disease.
- Individuals with chronic kidney disease who experience more disease-related stressors are less likely to choose a home-dialysis therapy.

Implications for practice and/or policy

- Routine assessment by healthcare professionals of common physiological stressors associated with chronic kidney disease is recommended.
- Health services for individuals with chronic kidney disease need to include interventions to reduce disease related stressors.
- Reducing stressors associated with chronic kidney disease may increase home-dialysis service usage.

Table 3.1

Pre-Dialysis Baseline Characteristics

	Overall	Dialysis Modality		
Characteristics	(n=76)	HD (n=49)	PD (n=27)	p-value[a]
Age, mean (SD)	62 (15.1)	62.8	59.9	0.42
Male, %	69.7	69.4	70.4	0.93
Highest level of completed education, %				
Less than high shcool	32.9	32.7	34.6	0.86
High school	65.8	67.3	65.4	
Employed (full or part-time), %	23.7	18.4	34.6	0.12
Years seeing nephrologist, median (ICR)	3.0 (1.0, 5.3)	3.0 (1.0,6.0)	3.0 (1.0,5.0)	0.99
Weight (kg), mean (SD)	85.4 (21.8)	90.2	76.6	.002
CKD stage, %				
Stage III	11.8	18.4	0	
Stage IV	48.7	49.0	48.1	0.04
Stage V	39.5	32.7	51.9	
Serum creatinine (umol/L), mean (SD)	447.5 (155)	421.0	495.6	0.04
Serum albumin (g/L), mean (SD)	35.4 (4.9)	35.0	36.1	0.35
Urea (mmol/L), mean (SD)	25.4 (8.4)	24.6	26.7	0.31
Hemoglobin (G/L), mean (SD)	113.4 (17.3)	113.2	113.7	0.89
Primary cause of renal disease, %				
Diabetes	43.4	46.9	37.0	
Glomerulonephritis	15.8	14.3	18.5	0.86
Renal vascular disease	13.2	12.2	14.8	
Other[b]	27.6	26.5	29.6	
Comorbidity Index, %				
Low risk	73.7	75.5	70.4	0.63
Medium to high risk	26.3	24.5	29.6	

Abbreviations: CKD, chronic kidney disease; IQR, inter-quartile range; SD, standard deviation.

[a] Proportions were compared using the Chi-squared test and continuous variables using the independent t-test or Mann Whitney U as appropriate.

[b] Drug induced nephropathy (n=3); Polycystic Kidney Disease (n=3); congenital/obstructive (n=4); Unknown (n=3).

Table 3.2

Association Between Pre-Dialysis Stress Levels and Treatment with Hemodialysis vs. Peritoneal Dialysis

	Age- and Sex-Adjusted		Multivariate-Adjusted	
	OR	95% CI	OR	95% CI
CKDSI score	1.12	1.02 to 1.23	1.16	1.01 to 1.34
Age (years)	1.06	1.00 to 1.11	1.08	1.00 to 1.16
Male sex	0.66	0.13 to 3.26	0.58	0.08 to 4.13
Serum creatinine (umol/L)			1.03	0.98 to 1.00
Weight (kg)			0.99	0.98 to 1.00

Abbreviations: CI, confidence interval; CKDSI, Chronic Kidney Disease Stressor Inventory; OR, Odds Ratio.

[b] Odds ratios were estimated using logistic regression with peritoneal dialysis as the reference category.

Figure 2

Relative Intensity of Pre-Dialysis Stressors

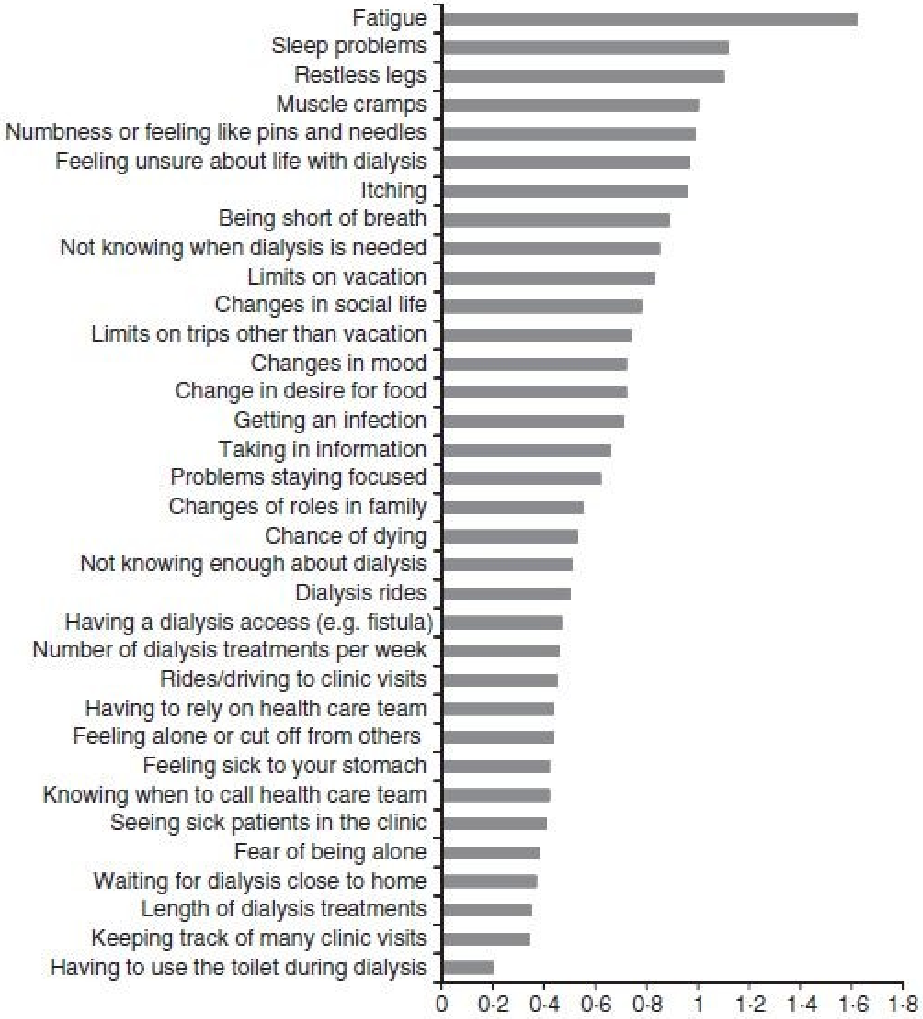
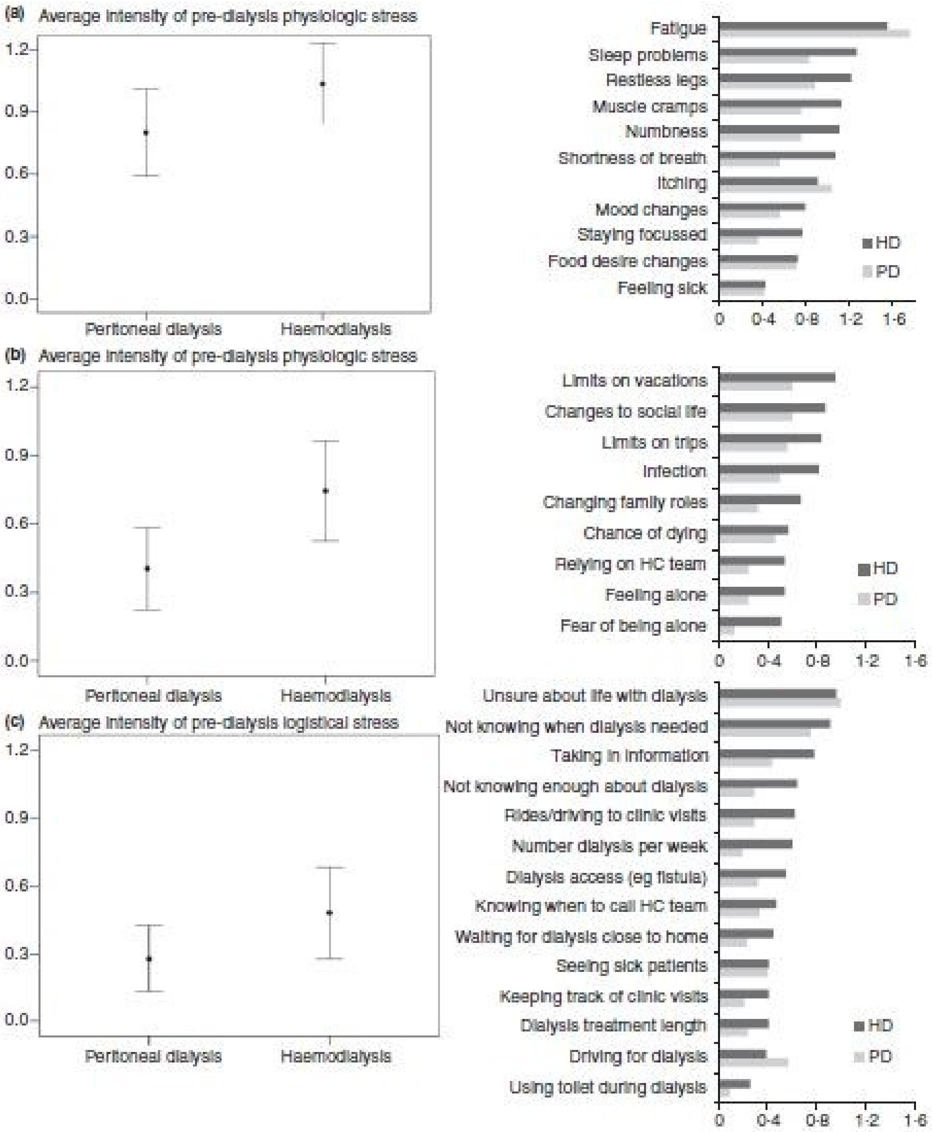


Table 3.3a *Average Intensity of Pre-Dialysis Physiological Stress*. 3.3b *Average Intensity of Pre-Dialysis Psychological Stress*. 3.3c *Average Intensity of Logistical Stress*
Figure 3.3a *Average Intensity of Pre-Dialysis Physiological Stress*. 3.3b *Average Intensity of Pre-Dialysis Psychological Stress*. 3.3c *Average Intensity of Logistical Stress*


(a) Average intensity of pre-dialysis physiologic stress

(b) Average intensity of pre-dialysis physiologic stress

(c) Average intensity of pre-dialysis logistical stress

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Chapter 4: Dialysis Modality Decision-Making for Older Adults with Chronic Kidney Disease

Preamble

Older adults with CKD are an important cohort. They are a population that is large and growing in Canada (CIHI, 2013). They are also least likely to benefit from home-dialysis due to lack of uptake (CIHI, 2013). This study grounded in critical realism was conducted to increase our understanding of the personal and structural barriers and facilitators for home-dialysis decision-making for people with CKD older than 65 years of age. This study received ethical approval from the University of Alberta Research Ethics Board (see Appendix F) and Western University (see Appendix G). The approved consent forms for the patient (see Appendix H) and health care professional (see Appendix I) are included. The semi-structured interview guide for the patient (see Appendix J) and health care professional interviews (see Appendix K) as well as the demographic data collection form (see Appendix L) are also included for the readers of this thesis. Permission to use the following publication in this thesis has been granted (See Appendix M).

The Peer Reviewed Paper[4]

JCN Journal of Clinical Nursing

ORIGINAL ARTICLE

Journal of
Clinical Nursing

Dialysis modality decision-making for older adults with chronic kidney disease

Lori Harwood and Alexander M. Clark

Aims and objectives. To examine the personal and structural facilitators and barriers for home-dialysis decision-making for older adults with chronic kidney disease.

Background. Chronic illness is a global problem. Older adults with chronic kidney disease form a large and growing segment of the dialysis population in many high income countries but are less likely to uptake home-dialysis despite its benefits.

Design. This qualitative ethnography framed in social theory took place in Canada and included adults with chronic kidney disease not on dialysis, older than 65 years of age.

