

**The Experience of Individuals Transitioning from In-Center Hemodialysis to Home  
Dialysis After a Suboptimal Start: A Mixed-Method Study**

Caroline Sauvé

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University of Ottawa

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## Transition to Home Dialysis after a Suboptimal Start

*A lot of people resist transition and therefore  
never allow themselves to enjoy who they are.*

*Embrace the change, no matter what it is;  
once you do, you can learn about the new world  
you're in and take advantage of it.*

Nikki Giovanni

## Transition to Home Dialysis after a Suboptimal Start

### **Thesis Abstract**

*Background* It is estimated that up to 50% of individuals begin dialysis with a suboptimal start.

*Objective* To explore the transition to home dialysis, with a special emphasis on this transition after a suboptimal start.

*Methods* A two-phased mixed methods study including: 1) a scoping review and meta-synthesis on the facilitators and barriers to home dialysis and 2) a qualitative study using thematic analysis on the transition to home dialysis after a suboptimal start.

*Findings* 12 studies were included in the scoping review. Principle facilitators and barriers included Support, Burden of Care, and Disruption of Life. Six individuals were included into the qualitative phase. Through their interviews, they expressed the importance of the timely delivery of information, support, living with loss, managing fear, living with hope, and learning to live with dialysis.

*Conclusions* The facilitators and barriers to home dialysis were similar in both studies suggesting that the transition to home dialysis is similar regardless of the nature of dialysis start. Several subthemes obtained from the qualitative study however revealed that a suboptimal dialysis start entails unique challenges, requiring the delivery of more support and education.

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## Transition to Home Dialysis after a Suboptimal Start

### **List of Abbreviations**

CAPD	Continuous Ambulatory Peritoneal Dialysis
CCPD	Continuous Cycling Peritoneal Dialysis
CKD	Chronic Kidney Disease
ESRD	End Stage Renal Disease
KDQOL	Kidney Disease Quality of Life
HD	Hemodialysis
ORN	Ontario Renal Network
RN	Registered Nurse
RRT	Renal Replacement Therapy
PD	Peritoneal Dialysis
PICO	Population Intervention Context Outcome
SDM	Shared Decision Making

# Transition to Home Dialysis after a Suboptimal Start

## **Chapter 1**

### **Research Problem**

### **Introduction**

As a Registered Nurse working on a Nephrology inpatient unit for the last four years, I have cared for many individuals suffering from End Stage Renal Disease (ESRD) who require immediate dialysis. These individuals find themselves in an emergency situation and often end up with a central venous catheter to initiate hemodialysis. This type of dialysis start is commonly referred to in the literature as a 'suboptimal dialysis start'. Following a placement at the Home Dialysis Unit at the Riverside Campus of the Ottawa Hospital in the context of my Master's Primary Care Course, I became interested in researching this population. From my experience, there are unique challenges for this group, including that there appears to be little time to provide these individuals with the much needed education and teaching that is normally given when dialysis is planned. This is likely due, in part, to the multitude of tests and the complexity of care that these individuals require within a short timeframe. Unfortunately, I have observed that many of these participants remain on in-center hemodialysis long-term. While dialysis programs exist to educate patients who have undergone a suboptimal start on the dialysis process and different available Renal Replacement Therapies (RRT), I question if these programs are sufficient to enable these individuals to take on home dialysis.

In beginning to plan this enquiry, I noticed a paucity of research on the transition of individuals from in-center hemodialysis to home dialysis after a suboptimal start. This gap in knowledge included a dearth of methodologically sound research on: 1) The perceived barriers and facilitators to home dialysis from the perspective of individuals living with

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ESRD, and 2) The experience of individuals who undergo a suboptimal dialysis start and who transition from in-center to home dialysis. These gaps in evidence and the recent priority announced by the Ontario Renal Network (ORN) that calls for an increase in the uptake of home dialysis by individuals suffering from ESRD (ORN, 2014), has led me to question what it is like for these individuals before, during, and after their transition to home dialysis. In order to provide an assessment of the state of knowledge on the topic, the following section provides a literature synthesis on what is known about End Stage Renal Disease, dialysis, choosing a dialysis modality, suboptimal dialysis starts, transitions, and the general transition to home dialysis. Finally, the research design and objectives are provided.

### **Background and Relevance**

#### **End Stage Renal Disease**

Chronic kidney failure (CKD) is characterized by the presence of kidney damage or decreased kidney function occurring in an individual for a minimum of three months (National Kidney Foundation, 2002). Chronic kidney disease is further delineated into 5 stages, each determined by the level of kidney function of an individual or their glomerular filtration rate; the rate at which the glomerules of an individual's kidney filters blood (National Kidney Foundation, 2002). The last stage of chronic renal disease, ESRD, will be of interest in this study. According to the Canadian Institute for Health Information (2011), the number of Canadians in 2009 living with kidney failure was close to 38,000 compared to 11,000 in 1990. The largest increase occurred in the older age group (65 or older). Of these 38,000 patients, 22,300 (59%) were on dialysis. The average age of adult patients starting dialysis in 2009 was 65 years (CIHI, 2011).

