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

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A B S T R A C T

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.

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What is already known about the topic?

- Home-dialysis has patient and economic benefits but in many high income countries 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 interventions may be effective in assisting individuals with dialysis modality decision making.

1. 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 and Maxwell, 2009). As dialysis has few absolute contraindications, it is the most common and vital means to treat people with CKD (Courtney and 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 and 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; KDOQI, 2006; Kelly et al., 2005; Levin et al., 2008).

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 and 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 et al., 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 to do 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 socio-demographics can predict modality choice. Lack of uptake of home-based dialysis is predicted by poor knowledge of dialysis, how to dialyze effectively (KDOQI, 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; Mehrotra et al., 2005; 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 comorbidities, early and frequent nephrologic care (Stack, 2002), 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 aggregate 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 qualitative 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 et al., 2011). One Australian study documented one in seven (14%) people with CKD selected conservative management (Morton et al., 2011). 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 care planning with their nephrologists (Davison, 2010). This suggests that the frequency of conservative management may be less than documented by Morton et al. (2011). 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.

2. Methods

A systematic review of qualitative studies was conducted using meta-ethnography to synthesize studies with an inductive and interpretive analysis (Noblit and 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).

2.1. 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.

2.2. 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 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.

2.3. 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, 2006) 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.

2.4. Data analysis

Meta-ethnography (Noblit and 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.

3. Results

3.1. 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/
<table>
<thead>
<tr>
<th>Authors/country</th>
<th>Population</th>
<th>Sample size</th>
<th>Focus/approach</th>
<th>Conclusions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Andrew, J. (Andrew, 2001) United Kingdom</td>
<td>CKD patients and family</td>
<td>n = 10</td>
<td>The pre-dialysis experience. Grounded theory</td>
<td>Patients and families accepted a different life view necessary to make modality decisions.</td>
</tr>
<tr>
<td>Breckenridge, D. (Breckenridge, 1997b) United States</td>
<td>HD</td>
<td>n = 22</td>
<td>Why, how and by whom dialysis was chosen. Grounded theory</td>
<td>Patients and/or others selected the modality. Modality was selected based on practical or clinical circumstances.</td>
</tr>
<tr>
<td>Courts, N.F. (Courts, 2000) United States</td>
<td>Home HD Patients and partners</td>
<td>n = 14 patients</td>
<td>How decisions were made to choose home HD. Interpretive descriptive</td>
<td>Patient or family made the decision based on distance, lifestyle, negative in-center experience and control over daily routine.</td>
</tr>
<tr>
<td>Jennette, C., et al. (Jennette et al., 2009) United States</td>
<td>HD</td>
<td>n = 35</td>
<td>Barriers to choice for renal replacement therapy.</td>
<td>Fear was a predominant theme. Distrust of medical system, denial and previous experience with modalities were barriers to care. Pre-dialysis education was needed.</td>
</tr>
<tr>
<td>Kaufman, R., et al. (Kaufman et al., 2006) United States</td>
<td>HD patients and HCP</td>
<td>n = 43 patients</td>
<td>Old age, life extension and medical choice. Ethnography</td>
<td>Dialysis extended life but not what was considered a good or full life. Choice reflected adaptation to dialysis and acceptance of a diminished life.</td>
</tr>
<tr>
<td>Kelly-Powell, M.L. (Kelly-Powell, 1997) United States</td>
<td>HD</td>
<td>n = 9</td>
<td>Patients’ experiences making treatment decisions. Grounded theory</td>
<td>Decisions were very personalized consistent with self-identity in the context of their life.</td>
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<tr>
<td>Landreneau, K. and Ward-Smith, P. (Landreneau and Ward-Smith, 2006) United States</td>
<td>HD</td>
<td>n = 2</td>
<td>Perceptions concerning choice among renal replacement therapies. Phenomenology</td>
<td>No one remembering making their own choice. There was uncertainty of future health and lack of information regarding renal replacement therapies.</td>
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<tr>
<td>Lee, J., et al. (Lee et al., 2008) Denmark</td>
<td>CKD</td>
<td>n = 3</td>
<td>Patient views regarding choice of dialysis modality. Interpretive descriptive</td>
<td>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.</td>
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<tr>
<td>Lin, C., et al. (Lin et al., 2005) Taiwan</td>
<td>HD</td>
<td>n = 12</td>
<td>Deciding about HD among Taiwanese. Phenomenology</td>
<td>Three themes emerged representing decision-making; fear caused by false beliefs, seeking further information and living with dialysis.</td>
</tr>
<tr>
<td>Morton, R., et al. (Morton et al., 2010b) Australia</td>
<td>HD</td>
<td>n = 8</td>
<td>Patient views about treatment of stage 5 CKD. Interpretive descriptive</td>
<td>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.</td>
</tr>
<tr>
<td>Sondrup, B., et al. (Sondrup et al., 2011) Canada</td>
<td>HHD</td>
<td>n = 3</td>
<td>Patient perceptions and possible barriers related to choosing home-dialysis therapies. Interpretive descriptive</td>
<td>Hardship was experienced due to loss of kidney function. There was need for support from HCPs, educational materials, recruitment strategies which focused on independent dialysis and technical support.</td>
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<tr>
<td>Tong, A., et al. (Tong et al., 2009) Australia</td>
<td>CKD</td>
<td>n = 21</td>
<td>Patients’ experiences and perspectives living with CKD. Interpretive descriptive</td>
<td>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.</td>
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populations ($n = 577$) 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 et al., 2011) with sixteen studies in total included in the meta-synthesis.