Methods. Thirteen people (seven men and six women, aged 65–83 years of age) who received care in a team chronic kidney disease clinic took part. Persons with chronic kidney disease were interviewed and group interviews were conducted with four of their chronic kidney disease clinic healthcare professionals. Content analysis was used for data analysis.

Results. The factors influencing older adults' chronic kidney disease modality decisions are similar to younger adults. However, older adults with chronic kidney disease are in a precarious state with persistent uncertainty. Age imposes some limitations on modality options and transplantation. Modality decisions were influenced by health status, gender, knowledge, values, beliefs, past experience, preferences, lifestyle and resources. Support from family and healthcare professionals was the largest determinant to home-dialysis selection.

Conclusion. The social and contextual factors associated with age influenced home-dialysis decision-making. Adequate social support, functional status and resources enabled home-dialysis selection.

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Relevance to clinical practice. Understanding more about the decision-making processes for older adults with chronic kidney disease is important for quality interventions and the economic sustainability of dialysis services.

What does this paper contribute to the wider global clinical community?
- Older adults with chronic kidney disease are a large and growing cohort but less likely to benefit from home-dialysis due to a lack of uptake.
- Several studies have examined dialysis modality decision-making; however, they are conducted retrospective to dialysis initiation and/or not focused on the older adult.
- The results of this study make a distinct contribution in examining older adults' decision-making processes predialysis when it is active and most amenable to interventions.

People with Chronic Kidney Disease (CKD) are asked to make important choices about if, how and where they will receive their dialysis. These decisions are important for people with CKD aged 65 years (henceforth: older adults) as the incidence of CKD increases with age and the prevalence of dialysis in such adults is increasing (USRDS, 2013). Crucially, older adults are the largest growing segment of the dialysis population in Canada, the United States and the United Kingdom (Brown & Johansson, 2011) but are least likely to start dialysis on a home-based therapy (CIHI, 2013). A greater understanding of the barriers and facilitators of home-dialysis modality decision-making for older adults is a prerequisite for quality interventions to impact health services and enhance the economic sustainability of dialysis services.

Background

In high-income countries home-dialysis services are widely available, beneficial (Harwood & Leitch, 2006) and cost effective (Mowatt et al., 2003). For example, home haemodialysis (HHD) offers better survival than haemodialysis (HD) (Woods et al., 1996) particularly when combined with more frequent dialysis. Patient survival from HD is the same as for Peritoneal Dialysis (PD) at least during the first one to three years (Nesrallah, 2006) and possibly five years (Mehrotra et al., 2011); then, HD outcomes exceed PD (Blake, 2000; Heaf et al., 2002; Murphy et al., 2000; Termorshuizen et al., 2003). However, the survival benefit for older adults on dialysis is less clear and significantly reduced when comorbid disease is present (see Table 4.1).

Despite the benefits of home-dialysis it is underused (Jiwakanon et al., 2010; Jung et al., 1999; Mendelssohn et al., 2001). Low uptake of home-dialysis in older adults has been attributed to many factors, including increased medical co-morbidity, poor vision, frailty, low cognitive function, accommodation issues and bias from professionals (Brown, 2011). People who initiate home-dialysis (PD) are more likely to be younger, have fewer co-morbid conditions (Chanouzas et al., 2012; Jager et al., 2004; Luijtgaarden et al., 2011) and be married or living with someone (Jager et al., 2004; Stack, 2002). Preferences and lifestyle also influence patient selection (McLaughlin et al., 2003; Wuerth et al., 2002).

Historically, age influenced the availability of dialysis services (Russ & Kaufman, 2012). Currently, dialysis initiation for older adults in high-income countries balances survival benefit, quality of life (Brown & Johansson, 2011) and patient choice (Elliott, Tam-Tham, & Hemmelgarn, 2013). Clinical practice guidelines also emphasize shared decision-making between physicians and people with CKD (RPA, 2010) and education and support (Covic et al., 2010; Kelly et al., 2005; Levin et al., 2008; NKF, 2006). Information on therapy options facilitates dialysis modality decision-making (Gomez et al., 1999; Klang et al., 1999), increases home-dialysis selection (Chanouzas et al., 2012; Goovaerts et al., 2005; Hanko et al., 2010; Lacson et al., 2011; Manns et al., 2005; Marron et al., 2006; Mehrotra et al., 2005; Pagels et al., 2008) and decreases uncertainty and decision regret (Chiou & Chung, 2011). Despite the heterogeneity of the education and evaluative research design, education consistently influences decision-making. Family/social support is a key factor in PD eligibility and selection (Jager et al., 2004; Oliver et al., 2010; Zhang et al., 2010). Providing professional home care assistance can increase PD usage with the elderly (Oliver et al., 2007).

Decisions made regarding dialysis modality are highly personal and strongly influenced by values of the patients and their family, in the context of their life which includes a dialysis modality that minimizes intrusive to their lifestyle (Harwood & Clark, 2012b). More specifically CKD treatment decisions are influenced by family, other persons on dialysis, interpersonal relationships, knowledge, and normalcy to preserve their well-being. People with CKD weigh the alternatives to maintain control/the status quo and make decisions which benefit what is personally important to achieve a satisfactory quality of life (Morton et al., 2010; Murray et al., 2009).

What is currently known about CKD modality decision-making provides some understanding of the processes involved. However, very little is known from the patient perspective of how aging influences these decisions. Social support has an influence on home-dialysis service usage for the older persons yet this has not been examined in-depth from the patient perspective. Three qualitative studies reviewed were conducted with aging adults (Kaufman et al., 2006; Lenci & Campbell, 2012; Visser et al., 2009). However these studies and many others used a design that included people on dialysis rather than prior to dialysis where decision-making is active and perhaps most amenable to interventions. This growing cohort and costly treatment is an important area of inquiry globally which is currently understudied. The purpose of this qualitative study sought to understand the personal and structural barriers and facilitators for home-dialysis decision-making in older persons with CKD.

Methods

Design

This ethnography used critical realism to explain complex decision-making (Pawson & Tilley, 1997; Sayer, 2000) and provide a sound basis for exploring decisions regarding CKD treatment (Harwood & Clark, 2012a). Critical Realist Ethnography (CRE) is distinct from other ethnographic methods because it is based on a theory of stratified ontology such that reality exists beyond our personal perceptions and our actions are somewhat patterned and structured (Bhaskar, 1975). CRE acknowledges the importance of understanding the emic perspective but also the relationship between personal perceptions and actions influenced by wider issues of social structure (Porter & Ryan, 1996). To understand determinants of home-dialysis modality selection, the interaction of underlying agency (personal) and structural factors must be examined.

This study included patients from a multi-disciplinary CKD clinic as well as their Health Care Professionals (HCP). After ethical approval people meeting the inclusion criteria (see Table 2) were approached for the study. Convenience and theoretical sampling techniques were used. The sample size for this study was guided by the principles of data saturation and the final sample size was thirteen. Seven participants (54%) were men and six (46%) were women (see Table 3); aged 65 years to 83 years; mean age: 74.3 years. Two group interviews were conducted with a total of four HCP.

Data collection

Realistic interviewing (Pawson & Tilley, 1997) with a semi-structured interview guide were used. Realistic interviewing is a theory driven method of data collection where the priority is 'what is to know', 'who might know' and 'how to ask' (Pawson & Tilley, 1997). Demographic information was collected. Group interviews were conducted with the HCP using a semi-structured interview guide. This is advantageous as HCP encounter large numbers of cases and have a working hypothesis about what produces favorable and unfavorable outcomes. The study took place in an urban academic health centre providing renal services for the region.

Data analysis

The interviews were audio recorded and transcribed verbatim. Conventional content analysis was used for the patient interviews. Data analysis was ongoing during the data collection phase and began once the first few interviews were transcribed. The data was examined for commonalities of images, words, phrases, patterns or concepts. Common themes were identified linking the underlying meaning from the categories which were derived from the data. Drawing on critical realism, the analysis of the interviews also focused on personal and structural barriers and facilitators influencing home-dialysis modality selection. A data analysis program NVivo10, QSR International, Burlington, MA USA was used for data management. Discussions with the co-investigator occurred throughout data collection and analysis. The group interviews with CKD staff were audio recorded, transcribed verbatim and analyzed for descriptive purposes.

Rigor was maintained in the design and conduct of this study using verification methods to ensure reliability and validity. These include researcher responsiveness, methodological coherence, sampling, concurrent collection and analysis and theoretical thinking (Morse, Barrett, Mayan, Olson, & Spiers, 2002). Critical realism guided this study and congruence between epistemology, ontology and method were addressed. The sample in this study was adequate, appropriate and chosen to best represent the topic including people with CKD and the HCP for comprehensiveness of data. Data collection and analysis were done concurrently which ensures a mutual interaction between what is known and what one needs to know (Morse et al., 2002). Negative cases were sought out and data saturation was used which prevents premature closure of the analysis. Lastly, verification can be obtained from 'thinking theoretically' (Morse et al., 2002) in making small cautious steps of analysis and avoiding large theoretical 'leaps'. The preliminary analysis was discussed with the co-investigator of this study. Multiple excerpts in the results sections are evidence of the analysis with a summary of themes (Table 4). Journaling was done of reflections and interpretations during analysis which can reduce author bias (Tong et al., 2007) and also serve as an audit trail. Assumptions about modality decision-making for older adults were articulated in the proposal stage.

Results

The following themes represented home-dialysis decision-making for older adults; 1) precariousness with limited choices for survival, 2) personal factors, 3) gender differences and 4) the necessity of support. Excerpts from the interviews will follow the themes. Analysis of the HCP interviews will be described below and then integrated into the themes.

The HCP described CKD services which included a formalised team education programme and clinical care map. This was used as a guide, as care is individualised focusing on a philosophy of patient choice and building relationships with patients and their family. The HCP described the ageing adult with CKD as having precarious health and for some, living one day at a time rather than planning for a future on dialysis. They described many as being overwhelmed and ‘not wanting to burden their adult children’. At times older adults with CKD lacked insight into their abilities to perform home-dialysis independently. The HCP acknowledged they had an opinion on best modality selection and would attempt to influence the choice if home-dialysis was not going to be successful based on their professional experience.

Precariousness with limited choices

Older persons with CKD in this study were in a precarious state due to their failing kidneys, persistent uncertainty and limited choices which included survival with dialysis or death from their kidney disease. This theme includes a changing health status, following the regimen to stay well and avoid the need for dialysis, choosing dialysis for survival, limitations for transplantation and persistent uncertainty. An awareness of the deterioration of their health status due to their CKD was widely expressed by the majority of participants. Common symptoms included restless legs, pruritis and leg cramps, while most experienced fatigue which impacted their lifestyle and limited their activities. The participants perceived that their age further limited their preferred choice of transplantation. None of the individuals in this study rated their health as poor or excellent but variations of fair, good and very good. The CKD staff described the older adult with CKD as having precarious health with an uncertain future. For example:

> ‘I’ve made this informed decision, I do not want dialysis because I am 87 and I’m going to die first’ still the majority at that last minute will say “I think I’ll reconsider”. That’s huge in terms of modality education in the elderly. It’s huge with anybody, but particularly with the elderly. Most 60-year-olds are hedging their bets saying “I really don’t think this is going to happen”, while the elderly are saying “will I die first” (HCP 1).

Chronic kidney disease is slow and insidious with symptoms not present until the late stages. There was recognition of a changing health status attributed to their CKD. The following represents an awareness of their changing health status:

> "Now lately, aside from the itchiness, I lack energy. I used to do this stuff 10 hours a day, 12 hours a day and now, you know, after a couple of hours I am exhausted, you…I wasn't swelling, I wasn't really holding fluids. But since that time, I definitely have, I'm itch like crazy" (Participant10).