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An estimated 1 in 1000 people living in Canada are affected with ESRD (Mendelssohn, Malmberg & Hamandi, 2009). These individuals are plagued with a high rate of mortality and morbidity. In fact, the five-year survival rate for older (65 years+), diabetic patients suffering from ESRD is 20%, while for non-diabetic patients who are younger (18 to 65 years), the five-year survival rate is nearly 60% (Mendelssohn et al., 2009). Renal replacement therapies, which include kidney transplantation, home dialysis, and in-center hemodialysis are currently the only options offered to individuals suffering from ESRD as a means of continued life. The ideal treatment is a kidney transplant because this treatment is associated with the lowest morbidity and mortality rates in this population (Abecassis et al., 2008). Unfortunately, in the current context, resources are limited and it is not always possible to receive an immediate kidney transplant. For most patients, dialysis is the treatment option available. Dialysis can prolong life, but it seldom returns patients to their level of health prior to developing ESRD (Hutchinson, 2005).

### **Dialysis**

Dialysis is used to purify the blood by removing nitrogen waste, salt, and water from the body, to regulate the levels of electrolytes such as potassium, calcium, urea, and creatinine and to regulate blood pressure (Smeltzer and Bare, 2006). There are two types of dialysis: hemodialysis (HD) and peritoneal dialysis (PD).

Hemodialysis is the most prevalent form of renal replacement therapy (Canadian Institute for Health Information, 2013; U.S. Renal Data System, 2012). It involves the filtration of blood outside the body with a machine using a specific form of vascular access to remove the biochemical waste that accumulates in the body. Hemodialysis can be undertaken in hospital or at home (Smeltzer & Bare, 2006). Peritoneal dialysis involves the

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use of a catheter, which is implanted in the peritoneal cavity, as well as the intermittent instillation, dwell and removal of dialysate solutions. This modality is only available as a home therapy in Canada (Smeltzer & Bare, 2006).

Considering the advantages and disadvantages of both dialysis forms, in-center hemodialysis is associated with increased socialization within the dialysis community and less onus on the individual, but also higher risk of infection and complications related to the access site, and lower rates of survival within the first two years (as opposed to peritoneal dialysis) (Sinnakirouchenan & Holley, 2011). Peritoneal dialysis has been associated with several benefits, such as a higher level of patient autonomy, higher patient satisfaction, lower cost, and the preservation of residual renal function (Sinnakirouchenan & Holley, 2011). The disadvantages include high rates of peritoneal membrane and technique failure, risk of peritoneal infections, and patient and caregiver burnout (Sinnakirouchenan & Holley, 2011).

## **Choosing a dialysis modality**

For patients with ESRD, choosing a dialysis modality can be very challenging, as each has different features. In some cases, patients may have to make this choice twice. The first time, while starting dialysis and again later if the modality needs to be changed due to complications or if the patient switches from inpatient to home dialysis. The choice depends on multiple factors, which can include physical condition, social circumstances, and patient preference (Nakamura-Taira et al, 2013). In one study, for example, Nakamura-Taira and colleagues (2013) found that the choice of modality between inpatient hemodialysis or peritoneal dialysis was dependent on whether it would burden family members. These researchers also found that if the modality had to change for medical

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reasons, then psychological support was necessary for patients in this transition. In a second study, authors Cousineau and colleagues (2003) explored this choice in patients who opted for in-centre hemodialysis. The reasons supporting their participants' decision related to loss of control and dependence, worry about interference of their care requirements on others, and the overall effect on their health.

## Home Dialysis

Home dialysis has been associated with higher satisfaction rates, increased quality of life, survival rates and blood pressure control, and lower health-care costs as opposed to in-center hemodialysis (Dimkovic & Oreopolous, 2009; ORN, 2014; Oreopolous, Thodis, Passadakis & Vargemezis, 2009; Sinnakirouchenan & Holley, 2011). As a result of these advantages, the increased uptake of home dialysis is being encouraged by the ORN. Home dialysis allows individuals to choose between two dialysis modalities, peritoneal dialysis and home hemodialysis.

Peritoneal dialysis can be done overnight with a machine using Continuous Cycling Peritoneal Dialysis (CCPD), or during the day using manual exchanges of bags of dialysate fluid (Continuous Ambulatory Peritoneal Dialysis (CAPD)). Both forms of home peritoneal dialysis require a surgery to install a dialysis catheter in the peritoneal cavity (Smeltzer and Bare, 2006).