3.2. Characteristics of included studies

All studies (total $n = 410$ participants) included in the review (see Table 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 et al., 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 ($n = 1$).

3.2.1. 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 and Ceaser, 2005), retrospective to starting dialysis (Breckenridge, 1997b; Courts, 2000; Jennette et al., 2009; Kaufman et al., 2006; Kelly-Powell, 1997; Landreneau and Ward-Smith, 2006, 2007; Lin et al., 2005; Morton et al., 2010b; Sondrup et al., 2011; Whitaker and 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 and 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.

3.3. 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 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 4) with specific exemplars of the various themes (Table 5).

3.3.1. 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 et al., 2006; Kelly-Powell, 1997; Landreneau and Ward-Smith, 2006, 2007; Lin et al., 2005; Morton et al., 2010b; Sondrup et al., 2011; Whitaker and 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 and 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.
Table 4
Summary of concepts and supporting studies.

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<thead>
<tr>
<th>Author</th>
<th>Illusion of choice – genuine or none</th>
<th>A matter of life or death</th>
<th>Minimization of perceived intrusiveness</th>
<th>Knowledge and support</th>
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<td>Andrew (2001)</td>
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<td>Breckenridge (1997b)</td>
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<td>Courts (2000)</td>
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<td>Jennette et al. (2009)</td>
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<td>Kaufman et al. (2006)</td>
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<td>Kelly-Powell (1997)</td>
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<td>Lin et al. (2005)</td>
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<td>Morton et al. (2010b)</td>
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<td>Sondrup et al. (2011)</td>
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<td>Tong et al. (2009)</td>
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<td>Tweed and Ceaser (2005)</td>
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<td>Visser et al. (2009)</td>
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<td>Whittaker and Albee (1996)</td>
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Table 5
CKD decision-making concepts and exemplars.

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<tr>
<th>Concepts</th>
<th>Exemplars</th>
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<tr>
<td>The illusion of choice – a matter of life and death</td>
<td>“The only thing the doctor said was that I was going to be on dialysis… I didn’t have a choice” (Breckenridge, 1997b, p. 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., p. 921). “I was thankful for dialysis and that gave me a second chance at life” (Breckenridge, 1997b, p. 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, p. 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., p. 494).</td>
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<td>Personal factors and the minimization of intrusiveness of dialysis</td>
<td>“I’d like to stay as normal as I possibly can… (hemodialysis) would be less disruptive of our life” (Kelly-Powell, 1997, p. 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., p. 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 and Albee, 1996, p. 372).</td>
</tr>
<tr>
<td>Other factors perceived to affect intrusiveness</td>
<td>Travel</td>
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<td>Knowledge and social support: essential and context bound</td>
<td>“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, p. 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, p. 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, p. 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 and Albee, 1996, p. 374).</td>
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<tr>
<td>OTHER OTHER OTHER OTHER OTHER OTHER OTHER OTHER OTHER OTHER OTHER OTHER</td>
<td>&quot;YOU THINK YOU'RE THE ONLY ONE IN THE WORLD AND I FOUND THERE WERE MANY 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 and Ceaser, 2005, p. 662). &quot;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, p. 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, p. 496).</td>
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</table>
et al., 2009; Visser et al., 2009; Whittaker and 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; Jennette et al., 2009; Kaufman et al., 2006; Landreneau and 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 and 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).

3.3.2. 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 and Ceaser, 2005; Visser et al., 2009; Whittaker and 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 and Ceaser, 2005; Visser et al., 2009; Whittaker and 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 and Ceaser, 2005, p. 661).

3.3.3. 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 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 and Ceaser, 2005; Visser et al., 2009; Whittaker and 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., 2010a,b; Tweed and Ceaser, 2005; Visser et al., 2009; Whittaker and Albee, 1996) and identity (Courts, 2000; Kelly-Powell, 1997; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b; Tweed and Ceaser, 2005; Visser et al., 2009; Whittaker and 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 and Ceaser, 2005; Whittaker and 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; Visser et al., 2009; Whittaker and Albee, 1996) such as “I decided to take it (dialysis) with the machine because I already knew what it was like” (Whittaker and 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 what’s happening to me” (Whittaker and 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.

3.3.4. 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 and Ward-Smith, 2007; Lee et al., 2008; Lin et al., 2005; Tong et al., 2009; Tweed and Ceaser, 2005; Whittaker and 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 and Ward-Smith, 2006, 2007; Lee et al., 2008; Lin et al., 2005; Morton et al., 2010b;
Tweed and Ceaser, 2005; Whittaker and 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 and Ward-Smith, 2007; Morton et al., 2010b; Tweed and Ceaser, 2005; Whittaker and 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 and 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 and Ceaser, 2005; Whittaker and 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).

4. 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 and 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 (KDOQI, 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 et al., 2011) 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 et al., 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., 1999, 2009). 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 et al., 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 withdrawal/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 et al., 2002; Jung et al., 1999; Mendelsohn et al., 2001; Thammer et al., 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 (Wang 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 interdisciplinary education and decision support. Health care systems therefore need to have health care policy to enable interdisciplinary teams to provide these services.

4.1. 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 et al., 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 and 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 and 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; Brekenridge, 1997b; Courts, 2000; Kelly-Powell, 1997; Whittaker and 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.

5. 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.

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