Many people described following the regimen to delay progression of their kidney disease. Living with CKD required following a burdensome regimen including frequent medical appointments, bloodwork, diet restrictions, injections, and monitoring of blood pressure. Despite efforts to prevent the progression of their CKD participants perceived need for dialysis was beyond their control; here is one woman's example:

> "Our family doctor and she told me Mary you look after yourself very well and if you continue to look after yourself you may never need to go on dialysis. So that was a big thing for me and I said I will look after myself. So I am trying my level best, but if I have to …
> [husband] Blood chemistry can change, you know about that" (Participant 6).

All the participants made a choice for dialysis when needed; however, this choice was limited, as a means for survival. They spoke about the possibility of dying from their kidney disease if they did not receive dialysis. Many participants described the need to start dialysis for survival and this quote is indicative of patterns reported:

> "Yeah, I was afraid of it. I didn't want to know because it's another thing that I have to, I wasn't my own person anymore. So, if it isn't one thing, it's something else. So, now you are going on this dialysis and it is something else you have no control over. But ... if I don't I would just lay down and die right there. And, I can't because I've gotta keep my wife going" (Participant 2).

Participants were also hopeful that dialysis would be an opportunity to feel better and regain some quality of life. Three participants had specific expectations of dialysis to reduce their uremic symptoms and improve their health. Expectations of dialysis were reported:

> "With me, shortness of breath is a definite one, nausea, I am getting some mornings but I just dismiss it. I won't let it happen, I just won't And no appetite, I eat but I don't taste it … they tell me that once you have dialysis that apparently it makes a big difference. But people are telling you all these things" (Participant 8).

Inherit in precariousness is uncertainty. Throughout the interviews the participants asked many questions to the researcher regarding dialysis. It was unclear if the participants were looking for reassurance or more information. Many of these questions were related to the different types of dialysis, the dialysis equipment, access and when dialysis will be initiated. The questions represent the uncertainty and indicate the need for ongoing education and support from HCP beyond modality decision-making. For example:

> [wife] "Well I'm just hoping he feels better. I see a lot of patients [wife is a dietitian] with diabetes and kidneys, through my work, and one guy says 'it's perfect, I feel so much better, more energy' and another family says 'I fee horrid and tired and exhausted after dialysis'. I don't know what's going to happen" (Participant 5).

Personal factors

Personal factors influenced dialysis modality decisions such as knowledge (previous and new) about dialysis and their individual preferences/lifestyle. Knowledge of the treatment options assisted participants to make a modality selection in the context of their life. Previous life experiences as well as new information provided by HCP or self-directed impacted on knowledge and perceptions. Advice from HCP was important as was seeing the different modalities and speaking to a person who was currently on that form of therapy.

Some participants had very little prior knowledge of dialysis. For example, "I didn't even know what it was when I first started, I had no idea. Oh, yes, I got a big book. No, I had no idea and I really didn't know anybody that was on it either. I hadn't any idea" (Participant 3). Many people had a previous awareness and preconceptions of dialysis based on life experiences such as; "I belong to the [community club] and any given week, we probably drive 20 people for dialysis and I don't think I want to do that. Three days a week for three hours or whatever" (Participant 10).

The HCP acknowledged that prior life experiences, values and beliefs can influence modality decision-making, for example:

> "…the life experiences and all that, chances are the longer they have lived, the more they have had the possibility of running into somebody or knowing somebody that has been on dialysis. And they have watched or heard the experiences of that person dying, so that definitely colours the whole….So those life experiences, 'Joe died on dialysis'. Yeah I'm not doing it" (HCP 1).

Learning about their options was an important component of decision-making. The education provided information about their options which they could place in the context of their own life to make modality choices. In addition to proving information on dialysis, the HCP believed their interventions should "not just [be] about a dialysis therapy but choices in your care, understanding what some of that is, but also clarifying values' asking the question of what, what is important to me and do I understand it" (HCP 1).

Many people with CKD found the classes and tour helpful; however, no one education method was superior. The HCP provided various educational opportunities; for example, "I was given options and I took the courses, the three classes. That helped to know the difference of what people were talking about" (Participant9), "then we went and had a tour of the peritoneal and home-dialysis" (Participant 5) and 'the book was good. So anything I didn't absorb in the class it was in the book. I also had a chance to ask different people in the hospital and they would give me more information" (Participant 9).

With some awareness of their options and no perfect form of dialysis, the participants made choices based on which modality best suited their preferences and lifestyle. Although there were some commonalities influencing their decisions such as avoiding the hospital setting, independence and concerns about driving for HD, these choices were very specific to each person and their life. One participant was concerned about infection and the maintenance of external access for dialysis:

> "I am not gung-ho about using my neck or the stomach....I really feel concerned about infection, I am concerned about tubes hanging in and out...at least when you go to the hospital, you get it done and you leave" (Participant 9).

Gender differences

Gender differences were noted between men and women in their approach to learning about dialysis and caregiving. Compared to the women, the men in the study were less likely to seek out information regarding dialysis and more likely to delay making modality decisions. Women in the study reported being more accepting of the need for dialysis and more readily sought out HCP services and information to prepare for dialysis. For some of the males with CKD, it was their spouses that sought out the information and initiated the process. One of the male participants hadn't made a decision for modality and another had chosen home dialysis but had not decided between HD and PD. One couple shared their observations of patterns noted from the education class, "I certainly think, you know of that group, let's say there were 6 or 7 people there, almost everyone had their partner with them and almost every one of the men said the same thing – it's the women driving it" (Participant 10). One woman expressed wanting to know more about her options and this quote was indicative of patterns expressed by many women:

> "I want to know what they are doing, why, and do I have to do anything to prepare for this, and what is it going to be like after. I just want to know.... Yes, education is, I don't like the word power, but education if you can educate yourself about it, it makes it easier I guess" (Participant 4).

Rather, the men were more likely to respond with delay for example:

> "If I have to have it, I have to have it. I'll do whatever I have to do to stay away from it. I guess, I'll probably deal with it when it comes. The fact of the matter is, I don't spend my life worrying about what if" (Participant 1).

The HCP also discussed observations they had made of caregivers.

> "You see so many unwell men and the women are placed in that caretaking role and, as women, we are so geared and oriented to caring for others at a great cost to ourselves. All of us really try to balance all of that. And I try not to put women in that situation. You do see men who support their wives, I don't want to wipe that totally. Generally, there are role definitions, and that's society generally right, and it plays itself out here" (HCP) 4).

The necessity of support

The largest enabler reported by the HCP for older adults with CKD to be successful with home-dialysis were support and resources. Having financial resources influenced access to resources. Without sufficient support and resources, older adults with CKD had limited choices. The HCP believed support for the older adult was:

> "Everything. From getting back and forth to appointments, feeling that they've got someone there trouble-shooting with them or for them, physically managing the lifting of bags, tubes and doing connections, writing down their results. The elderly can succeed very well depending on who is taking care of them. You can dialyze anybody at home, depending on who is doing it for them" (HCP 1).

Without resources the HCP believed modality options for the older adult were limited:

> "A huge part is the training time, but again, overwhelming that's a lot of other stuff. So, it's almost like the elderly don't have full choice. They are a little bit limited unless they can pay a nurse to go into their home to do it, that's not an option" (HCP 1).

Participants were also aware of the necessity of support. They described several ways in which they received/required support. For every participant decision-making was shared with either a spouse or members of their family. In order for family members to provide support during the decision-making process they too were required to gain knowledge about the dialysis. They often helped reinforce information regarding dialysis and advice from HCP. The use of language often changed from 'I' to 'we' in regards to decision-making. Family members also clarified information that was incorrect; for example, "I mean, I don't know everything about it either. That's why I take [my wife] along with me. She has a better understanding of it and if I don't pick it up she is there to explain" (Participant 5).

The availability of support in the home to assist with performing the dialysis and problem solving was a key determinant for home-dialysis. Of the four participants that chose HD three lived alone. Only one person who chose home-dialysis (PD) lived alone. Confidence in being able to manage home-dialysis also depended on the availability of supports such as home care and the access to resources. Many participants described essential support for home-dialysis for example:

> "She [wife] does most of that. She gets my pills and everything for me too. She gets it all lined up.
> *Researcher: Yeah, so if you didn't have your wife's support to do the dialysis at home that.*
> That would make a difference, yeah" (Particpant 2).

The HCP also provided support. The participants valued the relationship, opinion of the timing of when dialysis would be needed and their reassurance regarding modality decisions. For example:

> "Dr. Y went through the different types with me and also they did that with the classes and then when Dr. Y talked to me again about it, he thought the PD would be the best. It would be the most suitable for me. So, I go by that, I trust that he knows what he is talking about" (Participant 13).

The HCP also acknowledged they held some bias for best modality selection and will attempt to influence choice if they believe home-dialysis will not be successful. The participants did not appear to perceive any undue influence by the HCP:

> “I think every practitioner has their own experience with home-dialysis and brings their preconceived ideas about what is a good home-dialysis patient….I would go on a limb, though, that we need to open that up a bit and not have criteria and look at everyone as a potential home-dialysis patient and identify what the barriers will be....So I think as HCP we need to be banging down those barriers and identifying that they are not barriers anymore and that we have different resources” (HCP 3)…. “hopefully we will be able to work through it slowly over time. I am not going to go in double-barrel and be cruel and say “I don’t think that’s possible”, but develop that rapport over time and say that maybe these options might not be possible given what your physical body says” (HCP 2).

Discussion and Implications

In summary, the results of this study indicated that age alone is not a barrier to home-dialysis decision-making; however without adequate supports and resources the choices for older adults with CKD are limited. Older adults with CKD are in a precarious state with fluctuating health, persistent uncertainty about their future and faced with the decision of dialysis or death from their CKD. Decision-making is based in the context of their general health, preferences, lifestyle and social structures such as support, gender, role of caregivers, HCP and access to resources. Important facilitators to home-dialysis are functional status, resources and the amount of support required in the home. Gender differences were apparent.

Many authors have concluded that age is an important factor in home-dialysis uptake. Dialysis modality decision-making processes for the older adult are very similar to how younger adults with CKD make modality decisions (Harwood & Clark, 2012b; Morton et al., 2010). Rather, age is not a barrier to home-dialysis but a cue for more individualised care where home-dialysis is possible. Participants in this study spontaneously mentioned their age precluded them for transplantation. Some mentioned receiving unclear advice from the nephrologist in regards to their transplant suitability. Perhaps this reflects hesitancy on behalf of the HCP to explore transplantation with this older population particularly in the CKD period prior to dialysis. However, this needs further exploration as there is no age limit for transplantation but rather co-morbid status.

Dialysis modality education is important for decision-making and reducing uncertainty. This education is ongoing as patients expressed many questions about dialysis and life with dialysis throughout the interviews. CKD education and support requires a team approach. Modality decision-making is shared between the patient, family and HCP and every attempt should be made to include families in the process. The HCP believed face-to-face education was most efficacious for older adults due to changes in hearing and vision where use of technology varied greatly. Older adults may require ongoing education with more repetitions to understand concepts; however, more research in this area is needed.

HCP have a very large influence on access and uptake of home-dialysis and as stated biases are present. HCP need to be aware of how their influence can impact on modality choices particularly when giving opinions and reassurance regarding their selection. How, where and what content is given/not given to patients about home-dialysis can also affect their decision.

The participants stated it was their choice to have dialysis when needed and some had specific expectations that it would improve their deteriorating health. This is in contrast to another study which reported older adults did not make a choice for dialysis but simply went along with the HCP interventions and ‘acquiesced to dialysis’ (Russ & Kaufman, 2012). However, the HCP in this study described many older adults with CKD as ‘living one day at a time and not planning for a future on dialysis’. Perhaps people with CKD who do not plan for dialysis may be less included to volunteer for research which involved an interview on modality decision-making. The HCP stated patient choice was the philosophy in their clinic and it appears from this sample that they are achieving this. The research conducted retrospectively on satisfaction with dialysis is cautious with 60% of patients on dialysis expressed regret with their decision to start dialysis (Davison, 2010). Retrospective recollections with older people starting HD demonstrated that 90% were optimistic about dialysis and had high expectations at initiation but after 6 months only 45% found dialysis acceptable (Stringer & Baharani, 2011). Yet, high levels of satisfaction have been reported by older persons on home-dialysis (Derrett et al., 2010). With high levels of regret reported it raises the question if older people with CKD have realistic expectations about quality of life and symptom relief with dialysis and how potentially HCP influence these expectations.