Alternatively, home hemodialysis involves the use of an individualized hemodialysis machine at home and is most commonly done at night. Home hemodialysis necessitates the creation of a vascular access. The formation of an arterio-venous fistula in individuals' arms is prioritized over the use of a central venous catheter due its decreased risk of infection and mortality (Perl et al., 2011). However, in some individuals, for reasons

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such as lack of appropriate veins, the creation of a fistula is not feasible (Jindal et al., 2006). Therefore some patients undergo home hemodialysis with central venous catheter access.

Nurses in Canada occupy an important role with patients who adopt home dialysis. Nurses are often responsible for the majority of the extensive teaching and education that is required prior to the switch to an independent modality (Ontario Renal Network, 2015). Furthermore, nurses are also often responsible for a part of the dialysis modality teaching, informing patients on the advantages and disadvantages of each therapy and matching these attributes to their values and expectations (Hanko et al., 2011; Idier, Untas, Koleck, Chauveau & Rascle, 2011; McLaughlin et al., 2008).

It is important to note that despite the creation and the adoption of these home technologies, home dialysis remains underused in most countries for reasons that are complex and not entirely understood (Oreopolous et al., 2009). In one study, Ludlow et al elicited the views of Australian nephrologist's related to home dialysis to try to identify the causes. Using a survey, they found that although nephrologists were in favour of both forms of home dialysis, major impediments existed. These impediments were financial (for the patient and family) and a lack of infrastructure for training support and education. Furthermore, resources were not consistently available. While these barriers offer one explanation for the worldwide underuse of home dialysis, another possibility is frequently reported in the literature – the fact that many individuals begin dialysis in a suboptimal way (Mendelsson et al., 2011; Watson, 2008).

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### **Suboptimal Initiation of Dialysis**

Historically, the terms "unplanned start", "crash start", and "acute starts" were used interchangeably to describe individuals who begin dialysis in an urgent and unplanned manner. Unfortunately, these terms were not operationalized and provided little guidance for identifying and describing this patient population. More recently, Mendelhsson (2009) proposed the term "suboptimal", for which he offered a clear definition and well-defined limits. This definition identifies individuals who begin dialysis without a permanent dialysis access, while admitted in the hospital, or who initiate an undesired dialysis modality (Chiu, Alam & Iqbal, 2012; Hughes, Mendelhsson, Tobe, Macfarlane & Mendelhsson, 2013; Piwko et al., 2012). While the others terms are still somewhat used in practice, researchers most often refer to 'suboptimal' starts. As such, 'suboptimal' is used throughout this thesis.

### **Impact of Suboptimal Dialysis Starts**

Suboptimal dialysis starts account for 50 % of all dialysis initiations (Hanko et al., 2011). The causes behind suboptimal starts to dialysis are varied and include both modifiable and non-modifiable factors (Nadeau-Fredette, Tennankore, Kim, & Chan, 2013). For example, limited access to a nephrologist and poor understanding of chronic renal disease are modifiable factors, while comorbidities and psychosocial characteristics constitute non-modifiable factors (Lecouf, Ryckelynck, Ficheux, Henry, & Lobbedez, 2013; Chiu, Alam & Iqbal, 2012; Devins, Mendelssohn, Barre, & Binik, 2003). Regardless of cause, suboptimal dialysis starts are responsible for adverse clinical outcomes for individuals, such as an increase in blood transfusions, hospitalizations, and death (Mendelhsson et al., 2011; Watson, 2008). Individuals who undergo a suboptimal start are

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also more likely to remain on in-center dialysis; studies have demonstrated that this is partly due to the lack of discussion concerning renal replacement therapy that occurs with these individuals (Marron et al., 2005; Watson, 2008; Thodis & Oreopolous, 2011).

In 2008, Watson conducted a study on the education of individuals who have undergone a suboptimal dialysis start at the University Health Network in Toronto. In this study, Watson noted that due to the emergent nature of their dialysis initiation, these individuals, unlike individuals who began dialysis in a optimal manner, were not receiving education concerning dialysis modalities, dialysis accesses, the pros and cons of home dialysis, and the lifestyle alterations that are associated with dialysis. 87% of these individuals chose to continue in-center hemodialysis once discharged from the hospital (Watson, 2008). Additionally, a study conducted in 24 hospitals in Spain reported similar results. 92% of their participants who started dialysis in an unplanned way remained on in-center hemodialysis once discharged from hospital (Marron et al, 2005). Finally, Thodis and colleagues reported in their 2011 study that nephrologist and nurses often did not discuss home dialysis with patients who began dialysis in a suboptimal manner. This occurred for many reasons, such as concerns regarding a higher mortality risk in this population and inadequate training of nurses and doctors in home dialysis modalities. It is important to note that studies have, however, demonstrated that targeted interdisciplinary education and decision support at the time of the suboptimal start can help increase the proportion of patients who are capable of making an informed decision and ultimately choose home dialysis (Watson, 2008; Rioux et al., 2011).