Another important factor in enabling home-dialysis was access to services due to financial resources. Older persons are generally considered to have limited financial resources. The income of the participants in this study varied greatly (see Table 3). Having the financial ability to purchase services when they are not able to perform them independently may enable older adults to stay in their homes longer and possibly benefit from home-dialysis. This raises the question are older people with CKD who have access to more resources due to finances more likely to select home-dialysis?

Uncertainty

CKD is a liminal state (Molzahn, Bruce, & Sheilds, 2008) of in-betweens, not yet on dialysis but not feeling ‘normal’ and highly uncertain. High levels of uncertainty can impede decision-making with more emotional-orientated coping and poorer psychosocial adjustment (Mishel, 1988). Quantitatively feeling unsure about life with dialysis and not knowing when dialysis will be needed was ranked in the top ten of CKD disease related stressors (Harwood et al., 2009). Uncertainty about disease progression was commonly reported when the CKD trajectory of illness was examined with older adults with CKD and was believed to be mirrored from the physicians experiencing lack of control in predicting when dialysis will be needed (Schell, Patel, Steinhauser, Ammarell, & Tulsky, 2012).

Despite the uncertainty all the participants except one had made modality decisions and four already had an access inserted for dialysis. Factors such as good relationships with HCP, CKD education, resources and family support may have minimised the effect of the uncertainty for the people in this study and enabled decision-making, however; others may not be as fortunate. For those unable to make a decision interventions to reduce uncertainty could become a priority such as engaging and establishing a rapport, education, mobilising supports if they are absent and reducing decisional conflict (RNAO, 2009).

Gender Differences

Critical realists acknowledge the importance of structural factors such as age, race, place, and gender. The results of this study uncovered gender differences in the approach to decision-making. One other study examining socio-demographic differences with stressful experiences and coping in people with CKD (mean age 64.5 years) demonstrated gender differences. The amount of CKD related stressors was equal however, women reported using more coping strategies and found them to be effective. The authors concluded that women were more likely to seek out and use supportive interventions and services offered in CKD programmes (Harwood et al., 2011). The women in this current study responded to existing, traditional approaches in CKD programmes and coped with the uncertainty that dialysis may be needed in the future. Rather, the men wanted to be told a timeline when dialysis will be needed and a deadline for decision-making. It is unclear if men approach decision-making differently or if the womens' response is reflective of societal expectations for caregiving. For men who tend not to engage in CKD services it may be important to involve their spouses as facilitators to decision-making. More research is needed to understand this difference and examine how the social roles influence modality decision-making and find methods which assist men with this decision-making. Understanding these patient-care partnerships is important for successful home-dialysis in older adults (Namiki, Rowe, & Cooke, 2009).

Social Support

Several previous studies have demonstrated that support can increase the likelihood of a person starting on home-dialysis. The results of this study confirm that social support was essential for home-dialysis. This study is unique in that it provides more insight into the type of support needed by this population. Two types of support were present in this study. Firstly HCP provided support for information and reassurance. Secondly, social support provided by family members included performing dialysis, assisting with decision-making, problem solving, tasks related to their care, reassurance and emotional support.

Of the four people in this study who did not chose home-dialysis two made the decision based on personal preference while the other two did so based on their functional abilities and support. One indicated that if there was home nursing support for PD in her community she would have chosen home-dialysis. Currently home care support for PD in this setting is inconsistent and varied while formal assisted PD programmes (Cheng et al., 2013; Franco et al., 2013) are in use in other countries specifically to enable older adults to receive dialysis in the home. Providing home support for PD which is consistent and persistent should increase home-dialysis uptake. Further investigation of social support is a priority. The question needs to be asked ‘Can aspects of social support be duplicated and services provided?’ A more detailed understanding of social support for this population is a prerequisite for trials of supportive interventions. Funding policies may need to change to allow for more support in the home.

It is important when interpreting the results that the volunteers came from one renal program in one academic teaching centre. There was a sample bias as the volunteers for this study were highly functional with adequate levels of health literacy. All were living in their own homes and had good mobility with the exception of one who used a mobility aid and had difficulties with her activities of daily living. It is important to note that choice does not always equal service usage and this should be taken into consideration when interpreting the results.

Conclusion

The socio and contextual factors associated with age are important determinants for home-dialysis modality selection. Supportive interventions will be required to increase the numbers of older adults who can benefit from home-dialysis and this has health services and policy implications.

Relevance to Clinical Practice

The cohort of ageing adults with CKD is large and growing in many countries and research in this area is limited. A better understanding of the barriers and facilitators for home-dialysis decision-making for this population is needed for quality interventions. The findings of this study are relevant as this information may be used to improve healthcare services delivery to potentially enable older adults to benefit from home-dialysis, which also contributes to economic sustainability of dialysis services. Specific information in this study on education and supportive interventions can be applied by clinicians to CKD programmes and services to promote home-dialysis and meet patient needs.

Table 4.1

Summary of Studies on Survival Benefit of Dialysis Compared to Conservative Management (CM)

Author	Age	Mean Survival Time	Comments
(Murtagh et al., 2007)	Greater than 75	Dialysis 19.6 months CM 18 months No survival benefit with dialysis if ischemic heart disease was present	Survival on dialysis was decreased significantly with comorbid disease.
(Smith et al., 2003)	61.5 Mean age	No survival benefit	
(Joly et al., 2003)	Greater than 80	Dialysis 28.9 months CM 8.9	
(Carson, Juszczak, Davenport, & Burns, 2009)	Greater than 70	Dialysis 37.8 months CM 13.9 ($p<0.01$)	
(Chandna et al., 2011)	Greater than 75	Dialysis 61.7 months CM 21.2 ($p<0.001$)	

Table 4.2

Inclusion Criteria

• 65 years of age or older • stage 3-5 CKD • advised by a nephrologists that dialysis may be in their future • have no medical contraindication for a particular modality • the nurse in clinic has begun modality education (verbal and written) • not undergoing a pre-emptive transplant workup • able to speak and understand English
• The HCP working in the CKD clinic

Table 4.3

Demographics of Sample

Demographic	**Total**	**Male**	**Female**
Sex	13	7	6
Age			
65-74	7	5	2
74+	6	2	4
CKD Stage			
4	1	1	0
5	12	6	6
Modality			
No Answer	1	1	-
Home Dialysis-Undecided type	1	1	-
Home Peritoneal Dialysis	6	3	3
Home Haemodialysis	1	1	-
In-Centre Haemodialysis	4	1	3
Education			
Less than high school	1	0	1
High school graduate	5	2	3
University/College graduate	7	5	2
Employment			
Full time	1	1	0
Part time	1	1	0
Retired	10	5	5
On disability	1	0	1
Lives Alone			
Yes	4	1	3
No	9	6	3
Ethnic Group			
White/Caucasian	12	7	5
South Asian	1	0	1
Self Perceived Global Health Status	0	0	0
Poor	3	1	2
Fair	8	6	2
Good	2	0	2
Very Good	0	0	0
Excellent			
Income ($USD)			
Less than 20,000	2	0	2
20,000-40,000	8	4	4
40-99	2	2	0

Greater than 100,000	1	1	0
Education Sessions Attended			
None	2	1	1
One	1	0	1
Two	3	2	1
All (three)	7	4	3

Table 4.4

Summary of Analysis

Theme and Categories	Study Number Supporting Theme
1) Precariousness and limited choices	
a) Changing health status	2, 3, 4, 5, 7, 8, 9, 10, 11, 13 Not 1, 6, 7, 12
b) Staying well to avoid dialysis	1, 2, 3, 4, 5, 6, 7, 9, 10, 11, 13
c) Choosing dialysis for survival	2, 3, 4, 5, 6, 7, 8, 9, 10, 13 not 1, 11 12
d) Uncertainty	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13
e) Transplantation	1, 3, 4, 5, 7, 8, 9, 10, Not 2, 6, 11, 12, 13
2) Personal factors	
a) Gaining new knowledge Previous Knowledge	1, 2, 3, 4, 5, 7, 8, 9, 10, 11, 12, 13 1, 4, 5, 6, 10, 13
b) Preferences/Lifestyle	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 13
3) Gender Differences	1, 2, 8, 9, 10, Not 5, 7 (males only)
4) The Necessity of Support	1, 2, 3, 4, 5, 6, 7, 8, 9, 10, 11, 12, 13

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Chapter 5: Discussion

This chapter provides a summary of the major discussion points in the previous chapters. The contributions of this body of work to new knowledge will be synthesized and the implications for practice, policy and research will be discussed.

Major Discussion Points

In summary the results of the papers composing this thesis demonstrated:

1. Critical realism was used to guide how CKD decision-making was conceptualized. The worldview influenced what it is to know about CKD decision-making and how this knowledge was generated with the methodology. Dialysis modality decision-making is complex. Critical realism is a viable framework for investigation of CKD treatment decisions. Using critical realism as a framework for this body of work has contributed to our understanding of what types of patients choose home-dialysis and under what circumstances (Chapter 1).
2. The systematic review and meta-synthesis demonstrated that dialysis modality decisions were highly influence by personal and family values, made in the context of their life and a desire for minimal intrusiveness. Interventions should focus on planned and timely discussions, family preparation, knowledge of the different modalities and how they impact on

lifestyle. The results of this review revealed that research in this area was often conducted after the person starts dialysis and gaps were noted in the research of an important cohort; the older adult with CKD (Chapter 2).

3. Living with CKD is stressful and the amount and type of CKD related stressors predicts dialysis modality usage. High levels of CKD stress were associated with higher service usage of in-centre hemodialysis. Physiological stressors such as fatigue, sleep problems restless legs, muscle cramps and neuropathy were reported with the greatest intensity (Chapter 3).
4. Older adults with CKD make dialysis modality decisions similar to younger adults. Age is not a barrier to home-dialysis but the personal and contextual factors associated with age places limitations on their choice for home-dialysis selection. Living with CKD is a precarious situation for older adults. Functional status, resources and support provided by family and health care professionals are important determinants of home-dialysis selection for this age group. Gender differences were noted in decision-making (Chapter 4).

Contribution to New Knowledge

This thesis has contributed new knowledge about conceptualizing CKD in the areas of dialysis modality decision-making and home-dialysis decision-making for the older adult, CKD stressors and home-dialysis service usage and the use of critical realism to generate new knowledge in this area. The first paper in this thesis has made a theoretically contribution being the first to use critical realism to conceptualize CKD decision-making (Harwood & Clark, 2012a). This is important as it can change what we know and what it is to know by helping people think about CKD decisions differently. Critical realism informed the methodology with the use of critical realist ethnography (Porter & Ryan, 1996) and the method with realistic interviewing (Pawson & Tilley, 1997). This is important as the use of critical realism in framing the generation of nursing knowledge is relatively new and increasing. This contributes to the body of work using critical realism as a viable framework for the generation of new knowledge in nursing.

The systematic review (Chapter 2) demonstrated that several qualitative studies on dialysis modality decision-making existed and this literature was synthesized into an interpretive explanation. While two systematic reviews have been previously published on CKD treatment decisions (Morton et al., 2010; Murray et al., 2009), this was first to focus on dialysis decision-making. Decision-making in this study was highly personal and strongly influenced by patient and family values, the context of their life and a desire for minimal intrusiveness. The findings from this synthesis examined patterns and themes across the studies with are more generalized knowledge claims to guide practice and research. This work highlighted some weaknesses and gaps in what was known in this area such as the lack of studies with older adults conducted prior to the start of dialysis. It was also noted that socio-demographics were poorly reported in the studies reviewed. This provides support for the benefit of consolidated reporting criteria for qualitative research (Tong et al., 2007). Subsequently the demographics of the samples in the empirical work for this study are well described.

The quantitative work of this thesis is the first study to identify that CKD stress levels influence home-dialysis service usage (Harwood et al., 2012). This study contributed to our knowledge on the stressors, both personal and structural that people with CKD experience and influence their modality decisions. How these stressors influence their modality decision-making processes remains unknown. This study raised the important question if we target our interventions for people with CKD to reduce or help them cope with the common stressors related to the CKD (fatigue, sleep problems, restless legs, muscle cramps, neuropathy) would they be more inclined to choose a home therapy? The sixth most common stressor was “feeling unsure about life with dialysis” and the qualitative work of this thesis (Chapter 4) demonstrated that this uncertainty was universal in the participants but amenable to interventions such as education and supportive relationships with the health care team.

The qualitative study (Chapter 4) was innovative in that the sample was entirely composed of people pre-dialysis where active decision-making occurs and the potential exists for responsive interventions. This study also focused on one cohort (older adults) providing important information for this growing group in Canada**.** Many studies have concluded that age and co-morbid status are barriers to home-dialysis (Chanouzas et al., 2012; Jager et al., 2004; Luijtgaarden et al., 2011). The results of this study are unique in that age inherently is not a barrier to home-dialysis decision-making however, without adequate supports and resources, the choices for older adults with CKD are limited. While many other studies reported that social support is important for home-dialysis uptake (Harwood & Clark, 2012b; Jager et al., 2004; Morton et al., 2010; Oliver et al., 2010; Plantinga et al., 2010; Zhang et al., 2010), by using a qualitative method this study provided more insight in the type of support needed. This study was also one of a few studies to find differences in the approach to modality decision-making processes due to gender. The women in this study, even if they had CKD, or their spouse had CKD readily sought out information on dialysis and responded to the traditional educative and supportive interventions provided. It is unknown if gender differences exist in dialysis modality decision-making processes or if this response is influenced by societal expectations of female caregiving.

The course work for this thesis also resulted in the final paper for the multivariate statistics course being published in a national nephrology nursing journal (Harwood, Ridley, Wilson, & Laschinger, 2010). This multivariate analysis examined the relationship of occupational burnout and job retention and health outcomes for Canadian nurses working in nephrology. The results indicated that almost 40% of nurses' mental health symptoms and 27.5% of physical symptoms could be attributed to occupational burnout. This paper contributed to new knowledge about what is known in this area specific to the area of nephrology nursing in Canada.

Implications for Practice, Policy and Research

The findings from the papers in this thesis have implications for practice, policy and research specifically in the areas of CKD education, support and resources and gender.

Practice Implications

A universal implication of this study and many others is that modality education for people with CKD is an essential service to be offered. The recommendations from this thesis specific to dialysis modality education have been summarized (see Table 5.1).

Table 5.1

Recommendations for Dialysis Modality Education

Findings	Recommendation	Rationale	Research
Education is important to decision-making.	This thesis provides further support for clinical practice guidelines that CKD programs have a multi-disciplinary modality education program in place and that this is a priority.	Many studies have shown that education improves home-dialysis selection.	See Table 1-1 in Chapter 1 (Harwood & Clark, 2012b; Morton et al., 2010)
Family/support persons also acquire knowledge of modalities to help support decision-making.	Family/support persons should be included when the information is provided.	Support is needed for decision-making and home-dialysis selection.	(Harwood & Clark, 2012b; Harwood & Clark, 2014; Jager et al., 2004; Morton et al., 2010; Murray et al., 2009; Oliver et al., 2010; Rosenroll, Higuchi, Dutton, Murray, & Stacey, 2013; Zhang et al., 2010)
Patients expressed valuing the opinion of others on dialysis.	Provide opportunities for discussions with other people on dialysis.	Peers influence modality decision-making.	(Harwood & Clark, 2012b; Harwood & Clark, 2014; Morton et al., 2010; Murray et al., 2009; Winterbottom et al., 2012).
People experience uncertainty when making modality decisions.	Modality education should be ongoing even after the decision has been made and access created.	Education reduces uncertainty.	(Chiou & Chung, 2011; Harwood & Clark, 2014; Harwood et al., 2009; Schell et al., 2012)
Men may be less likely to seek out information about dialysis.	HCP may need to use other methods to engage men in decision-making.	Men may use different methods of obtaining information and making health decisions than women.	(Harwood & Clark, 2014; Martinez et al., 2012)

Older adults with CKD and their HCP in the qualitative study (Chapter 4) voiced some other important educational interventions however due to the publication length of the journal did not make it into the final publication. These suggestions for practice are as follows:

- People with CKD need to have verbal instruction on the different types of dialysis (HD and PD) but also need to see the different equipment used for PD and HD.
- Tours of the dialysis area help the people understand the different types of dialysis and provide an orientation to the environment.
- Face-to-Face education may work best for older persons. Older persons may need repetition and reinforcement of important material.
- Written material to take home for reference was important.
- The use of technology is variable with older adults.
- Providing patients with HCP contact information was viewed as being supportive if they had further questions.
- Following the renal diet was difficult. Support provided by the HCP was perceived as being helpful and appreciated by the patients.

The support of health care providers was an important influence on home-dialysis decision-making. Older persons with CKD highly valued the recommendations from the physician on a suitable form of dialysis (Harwood &

Clark, 2014). Subtle differences in how this is done or framed can have an impact on decisions. For example, in this study some people stated they were told about the different types of dialysis and the decision regarding the type of modality was their choice (Harwood & Clark, 2014). However others stated they were given a choice but the physician recommended one type of dialysis over another would be ‘good’ choice for them (Harwood & Clark, 2014). It is a subtle difference in how the information is presented but as the HCP opinions are highly valued by patients this difference could affect decision-making.

The findings of this thesis indicate that support was needed not only for decision-making and for other aspects of the CKD regimen, such as transportation to and from appointments, meal preparation following the renal diet and reinforcing information from the healthcare team (Harwood & Clark, 2014). HCP in CKD clinics are required to become skilled as assessing for adequate support in the home. The individuals who volunteered for this study all indicated they had good supports in place however this raises the question what happens to modality decision-making, the ability to follow the CKD regimen and access to care when adequate supports are not available?

The results of the qualitative study in this thesis (Chapter 4) demonstrated sex-differences between men and women. The men appeared to delay seeking out information on dialysis and making modalities decisions. In comparison, women regardless if they had CKD or were the caregiver they were more likely to initiate obtaining more information about dialysis and make modality decisions. It is important to note that in two cases in this study the men were in the supportive caregiver role. This gender difference has important practice implications as preparing for dialysis with the appropriate access takes time and delays in modality decision may influence who starts on home PD in a planned manner or who starts in-centre HD with an urgent access. Further research on these potential gender differences to decision-making processes needs to be explored and if they have any impact on outcomes. Research in this area is important as men comprise 62.2% of new dialysis starts in Canada (CIHI, 2013).

Policy Implications

Education is an important factor in dialysis modality decision-making and the healthcare system in Canada provides universal access to this education. In comparison, in the United States Medicaid and Medicare only passed the legislation in 2008 mandating free education programs for people with stage 4 CKD which includes modality options (Young, Chan, Yevzlin, & Becker, 2011). People with CKD require information on their options in order to place them in the context of their life (values and beliefs) and make health decisions (Harwood & Clark, 2012a, 2012b). However, it is important to acknowledge that modality decision-making is complex, highly personal and is influenced by factors other than education. If a person does not place importance on being autonomous with their dialysis schedule and/or lack support and feels insecure about performing own their dialysis, education will not be enough to enable the person to select home-dialysis. This is particularly important for renal programs to consider when policy and utilization targets have been set (ORN, 2013) and what is amenable to health services and what is not.

The availability of support in the home to perform home-dialysis was an important enabling factor and increased access to home-dialysis for the older adult (Harwood & Clark, 2014). All of the individuals in the qualitative study who choose a home therapy relied on a support person regardless of their level of physical and cognitive functioning (Harwood & Clark, 2014). For the individuals with CKD who did not have support to assist/perform the dialysis home-dialysis was not possible. Many studies have shown support to be important for home-dialysis (Harwood & Clark, 2014; Jager et al., 2004; Morton et al., 2010; Oliver et al., 2010; Zhang et al., 2010), yet, supportive services in the home (in the setting where this study took place) are inconsistent and variable (Harwood & Clark, 2014). If changes to funding allocation and supportive services are not available a large subset of the largest cohort requiring dialysis are unlikely to benefit from home-dialysis (Harwood & Clark, 2014).

Research Implications

This body of work discusses the importance of dialysis modality education. The results of many studies have demonstrated an impact on home-dialysis selection despite great variation in the education programs (see Table

5.2). Given the large variation in education programs it is unclear what content and what method to deliver the education is most effective and thus the best use of resources. A systematic review on this literature would provide a comprehensive synthesis of the studies in this area. A realist review would be well suited to explain how these programs work (or why they fail) and provide a deeper understanding of how these programs can be made to work most effectively (Pawson, Greenhalgh, & Walshe, 2005). There is a lack of information on dialysis modality education specific to the older adult and this should be a priority area of further research. The realist review method conducted with older adults with a chronic illness in determining what health education programs are effective and the possible application to older adults with CKD may be beneficial.

The support required in the home for CKD and home-dialysis is personal and variable depending on the needs of the individual. In order for CKD teams to design supportive interventions for this population to increase the uptake of home-dialysis more needs to be known about social support. Current gaps exist in our understanding of what social support is needed in the home to perform home dialysis for the aging adult with CKD. Social support is a very important area of study as it is a modifiable risk factor in chronic illness, and can positively impact on health outcomes for people on dialysis such as depression, quality of life, access to health care, patient compliance and survival (Cohen et al., 2007).

Further research exploring what support is required from the perspectives of the health care professionals, patients, caregivers and community providers should be conducted for pre-dialysis, home PD and HHD before trials of interventions and economic evaluations can begin. Quantitatively, knowing what predictors of social support are most associated with home-dialysis selection and service usage would also be important to guide decisions for health services.

From the qualitative component of this thesis it is evident that modality decision-making was done in the context of shared decision-making. Elements of normative decision-making theory particularly utility theory can also be seen in the results whereby the people with CKD were making reasoned decisions weighing the personal benefits of one type of dialysis over another. This decision-making also appears to go beyond shared decision-making which is generally considered to be between the patient and physician (Charles et al., 1997) with the important involvement of the healthcare team (Harwood & Clark, 2014). This is more reflective of inter-professional shared decision-making where patients are supported to make decisions and choices by a team and have their decisional needs met (Legare, Stacey, & Graham, 2008). This opens up a new area of research in modality decision-making in which nursing research can play a large role.

Having financial resources enabled access to services to help with their CKD regimen, such that if one is not able to provide the activity him or herself (such as performing home-dialysis, driving or grocery shopping) and has the financial means to do so services could be purchased decreasing the limitations imposed by age on modality selection (Harwood & Clark, 2014). It was apparent from observations from conducting the home interviews and hearing patient and caregiver concerns that the participants in this study with more financial resources had more modality options; whether it be purchasing services (people to perform the home dialysis), renovating the home to accommodate home HD, travelling with HD and knowing people in leadership positions in healthcare to access if needed. The only Canadian study using area-level data to examine the impact of socioeconomic status on home-modality (PD) service usage did not find that socioeconomic status was a significant predictor of home-dialysis choice or eligibility (Prakash et al., 2013). However, patients residing in lower income areas had more space and family/social support barriers (Prakash et al., 2013) than those people living in the higher income areas. The authors concluded that socioeconomic status was not associated with PD choice however socioeconomic status may influence specific barriers to PD choice. The authors recommended a future study including in-depth interviewing which would be better suited to analyzing barriers and choices to home-dialysis (Prakash et al., 2013). Qualitative methods using social theory enhance objective measures of opportunity structures for a more complete understanding of the impact of these resources on population health (Frohlich et al., 2007). The qualitative study in this thesis, by examining the context of modality decision-making provides some insight into how financial resources could be an enabler of home-dialysis service usage. Further research is needed in this area.