## Transition to Home Dialysis after a Suboptimal Start

### **Transitions**

A transition is defined as “the passage from one state or condition to another” (Merriam-Webster, 2015). Transitions have been recognized as a major point of focus for the discipline of Nursing (Schumacher & Meleis, 2014). Transitions explored by the discipline include, amongst many others, developmental, situational, health and illness, and organizational transitions (Meleis & Trangestein, 1994). Although many nursing theorists and researchers have explored transitions, I chose to focus on Meleis’ conceptualization of transitions. Meleis defines a transition as “a passage from one fairly stable state to another fairly stable state” that is brought on by some form of change (Meleis, 2010 p.11). There are many transitions in persons with ESRD, such as dealing with a chronic life-threatening illness that will be fatal without treatment (dialysis or transplant), obtaining access for dialysis, possible loss of employment, dealing with co-morbidities, and the commencing of dialysis treatments (Hutchinson, 2005).

### **Transition to Home Dialysis**

Although there exists a paucity of research exploring the transition to home dialysis after a suboptimal start, literature exists on several aspects of the transition to home dialysis and the perspectives of individuals living with ESRD who adopt peritoneal or home hemodialysis.

**The importance of pre-dialysis training.** Two studies have eschewed the importance of pre-dialysis education programs in enabling participants to begin home dialysis. A study by Goovaerts and colleagues (2005), for example, demonstrated how individualized information session, undertaken in conjunction with an experienced nurse, resulted in the majority of individuals starting home dialysis. A second study, undertaken

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by Marron and colleagues in Spain (2006), demonstrated how planned dialysis starts, which involved the reception of education concerning RRT and multidisciplinary care from nephrologists, renal nurses, nutritionists, psychologists, and social workers, resulted in more individuals adopting peritoneal dialysis as opposed to individuals who underwent an unplanned dialysis start.

### **Factors contributing to an unsuccessful transition to home dialysis.**

A study conducted by Schatcher and colleagues (2013) on the factors leading to the technical failure of individuals who begin home hemodialysis training revealed three types of barriers to the successful uptake of home hemodialysis. Individuals who withdrew from home hemodialysis within one year did so due to logistical barriers (eg. lack of proper housing), medical factors (eg. high incidence of comorbidities), and psychosocial factors (eg. burden of performing dialysis at home). Furthermore, a study undertaken by Kolesnyk and colleagues (2010) on technique failure of individuals undertaking peritoneal dialysis revealed that the main factors contributing to peritoneal dialysis dropout within the first few months of therapy were also medical in nature (eg. catheter and abdominal surgery related complications), psychosocial (eg. patient preferences), and circumstantial (eg. successful kidney transplantation).

**Studies examining individuals who adopt peritoneal dialysis.** A thematic synthesis undertaken by Tong and colleagues (2013) highlighted several aspects of the journey to adopting peritoneal dialysis. Specifically, individuals need to have the resilience and confidence necessary for successful home dialysis. Aspects of this journey included overwhelming responsibility, as well as the importance attributed to support networks. In the article, several important considerations were discussed. On the positive side, these

Transition to Home Dialysis after a Suboptimal Start included the importance of control over one's health and of freedom, both made possible by peritoneal dialysis, and on the negative side, these included the unfortunate physical disablement and loss of positive body image occasioned by the treatment.

### **Studies examining individuals and/or their families who adopt home**

**hemodialysis.** Despite the advantages of home hemodialysis, many patients are anxious about self-cannulation, being alone on the therapy, risks of errors, lack of medical support, and caregiver burden (McLaughlin, et al, 2003), Namiki, Rowe & Cooke, 2010). Walker et al. (2015) conducted a systematic review of patient and caregiver perspectives of home hemodialysis. In this synthesis, fear of dialyzing independently, fear of being alone, and fear of caregiver burden were paramount. They did, however, also offer certain opportunities to thrive on home hemodialysis. These included the chance to strengthen personal relationships, the to gain freedom, and to re-establish a healthy self-identity through the use of the therapy. Although the perspectives of individuals on both modalities of home dialysis are explored in these two review studies, a focus has not yet been placed on summarizing and synthesis the specific facilitators and barriers to home dialysis. Furthermore, the perspectives of the suboptimal start population on the transition home are missing from existing literature.