The focus of this research was largely on the individual with CKD yet, the influence of family was an important factor in modality decision-making. It is evident from the results of this study that dialysis modality decision-making is shared with their family/support person/caregiver and should not be overlooked (Harwood & Clark, 2012b; Harwood & Clark, 2014). A recent systematic review and thematic synthesis conducted on patient and caregiver's views of treatment decisions for CKD included 375 patients and 87 caregivers. None of the studies included in the review focused entirely on the caregivers' perspective. When the caregivers were included in the studies they were interviewed with the patient and only one of the studies explored the caregivers experiences as one of the main experiences studied (Morton et al., 2010a). This is consistent with a prior systematic review on support interventions of caregivers of people with CKD in which the authors concluded high quality evidence on the effect of information or support interventions on the physical or psychosocial well-being of informal caregivers and the people with CKD does not exist (Tong, Sainsbury, & Craig, 2008). However, a very recent study examined the perspectives of significant others in dialysis modality decision-making and their roles included providing a positive outlook, 'being with', advocating, caregiving, learning together, sharing opinions and communicating values, preferences and treatment feasibility (Rosenroll et al., 2013).

Knowing the needs, concerns and perspective of the caregivers of people with CKD undergoing treatment decisions is helpful for quality interventions to increase home-dialysis uptake as well as providing support to the caregivers as significant others may have concurrent emotional, informational, and physical needs that affect the decision-making process (Rosenroll et al., 2013). This may be crucially important with older adults as the caregivers may also be aged and may have functional and health problems. The health care team members in the group interviews were aware of the potential stress and burden of caregiving for home-dialysis in older adults (Harwood & Clark, 2014).

It is unknown if the sex differences observed in this study were due to men approaching the problem differently or if the women readily stepped into the caregiver role. Only one other recent study was found which demonstrated gender differences and chronic illness in regards to health decision-making processes and education/information approaches. Men with Chronic Obstructive Pulmonary Disease (COPD) were more likely to obtain information from the physician about their disease while women with COPD were more likely to rely on other sources such as other people with COPD and online support groups (Martinez et al., 2012). Further research in this area is needed with a gender based approach. Secondary data analysis of this study with a gender based approach may enhance the evidence for gender differences in the processes involved in modality decision-making. It remains unknown if gender differences only occur in the older cohort or if they are present in younger adults with CKD.

This study was situated in social theory and framed in a world view of critical realism which has contributed to our knowledge of dialysis modality decision-making and home-dialysis service usage for aging adults with CKD. Future research applying mid-range theories of aging and gender will further contribute to what is known in this area and enhance our understanding.

Limitations

The first limitation of the empirical work for this thesis was the two samples originated from one CKD program and the individuals were self-selecting. In the qualitative study of this thesis the participants had precarious physical health due to their kidney disease but otherwise appeared to be highly functional, seemingly with high levels of health literacy, and living in their own homes. Only one participant used a mobility aid (walker) and required assistance with many of her activities of daily living. Older age can predispose an individual for vulnerability. In addition, frailty is extremely common for older people on dialysis particularly in-centre HD and is associated with a high risk of death (Johansen et al., 2007). One of the CKD registered nurses doing the recruitment for this study commented she observed the more vulnerable older adults in the CKD clinic tend to attended the clinic with their adult children/support persons.

These people were less inclined to volunteer for this study. Concerns were raised about receiving a phone call from the researcher who is unknown to the person would be problematic as this population had a heightened awareness of misrepresentations and being taken advantage of over the phone. The adult children/support person also indicated that they should be present during the interview however, were often too busy to volunteer for the study with working and looking after aging parents. Future studies with older adults with CKD and their caregivers may yield important information in regards to support needed for home-dialysis for a more vulnerable older population. Recruitment strategies with the researcher directly in the clinic may have been a better method of recruitment to capture a more aged vulnerable population.

Another area that is problematic for research conducted in the area of CKD relates to the terminology of CKD. In this study CKD was defined using the National Kidney Foundation Criteria in Appendix A and referred to people not on dialysis. However this criteria is based on estimated glomerular filtration rate not the treatment for kidney disease. Previous terminology tended to use pre-dialysis for what is now CKD. However confusion exists as CKD also can be used to include those on dialysis who previously may have been labeled end stage renal disease. When searching for and reviewing studies in this area caution is needed to determine who the sample refers i.e., CKD on dialysis or CKD not yet on dialysis.

There are benefits to using a theoretical framework to guide methodology. There are also some limitations when using a worldview such as critical realism. When using complexity as the lens to qualitatively explain an experience, in this case modality decision-making, there are trade-offs in studying what is outside of the lens. For example there are benefits in quantifying some experience, despite the fact that critical realist research is predominately qualitative and is cautious of the use of quantitative research. There are benefits in knowing predictors of an outcome which can provide cues further understanding.

Critical realism as a worldview informs research methodology and research conducted with critical realism tends to be theoretical cohesive (Lipscomb, 2008). However gaps remain in how critical realism influences method. For example, crucial realism provides a framework for who is included in the sample and why but not how to determine sample size, what method to use to analyze the data or how reliability or credibility of a research study is to be determined beyond theoretical cohesiveness. All of these questions are for the researcher to determine and maintain consistently with the worldview and can be difficult for the novice researcher. Since critical realism is fairly new as framework for nursing research this raises another area for future research on the evaluation and critique of methods used in critical realist studies in nursing and health research.

Conclusion

In conclusion, this thesis framed in critical realism conceptualized CKD decisions as complex, stressful, and uncertain. Modality decision-making was influenced by personal factors such as lifestyle, preferences, and functional abilities and structural factors such as support, resources and CKD programs (education and support). This body of knowledge has contributed to the evidence base and our understanding on how people make modality decisions and under what circumstances particularly for home-dialysis and older adults with CKD. The results of this conceptualization of CKD decisions have practice, policy and research implications specific to education, support, resources, and gender.

Table 5.2

Education Programs on Dialysis Modality Selection

Authors/ Reference	Sample	Purpose/Method	Educational Intervention	Conclusions
Chanouzas et al., (2011)	Total n=118 pre-dialysis patients from one centre completed a questionnaire	How patient modality choice is influenced by personal and demographic parameters	One day educational session 2 to 4 hours provided by a multi-disciplinary team. All modalities are described in detail. Visual, verbal and written format.	Provision of written information was important. Those who attended the education session were more likely to choose PD.
Chiou & Chung (2011)	Total n=60 Experimental group n=30 Control n=30 CKD patients with eGFR <15	Quasi-experimental design with an experimental group to evaluate the impact education. Pre- and post testing.	A multimedia interactive DVD and nursing guided modality education with telephone follow-up.	The experimental group had higher knowledge of modalities and lower uncertainty and decision regret.
Gomez et al., (1999)	Total n=304 including pre-dialysis and dialysis patients. 174 completed questionnaire following dialysis initiation.	To evaluate a pre-dialysis information package. Multi-centred controlled study. Three questionnaires were given: 1)	Standard education package was distributed including: a flip chart of options, a guidebook on options, a video, and a handbook of questions and answers for	After receiving the education patients had equal knowledge of all the treatments which enabled patients to choose a therapy according to

		knowledge pre intervention, 2) knowledge, post intervention 3) Starting dialysis questionnaire regarding choice of modality.	the educator.	their preference.
Goovaerts, et al., (2005)	n=240 individuals on dialysis.	To evaluate the effect of the education on dialysis modality choice. Retrospective reviews of all modalities chosen during the study period of 6 years.	Structured education program given by a RN including audio-visual tapes.	Patients with *GN or interstitial nephritis were more likely to be on a self-care modality than those with hypertensive nephrosclerosis and diabetic nephropathy. A high percentage of patients exposed to a structured education program started on a self care modality.
Hanko et al., (2011)	All (n=173) patients starting HD with <180 days of nephrology follow-up were	To evaluate the impact of renal triage nurse to educate the suboptimal HD starts	Face-to-face meeting with nurse then counseling, written material, audio/visual, we browsing.	Those seen by the nurse were more likely to transition to home dialysis. 27.8%

	included; suboptimal HD starts n=78 and those who received pre-dialysis care n=98.	on transition to home modalities and transplant.	Patients were encouraged to consider a home therapy.	of patients changed modality.
Klang et al., (1999)	n=28 in experimental group (Uremic patients GFR<20 mls/min) and n=28 comparison group on hemodialysis for 9 months.	To evaluate the effects of an education program on knowledge and perceived amount of information, sense of coherence and perceptions of dialysis.	Education program consisted of 4 group sessions with classroom approach, 2 hours in length covering the different themes: renal diet, therapies, physical exercise, impact on family, social life and finances. Comparison group received conventional treatment only.	The education program enabled patients to choose a modality and understand their illness. The authors noted special needs of the elderly and recommended program specific to their needs.
Lacson et al., (2011)	Total n=3165 new dialysis starts who attended a CKD educational program.	To evaluate the impact of a quality improvement project to educate pre-dialysis patients on dialysis modality.	A nationwide treatment options program (TOPS) for modality education. Single group class session with follow-up at 30, 90 &180 days.	A modality education program was associated with more home dialysis selection (8 times more likely).
Maaroufi	228 patients seen	Patient preferred	One interview with nurse,	Patients should be

et al., 2013	between January 2009-June 2011	treatment after information delivery. Prospective cohort study.	family could be present, more sessions were delivered if the patient asked.	systematically informed before starting dialysis. Note HHD not offered in this centre.
Manns et al., (2005)	Total n=64 in a CKD clinic GFR<30 mls/min. 34 patients in standard care. 30 patients in education group.	Randomized control trial The impact of a patient-centred education on intention to start on a self care modality.	Patients were randomized to: 1) two-phase education intervention including booklets and small group sessions on self care dialysis & multi-disciplinary care, 2) standard care, education and multidisciplinary care.	Significantly more patients in the intervention group intended to start dialysis with a self care modality compared to the standard group.
Marron et al., (2006)	n=1504 from 35 hospitals who started dialysis in 2003.	Multi-centred retrospective study. To analyze the effect of CKD care and education on dialysis modality and planned vs. non-planned starts.	No description.	Peritoneal dialysis was more prevalent in planned starts when education was provided. 50% patients did not received education and did not have a planned dialysis start.
Pagels et	n=70 individuals with CKD in a nurse-led	To evaluate the effect	Referred by MD to nurse-	Those who chose

al., (2008)	clinic, 153 in routine CKD care. GFRs<20mls/min.	of a nurse led clinic on disease-related knowledge, self-care ability and dialysis outcomes.	led clinic. Frequency of visits varied depending on care needs. Alternated between RN and nephrologist clinic every other clinic. Nurse visits lasted 1 hour, used motivational interviewing and focused on support, motivation, education, medication, diet and quality of life.	home hemodialysis had greater self-care ability scores. Those in the nurse led clinic more started dialysis with permanent vascular access and on a self care modality.
Pritchard (1996)	n=150 on dialysis in one centre	Retrospective chart reviews to assess the reason for dialysis modality selection for hemodialysis and peritoneal dialysis. Modality was recorded at start of dialysis and at six weeks.	No description	If given the choice, the majority of informed patients will choose self-care dialysis (PD).

Ribitsch et al., (2013)	Modality was recorded from all (n=227) incident dialysis patients who started with a PD catheter or arteriovenous fistula	Frequency distribution of those attending the education session and not attending (control group) in a 4 year period.	On 2 consecutive days patients/family were given 2 hour information on medication, diet lifestyle issues, transplant, PD and HD. Standard care did not receive structured education.	Multi-disciplinary program had a significant impact on increasing the proportion starting on PD. Note people starting dialysis with a central venous catheter were excluded and HHD not offered.