### **Research Objectives**

The purpose of this study was twofold: 1) To systematically review and summarize the facilitators and barriers for individuals who transition to home dialysis and 2) To explore the transition from hospital to home dialysis in a sample of individuals who began dialysis in a suboptimal way. Specific research questions were: a) Based on existing evidence, what are the facilitators and barriers to the uptake of home dialysis for

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individuals suffering from ESRD?; and b) How do individuals with ESRD experience the transition to home dialysis after a suboptimal start?

### **Design**

A mixed methods study design was employed, including a systematic scoping review and qualitative descriptive study. Mixed methods approaches can be undertaken sequentially or simultaneously (Morse, 2010). This Master's thesis used a simultaneous approach. As is recommended by Morse (2010), one phase of the study, the scoping review, was undertaken to answer a research question with a broader scope, while the second phase, the qualitative study, was used to obtain different data (interviews) on the perspectives of a specific population - individuals who began dialysis in a suboptimal way.

### **Layout of thesis**

Chapter 2 is structured as a manuscript and provides a scoping review of the facilitators and barriers to home dialysis. Chapter 3 is also structured as a manuscript that describes a qualitative study undertaken with patients who commenced home dialysis after a suboptimal start. Chapter 4 provides an integrated discussion of the findings from the scoping review and qualitative study within the broader context of ESRD and home dialysis and also highlights the implications for practice, policy, research, and education.

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## **Chapter 2**

### **Exploring the Facilitators and Barriers to Home Dialysis**

#### **A Scoping review**

This chapter is based upon an unpublished manuscript formatted for submission to the Nephrology Nursing Journal (America Nephrology Nurses' Association). Recommended article

length: 14-18 pages.

#### **Authors**

Caroline Sauve, RN, BScN  
*University of Ottawa, Faculty of Health Sciences*

Amanda Vandyk, RN, PhD  
*University of Ottawa, Faculty of Health Sciences*

Frances Fothergill Bourbonnais, RN, PhD  
*University of Ottawa, Faculty of Health Sciences*

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### **Abstract**

*Purpose* To summarize and describe the facilitators and barriers to home dialysis from the patient perspective.

*Methods* Systematic scoping review modelled on the Joanna Briggs Methodology, using MEDLINE, CINAHL and EMBASE (2004-2015). Two-step study screening and double data extraction done. Data analyzed descriptively and by content analysis.

*Results* 848 citations retrieved, leading to 12 included studies. Barriers to home dialysis were: burden of care, invasion of the body, disruption of lifestyle while facilitators included: support, physical and mental wellbeing, ability to maintain a normal life, and autonomy.

*Conclusions* Efforts must focus on increasing support and decreasing disruption of lifestyle.

### **Background**

Over 2 million individuals worldwide suffering from End Stage Renal Disease (ESRD) rely on dialysis as a main source of life support (Jha et al., 2013). Dialysis accounts for a significant portion of health care expenditures in developed countries (Levey et al., 2007), and with an ever-aging population, these costs are expected to rise (Menzin et al., 2011). Dialysis may be delivered in hospital or at home. While both options offer benefits and challenges, rates of home dialysis are only eight percent in the United States (American Journal of Kidney Diseases, 2010). This is surprising given that home dialysis is known to be associated with higher levels of patient autonomy, increased patient satisfaction, better preservation of residual renal function, greater quality of life, and overall improved survival rates. Furthermore, home dialysis is more cost-effective than dialysis delivered in hospital (Sinnakirouchenan & Holley, 2011).

Despite the creation of home dialysis technologies, it remains underused in most countries for reasons that are complex and not entirely understood (Oreopolous, Thodis, Passadakis & Vargemezis, 2009). Several studies have explored the facilitators and barriers encountered during the transition to home dialysis; however findings have yet to be summarized across studies. While two syntheses on the perspectives of individuals concerning home hemodialysis or peritoneal dialysis exist, no syntheses on the facilitators and barriers to home dialysis have been published (Tong et al., 2013; Walker et al., 2015). A rigorous review is needed to guide the development of best-practice guidelines, as well as to inform recommendations for health professionals providing care during this process.

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### **Objective**

The purpose of this study was to explore and synthesize the facilitators and barriers to home dialysis identified in existing literature. The specific research question was: Based on existing evidence, what are the facilitators and barriers to the uptake and continued use of home dialysis for individuals suffering from ESRD?

### **Methods**

#### **Study Design**

This was a systematic scoping review modeled on the Joanna Briggs Methodology. It was designed specifically to identify and summarize publically available literature on the facilitators and barriers to home dialysis from the patient perspective. The research team had expertise in the care of individuals on dialysis, and systematic review methodologies. The search strategy was developed a priori with the help of a library scientist.

#### **Selection Criteria**

The PICO (Population, Intervention, Context, Outcome) strategy (Stone, 2002) was used to delineate inclusion criteria (Table 1). Qualitative, full text studies published in English or French were included if they explored facilitators and barriers to home dialysis in adults (>18 yrs) established on a home dialysis modality at the time of the study. We excluded abstracts, unpublished thesis, books, and conference summaries.

#### **Search Strategy**

A three-step strategy was employed to search three databases: MEDLINE (2004-September 4<sup>th</sup>, 2014), EMBASE (2004-September, 2014), and CINHAL (2004-September, 2014). First, we searched each database using the keywords dialysis and patients. This

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helped us to identify the following relevant MESH headings in each database: ‘continuous ambulatory peritoneal dialysis’, ‘peritoneal dialysis’, ‘home dialysis’, ‘patient attitude and experience’, ‘patient compliance’, ‘health belief’ and ‘health behavior’. Second, we tailored searches specifically for each database using these MESH headings and a pre-determined set of key words. Finally, we hand- searched reference lists of all included citations to identify any missing, yet pertinent literature (see Table 2 for an example of a search strategy).

### **Study Selection**

After removing duplicate citations, we selected studies using a two-level screening process. First-level screening was done by title and abstract. In this step, citations were either excluded, kept based on their compatibility with inclusion criteria, or marked as unsure. The primary reviewer screened all citations, those deemed excluded were confirmed by a second person. Second-level screening involved reading the full texts of all kept or unsure citations to verify compatibility with the inclusion criteria. This step was completed by two reviewers and a consensus meeting was held to agree upon the final list of included citations.

### **Data Extraction**

The primary reviewer extracted data from the chosen studies using synopsis tables. Data included: a) Study characteristics (i.e.: title, year, country of origin, methodology, data collection method, and data analysis method); b) Study participant characteristics (i.e.: number of participants, gender, age range, time on dialysis, type of dialysis modality utilization, and living situation); and c) Study outcomes (i.e. reported facilitators and

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barriers including themes and supporting quotes). Synopsis tables were reviewed and discussed in team meetings to ensure accuracy of the extraction.

### **Data Analysis**

Study and participant characteristics were summarized and reported descriptively. The facilitators and barriers identified in the studies were also summarized and described. Furthermore, for facilitators and barriers identified in the majority of studies (facilitators n=7 studies, barriers n=6 studies), we aggregated the data and conducted a Content Analysis. This was guided by the Constant Comparison approach (Lincoln & Guba, 1985) and we reported the synthesized interpretations narratively. More specifically, we first grouped all facilitator and barrier themes/categories by exact wording. Second, we compared the definitions provided for each theme/category and regrouped based on their similarity. Third, we identified the facilitators and barriers with the most supporting evidence and synthesized, according to the Constant Comparison process, the descriptions into a narrative. Finally, we extracted direct quotes from the included studies to enhance the credibility of the synthesis and give voice to the original participants.

### **Results**

The search strategies produced a total of 848 citations. From these citations, we removed 37 duplicates and deemed 640 as irrelevant after first-level screening. A total of 171 citations were subjected to second-level screening, during which we further excluded 161 citations. The primary reasons for citation exclusion included: 1) Focus (i.e. articles that solely discussed patient choice, 2) Topic (i.e. not home dialysis), and 3) Study design (i.e. quantitative methods or program evaluation). We retained 10 full-text articles from the

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database search and subsequently included two additional studies from the hand search.

Thus, a total of 12 articles were included into this scoping review. Please refer to Figure 1 for the search decision tree diagram.

### **Study Characteristics**

The included studies were conducted in New Zealand (n=3), Canada (n=3), the United States (n=2), Australia (n=1), Norway (n=1), and Brazil (n=1). The study sample sizes ranged from four to ninety-five participants. Ninety-two percent of the studies were qualitative (n=11) and guided by a recognized qualitative methodology (rather than mixed methods, n=1). The majority were undertaken in dialysis centers (n=4) and hospitals (n=3). Interviews were the most common form of data collection (n=11), though these ranged in level of structure (i.e. unstructured n=1, semi-structured n=6, structured n=4). As it pertains to data analysis, thematic analysis was used most often (n= 6), followed by content analysis (n=5). One study did not specify method of analysis (Table 3).

### **Participants Included in the Studies**

Eleven of the 12 studies reported the sex, age, and length of time on dialysis for their participants. Males represented 60.5% of the total sample and ages ranged from 20 to 87 years old. The overall length of time spent on dialysis varied from 0 to 20 years. Sixty-four percent of participants were on home hemodialysis at the time of the study, with the remaining using peritoneal dialysis. Living situation (e.g. in own home, shelter, etc.) was only reported in two studies (Table 4).