GFR=glomerular filtration rate, *GN= glomerulonephritis

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Appendix A

National Kidney Foundation CKD Classification

Stage	Description	GFR (mL/min/1.73m^2)
1	Kidney damage with normal GFR	≥ 90
2	Mild ↓ in GFR	60-89
3	Moderate ↓ in GFR	30-59
4	Severe ↓ in GFR	15-29
5	Failure	< 15

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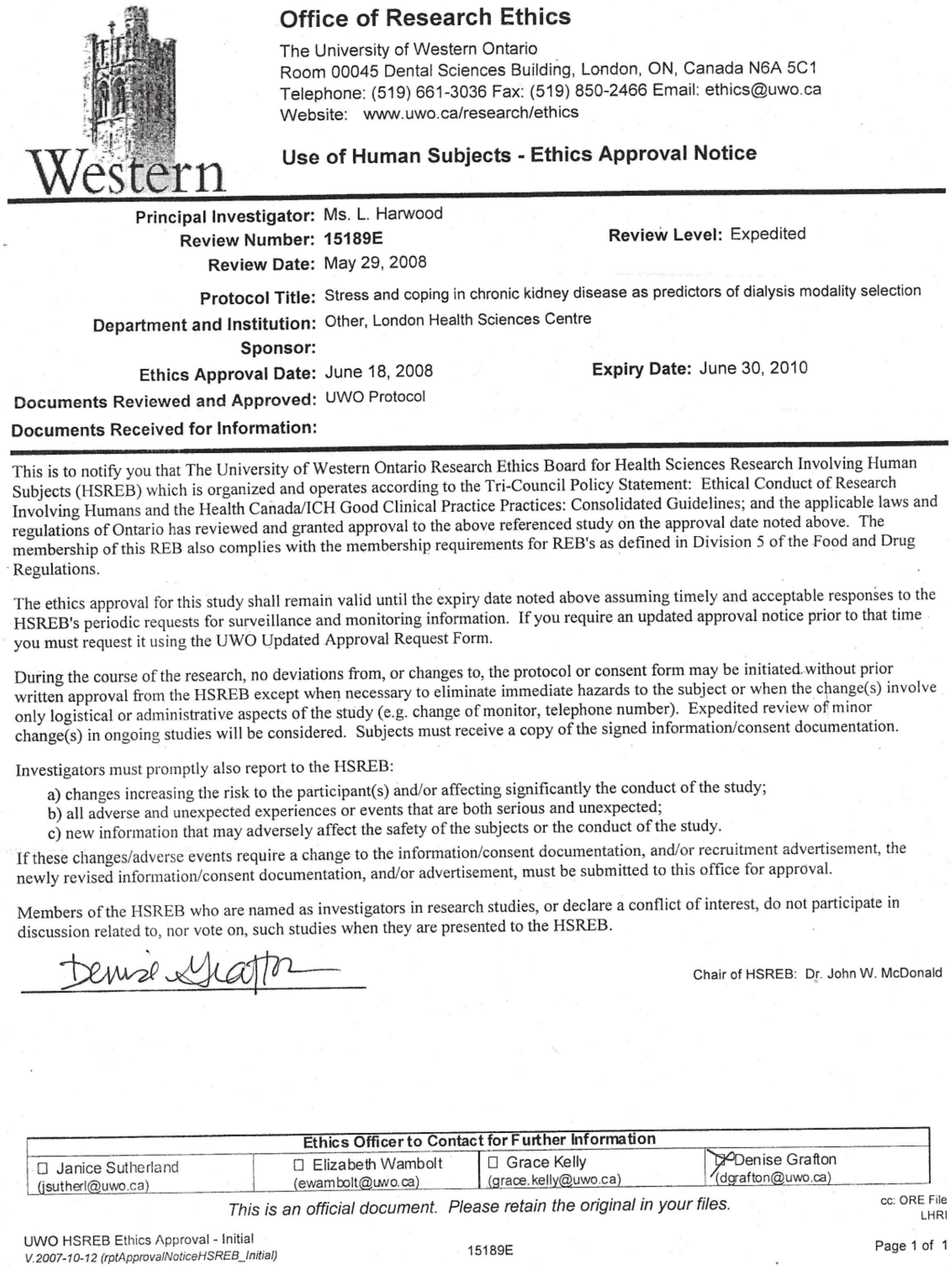

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Documents Reviewed and Approved: UWO Protocol
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The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

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c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

Denise Grafton

Chair of HSREB: Dr. John W. McDonald

Ethics Officer to Contact for Further Information			
☐ Janice Sutherland (jsutherl@uwo.ca)	☐ Elizabeth Wambolt (ewambolt@uwo.ca)	☐ Grace Kelly (grace.kelly@uwo.ca)	☒ Denise Grafton (dgrafton@uwo.ca)

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UWO HSREB Ethics Approval - Initial
V.2007-10-12 (rptApprovalNoticeHSREB_Initial)

15189E

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Appendix E

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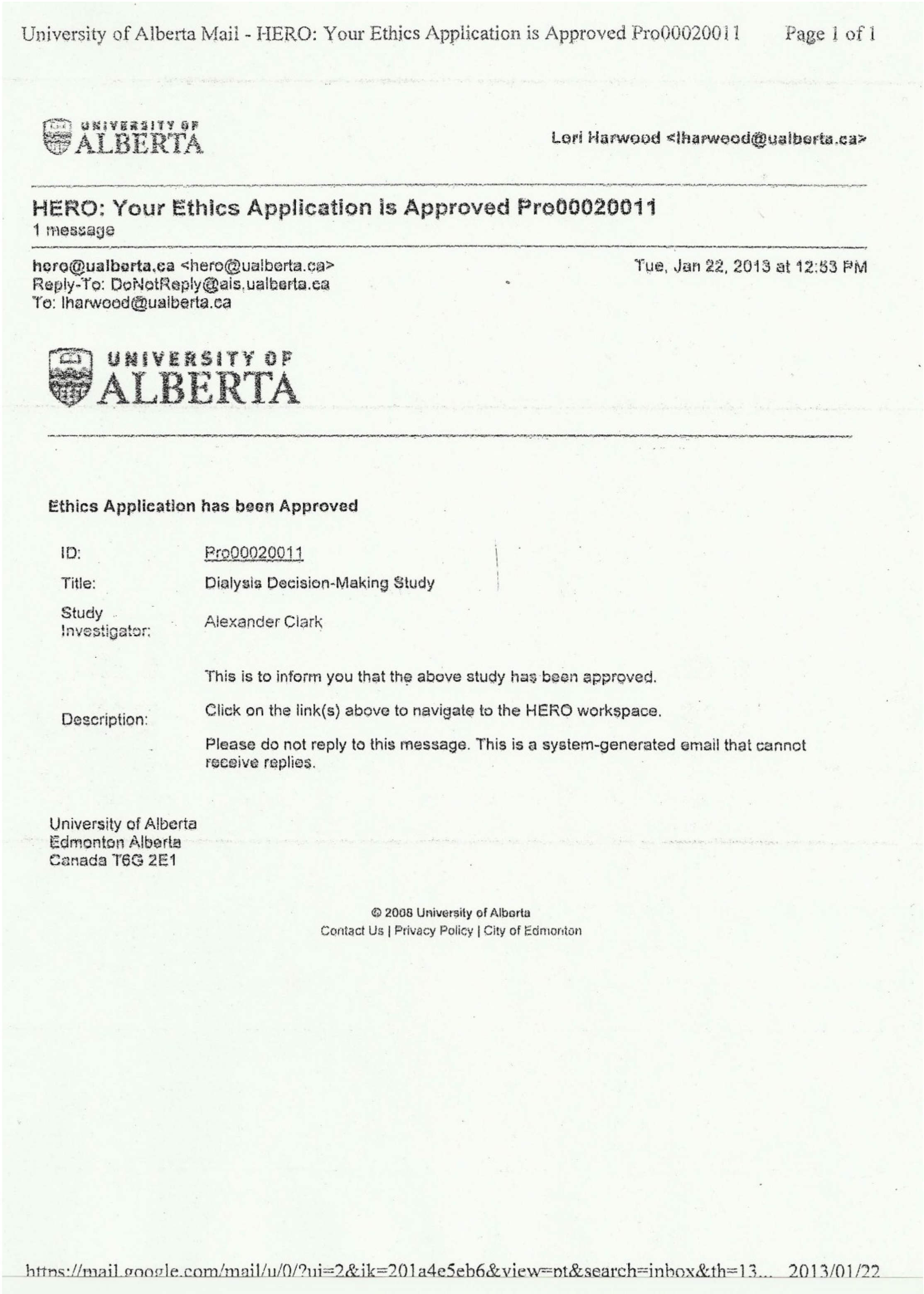

University of Alberta Mail - HERO: Your Ethics Application is Approved Pro00020011 Page 1 of 1

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Lori Harwood <lharwood@ualberta.ca>

HERO: Your Ethics Application is Approved Pro00020011

1 message

hero@ualberta.ca <hero@ualberta.ca> Tue, Jan 22, 2013 at 12:53 PM

Reply-To: DoNotReply@ais.ualberta.ca

To: lharwood@ualberta.ca

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Ethics Application has been Approved

ID:	Pro00020011
Title:	Dialysis Decision-Making Study
Study Investigator:	Alexander Clark
Description:	This is to inform you that the above study has been approved. Click on the link(s) above to navigate to the HERO workspace. Please do not reply to this message. This is a system-generated email that cannot receive replies.

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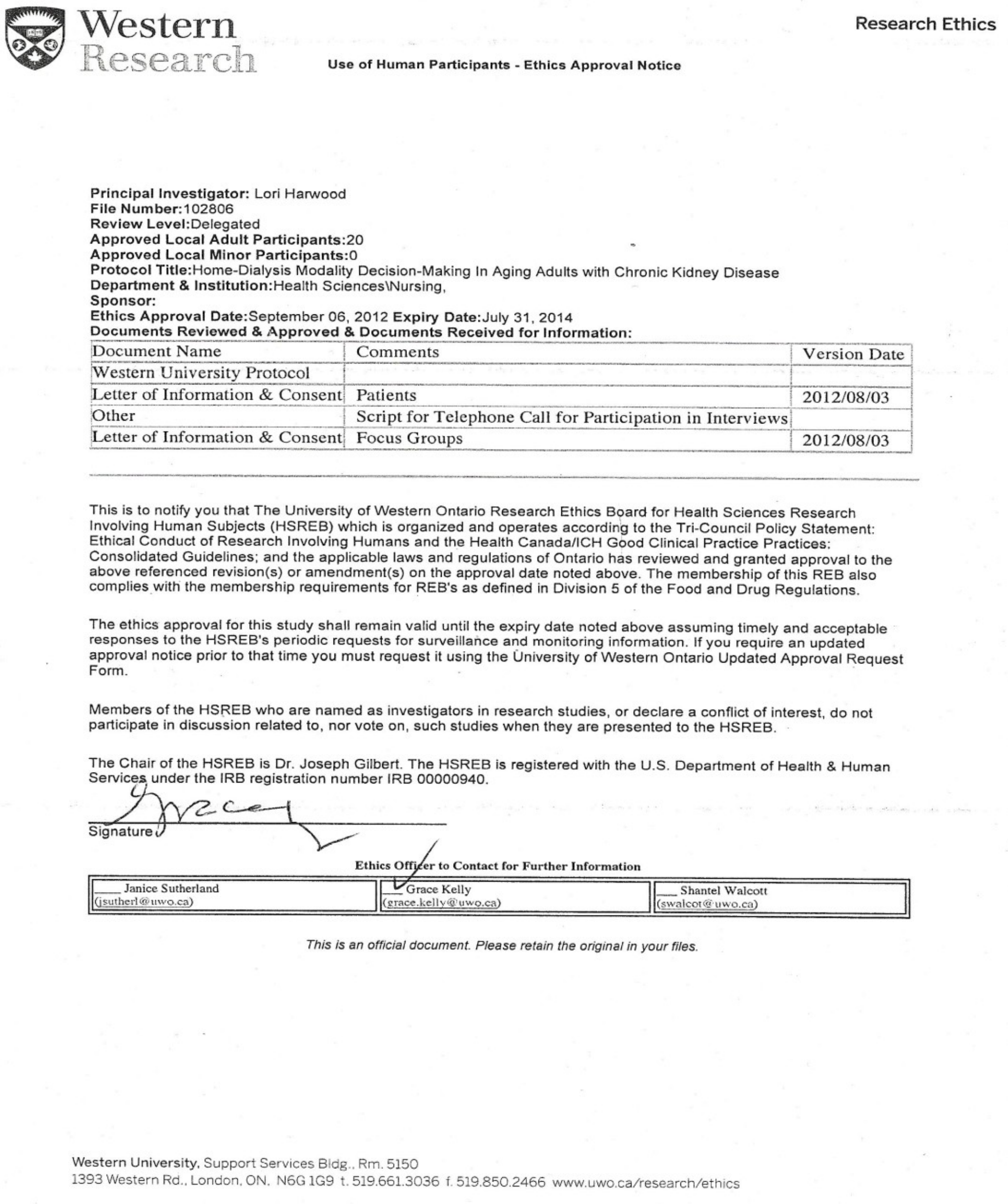
Appendix G
Ethical Approval for Qualitative Study from Western University