### **Categories and Themes Reported in the Studies**

In 11 studies, the authors reported their results using themes (n= 7 studies) and

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categories (n=4 studies). Interestingly, in one study, neither themes nor categories were reported. In total, we identified 74 themes (supported by 15 subthemes) and 44 categories (supported by 10 subcategories) on the facilitators and barriers to home dialysis. Using exact wording, these categories and themes were condensed into 68 groups of facilitators and 42 groups of barriers. Further grouping these categories by definition yielded 22 facilitators and 15 barriers. Finally, by comparing each of the conceptual definition for these, we identified seven unique categories of facilitators and five unique categories of barriers. Facilitators included: Support, Physical and mental wellbeing, Ability to live a normal life, Autonomy, Convenience, Establishing habits, and Personal motivation. Barriers included: Burden of care, Invasion of the body, Disruption of lifestyle, Uncertainty for the future, and Environmental concerns (see Table 5 for complete information on the facilitators and barriers, including supporting quotes from the original studies).

### **Facilitators**

For each of the most strongly supported facilitators below, we first present a conceptual definition reflective of the aggregated data and then provide a synthesis of the original interpretations.

**Support.** Support was identified in eight articles (1, 2, 3, 4, 6, 8, 9, 10). This facilitator is characterized by the emotional support obtained from personal relationships, informational support from home dialysis staff, and practical support from peers also undergoing home dialysis that encourage uptake and continued use of home dialysis.

Support specifically from family and friends was reported in four studies (2, 4, 6, 9). This related to factors that motivated individuals to persevere with their treatment. The participants felt as though they had to fulfill certain obligations to their families, especially

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for their children, which encouraged them to continue their treatment in order to feel well enough to follow through. The support received from doctors and nurses was also important (1, 2, 8, 9). This entailed a sense of partnership in which participants engaged in shared decision making with their health care providers. In addition to open communication with providers, there was also informational support as the participants described how clear information sharing and education regarding their chronic kidney disease and surgical procedures helped alleviate concerns, and how concrete demonstrations of the technique improved their uptake (1, 3, 4, 10). A final form of support described by the participants, was the practical support received from peers who were also undertaking home dialysis. These peers were able to help study participants at every step of their dialysis journey; from assisting them in choosing a renal replacement therapy method to helping them solve troubleshooting issues with their home dialysis machines (4, 10).

**Physical and mental wellbeing.** Physical and mental wellbeing was described by participants as a facilitator to home dialysis in seven studies (1, 5, 6, 7, 8, 10, 11). It entailed the relief of symptoms of ESRD and alteration of the sick image, each of which contributed to an ongoing desire to remain on home dialysis.

Home dialysis was described as leading to better physical and mental health outcomes in six studies, which ultimately led to the continued use of home dialysis (5, 6, 7, 8, 10, 11). When starting dialysis, participants in a study by Polaschek and colleagues (2007) often experienced relief from the physical symptoms of ESRD including cramps, nausea, and weakness. Furthermore, individuals on home dialysis in a study by Sondrup and colleagues (2011) reported that because they were dialyzed more often with home dialysis than with in-center dialysis, they experienced relief from these symptoms and

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better overall health. A general improvement in mental health after starting home dialysis was also cited by participants in a study by Nakamura-Taira and colleagues (2013). The improved physical outcomes therefore motivated participants to remain on home dialysis. Participants also perceived themselves to be less sick than their peers on in-center hemodialysis because they were responsible for their own treatment. An alteration of sick image leading to increased mental wellbeing was described in two studies and motivated participants to remain on home dialysis (1, 8).

**Ability to maintain a normal life.** The ability to maintain a normal life was described in nine studies (1, 2, 3, 5, 6, 7, 8, 10, 11). This facilitator was characterized by the ability to maintain a certain freedom and flexibility with ones' own life and contributed greatly to the desire to remain on home dialysis.

The study participants described how their home dialysis schedule often allowed them to dialyze during the night leaving them free to accomplish their activities during the daytime. The ability to continue to work while on dialysis because of the flexible schedule allowed participants to lead a more normal life (3, 5, 8). Similarly, they described how the flexibility of home dialysis allowed for maintained social relationships with friends and families, and the ability to take part in one's activities of choice (1, 2, 5, 6, 7, 8, 10, 11). Finally, in two studies (5, 10), the participants further described this facilitator by linking the less-extensive dietary and fluid restrictions associated with home dialysis (compared to in-center hemodialysis) to the continued use of the modality. Both of these studies also demonstrated how the flexibility to coordinate their supply delivery allowed participants to travel and gave them a sense of freedom that further contributed to the continued use of home dialysis.