Western Research

Research Ethics

Use of Human Participants - Ethics Approval Notice

Principal Investigator: Lori Harwood
File Number:102806
Review Level: Delegated
Approved Local Adult Participants:20
Approved Local Minor Participants:0
Protocol Title: Home-Dialysis Modality Decision-Making In Aging Adults with Chronic Kidney Disease
Department & Institution: Health Sciences\Nursing,
Sponsor:
Ethics Approval Date: September 06, 2012 **Expiry Date:**July 31, 2014
Documents Reviewed & Approved & Documents Received for Information:

Document Name	Comments	Version Date
Western University Protocol		
Letter of Information & Consent	Patients	2012/08/03
Other	Script for Telephone Call for Participation in Interviews	
Letter of Information & Consent	Focus Groups	2012/08/03

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Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

Grace

Signature

Ethics Officer to Contact for Further Information

___ Janice Sutherland (jsutherl@uwo.ca)	✓ Grace Kelly (grace.kelly@uwo.ca)	___ Shantel Walcott (swalcot@uwo.ca)

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Appendix H

Consent Forms- Patient Interviews

London Health Sciences Centre

UNIVERSITY OF ALBERTA

LETTER OF INFORMATION-Patient Interviews

Home-Dialysis Modality Decision-Making In Aging Adults with Chronic Kidney Disease

Lori Harwood RN(EC) MSc CNeph(C), Nurse Practitioner, Doctoral student,
University of Alberta
Dr. Alexander Clark RN PhD, Supervisor, Professor University of Alberta

You are being invited to participate in a research study at London Health Sciences Centre (LHSC) conducted by Lori Harwood and Alex Clark. People with chronic kidney disease are asked to make choices about future types of dialysis treatments. We are interested in learning more about what influences this decision for people older than 65 years of age. Knowing more about this topic will help us to design better services for people who are making decisions about dialysis. This study is being conducted as part of the requirements for a PhD in nursing.

You have been chosen to participate in this study because your kidney doctor has indicated that you have a type of kidney disease with no cure and have been given information regarding dialysis. If you take part in this study you will be asked to participate in one interview. You will also be asked to complete a small survey. We require 20-30 individuals from the kidney clinics at University and Victoria Hospital to complete the interviews. The interviews will be done at a time and place convenient for you including in your home. Your spouse or support person can also participate in the interview. The interview will last approximately one hour.

You will not be compensated for your participation in the study however, if you choose to have the interview at the hospital you will be given money to pay for your parking. The interview will be audio taped, transcribed verbatim, and then erased.

Information about study participation:
It is very important you understand this information thoroughly before agreeing to participate:

a) Taking part in this interview is entirely voluntary.
b) Personal benefit may not result from taking part in this study, but knowledge gained may benefit other patients who receive care in the kidney clinic.
c) You may refuse to participate, may refuse to answer any questions or withdraw from the study at any time with no effect on your care.
d) There will be no charge or cost to you for the research procedures.
e) All information you provide will remain confidential.
f) When results of a study such as this are reported in nursing, medical journals or at meetings the identification of those taking part is withheld.
g) There are no known risks to participating in this study

Your research records will be stored in a locked cabinet in a secure office and destroyed after 5 years. No information will be released that discloses your identity. This letter is yours to keep.

If you have any questions in regards to this study, please contact Lori Harwood, Nurse Practitioner. If you have any questions about your rights as a research subject or the conduct of the study you may contact Dr. David Hill, Lawson Health Research Institute.

Yours sincerely, Lori Harwood, RN(EC) MSc CNeph(C)

London Health Sciences Centre

UNIVERSITY OF ALBERTA

Consent for Interview

Home-Dialysis Modality Decision-Making In Aging Adults with Chronic Kidney Disease

Lori Harwood RN(EC) MSc CNeph(C), Doctoral student, University of Alberta
Dr. Alexander Clark RN PhD, Supervisor, Professor University of Alberta

I, ____ have read the Letter of Information and have had the nature of the study explained to me and I agree to participate in the interview. All questions have been answered to my satisfaction.

___________________	___________________________________
Date	Signature of research participant
___________________	___________________________________
Date	Person responsible for obtaining informed consent

Appendix I

Consent Forms- Group Interviews

London Health Sciences Centre

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LETTER OF INFORMATION-Group Interviews

Home-Dialysis Modality Decision-Making In Aging Adults with Chronic Kidney Disease

Lori Harwood RN(EC) MSc CNeph(C), Nurse Practitioner, Doctoral student, University of Alberta
Dr. Alexander Clark RN PhD, Supervisor, Professor University of Alberta

You are being invited to participate in a research study at London Health Sciences Centre (LHSC) conducted by Lori Harwood and Alex Clark. People with chronic kidney disease are asked to make choices about future types of dialysis treatments. We are interested in examining the barriers and facilitators for home-dialysis decision-making for people older than 65 years of age. Knowing more about this topic will help us to design better services for people who are making decisions about home-dialysis. This study is being conducted as part of the requirements for a PhD in nursing.

You are being invited to participate in a focus group for this study because you work directly with CKD patients. For this study 20-30 individuals older than 65 years of age will also be interviewed. This study is being conducted at the clinics at University and Victoria Hospital. The focus group will last approximately 60-90 minutes and will be held at the hospital. The interview will be audio taped, transcribed verbatim, and then erased. You will not be compensated for your participation in the focus group.

<u>Information about study participation</u>:
It is very important you understand this information thoroughly before agreeing to participate:
a) Taking part in this focus group is entirely voluntary.

b) Personal benefit may not result from taking part in this study, but knowledge gained may benefit other patients who receive care in the kidney clinic.
c) You may refuse to participate, may refuse to answer any questions or withdraw from the study at any time.
d) There will be no charge or cost to you for the research procedures.
e) All information you provide will remain confidential.
f) When results of a study such as this are reported in nursing, medical journals or at meetings the identification of those taking part is withheld.
g) There are no known risks to participating in this study

Your research records will be stored in a locked cabinet in a secure office and destroyed after 5 years. No information will be released that discloses your identity. This letter is yours to keep.

If you have any questions in regards to this study, please contact Lori Harwood, Nurse Practitioner. If you have any questions about your rights as a research subject or the conduct of the study you may contact Dr. David Hill, Lawson Health Research Institute.

Yours sincerely,

Lori Harwood, RN(EC) MSc CNeph(C)

London Health Sciences Centre

UNIVERSITY OF ALBERTA

Consent for Group Interviews
Home-Dialysis Modality Decision-Making In Aging Adults with Chronic Kidney Disease

Lori Harwood RN(EC) MSc CNeph(C), Doctoral student, University of Alberta
Dr. Alexander Clark RN PhD, Supervisor, Professor University of Alberta

I, ____ have read the Letter of Information and have had the nature of the study explained to me and I agree to participate in the focus group. All questions have been answered to my satisfaction.

__________________ __________________________________
Date Signature of research participant

Appendix J

Interview Guide- Patient Interviews

Background question

1. Can you tell me about your kidney disease? How long have you known you had kidney disease? How long have you been seeing your kidney doctor and been to the kidney clinic?

Knowledge of options

2. What do you know about the different types of dialysis? Where have you received your information about home-dialysis?

Decision-making processes

3. Can you tell me about how you are making the decision about which type of dialysis to use?
   a. What most concerns you about dialysis/home-dialysis?
   b. What/who helped you make this decision?

Factors influencing decision-making

4. Has ________influenced your decision to do home-dialysis? If so how? Age (vision, strength, memory, learning new things, technology) sex, general health (pain, fatigue, sleep problems), financial concerns and uncertainty?

5. If you were to do home-dialysis what kinds of support and resources would you need to do it successfully?

6. How can health care professionals improve how they inform people about the different types of dialysis and support people with making this decision?

Other

7. Is there anything else you would like to say?

Thank you for taking part in the interview.

Appendix K

Interview Guide- Health Care Professional Interviews

1. Can you tell me about current practices in the clinic:
    a. Who decides what modality a patient starts on?
    b. What approach/interventions/care map do you have in the clinic to help a person with modality decision-making?
    c. Any eligibility criteria for home-dialysis?
    d. Modality education program?-- elderly persons with CKD?

2. Can elderly persons successfully dialyze at home-what would that look like? Resources/support?
3. What are the patient challenges for the modality decision-making for elderly persons?
4. What challenges do health care professionals encounter when helping elderly patients to choose home-dialysis?

Appendix L

Demographic Data Form

Thank you for agreeing to participate in this study. Your comments are appreciated. This study will help us know more about how people choose from the various forms of dialysis. Asking people like yourself who are experiencing this is important in our understanding in order to better help you. Your answers are confidential.

These first questions are related to your dialysis choices. When answering please place an "X" or write the answer in the space provided.

1. Please indicate which type of dialysis you have chosen. If you have not yet made your decision on which type of dialysis you will choose please answer which type of dialysis you believe you will most likely choose.
    - ☐ Home Peritoneal Dialysis
    - ☐ Home Hemodialysis
    - ☐ Hospital Hemodialysis

The next few questions ask about some personal characteristics. The purpose of these questions is to help us to know more about why people select a certain dialysis modality. All information is confidential.

2. Please indicate what is the highest level of education that you have completed?
    - ☐ Less than grade 9
    - ☐ High school
    - ☐ College or University
    - ☐ Prefer not to answer

3. Do you work outside the home?
    - ☐ Employed Full Time (>30 hours per week)
    - ☐ Employed Part Time (<30 hours/week)
    - ☐ Retired
    - ☐ On disability/leave from employment
    - ☐ Other, please list ___________________________
    - ☐ Prefer not to answer

4. Do you live alone? ☐ Yes ☐ No If no, how many people live in your household ___________________.

5. Based on your ancestry with which group do you personally identify with? Please indicate what ethic/cultural group you belong to.
   - ☐ White/Caucasian
   - ☐ South Asian (East Indian, Pakistani, Sri Lankan etc…)
   - ☐ Chinese
   - ☐ Black
   - ☐ Filipino
   - ☐ Latin American
   - ☐ Arab
   - ☐ Southeast Asia (Vietnamese, Cambodian, Malaysian, Laotian…)
   - ☐ West Asian (Iranian, Afghanistan)
   - ☐ Korean
   - ☐ Japanese
   - ☐ Aboriginal
   - ☐ Other specify ____________________

6. These questions will help us to understand more about dialysis selection. Please indicate your before tax total household income?
   - ☐ Less than $20,000
   - ☐ $20,000 to $40,000
   - ☐ $40,000-$99,000
   - ☐ Greater than $100,000
   - ☐ Prefer not to answer

7. In general, would you say your health is:
   ☐ Excellent ☐ Very good ☐ Good ☐ Fair ☐ Poor

8. The kidney clinic offers three information sessions/classes about kidney disease and treatment options. Please indicate which sessions you have attended.
   - ☐ Session #1
   - ☐ Session #2
   - ☐ Session #3
   - ☐ None

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