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**Autonomy.** Autonomy was described in six studies (1, 5, 7, 8, 10, 11) and referred to the sense of empowerment felt by persons when they mastered self-dialysis, as well the importance they attributed to self-care. The participants described the ability to self-dialyze and to make adjustments to one's dialysis therapy regimen and how this contributed to a feeling of control over their health and destiny (1, 5, 7, 10, 11). Furthermore, the participants stated the importance of having confidence in their ability to be responsible for their care and to obtain desired outcomes as a direct result of their actions (1, 8).

## Barriers

For each of the barriers below, we first present a conceptual definition representative of the aggregated data and then provide a synthesis of the original interpretations.

**Burden of Care.** The barrier Burden of care was described in eight studies (2, 5, 6, 7, 8, 9, 10, 11) and was characterized by the difficulties endured by the participants because of technological issues, aging and loss of physical abilities, hardships placed on caregivers, and the difficulties arising from lack of support. The act of home dialysis required participants to be capable of problem solving technological issues arising from the machinery itself. In two studies (8, 10), the participants described a fear associated with electricity and alarms. This fear was founded on the possibility of encountering unsolvable technical glitches, ultimately eliminating their ability to dialyze. This barrier also addressed the need for dexterity, mental capacity, and physical capability, which may not exist for experienced difficulties with home dialysis because of the loss of physicality from aging and diseases such as diabetes. The hardships placed on caregivers were described in three studies (5, 7, 11). The participants explained how their family

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members were often directly, or in part, responsible for their care during home dialysis, thus limiting their own activities. Furthermore, they frequently shared in the stress of undergoing dialysis at home, fretting about the possibility of complications with the therapy. Participants in three studies (2, 6, 10) described not receiving enough support to successfully undertake home dialysis. This lack of adequate support emerged from many sources, such as a recent spousal separation, the need to receive more educational material and health provider support when first choosing home dialysis, and the overall lack of training of primary care providers in dealing with home dialysis patients.

**Invasion of the body.** Invasion of the Body was reported in six studies (1, 2, 5, 6, 10, 11). This barrier concerned the side effects, body image issues, and fear of infection brought on by home dialysis. Participants described unpleasant physical effects, such as pain, muscle cramps, headaches, and itching, resulting from treatment (5, 6, 11). In the study by Curtin and colleagues (2004), the participants emphasized the self-consciousness and negative body image felt related to their peritoneal dialysis catheters situated in their abdomens. Individuals on home dialysis also had to learn to cope with the possibility of developing an infection, such as peritonitis or blood sepsis. Fear of infection was presented in three studies as part of this barrier (2, 5, 10).

**Disruption of lifestyle.** Disruption of lifestyle was discussed in eight studies (3, 5, 6, 7, 8, 9, 10, 11). This barrier included the costs incurred as a result of home dialysis, such as loss of activities, loss of time, and loss of freedom to eat as one chooses, because of the dietary regimen necessary when on dialysis.

The loss of activities related to home dialysis was identified in four studies (3, 5, 6, 10). Individuals on home dialysis were often unable to continue to work and they lost the

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ability to take part in leisure activities. Typically, this was because of a deteriorated physical condition and led to feelings of distress and a sense of sacrifice (3, 5, 6, 10). Similarly, the loss of time was also disruptive to their lives (5, 7, 8, 11,). Participants described how the time required to undergo home dialysis made them feel tied down to their machines (7, 8, 11). Participants also described this barrier in terms of the strict fluid and dietary restrictions necessary when on home dialysis (5, 6). This impinged on their ability to access social settings where dining or drinking occurred.

## Discussion

This is the first meta-synthesis of the facilitators and barriers to home dialysis from the perspective of individuals established on this modality. Support, Physical and Mental Wellbeing, the Ability to Lead a Normal Life, and Autonomy were the facilitators for which there was the strongest evidence in our study. The most strongly supported barriers were Burden of Care, Invasion of the Body, and Disruption of Lifestyle.

In executing the search strategy, we noted that 37 duplicate articles were retrieved. Typically, when conducting systematic searches in several databases, one would expect duplicates to encompass up to 75% of the total citations identified (Rathbone et al., 2015). This finding highlights the importance of searching multiple databases, given that each database contained a different set of eligible studies. Of the included studies, seven were retrieved from MEDLINE, two were retrieved from EMBASE, and one from CINHALL. Furthermore, given that we did not limit the search by research design, we retrieved all articles on the topic and the large majority were for quantitative studies or discussion papers. The relatively small subset of qualitative studies found is surprising for this topic. Facilitators and barriers are very personal and the best way to elicit an individuals'

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experience is to ask them (Patton, 2002). We suggest caution when interpreting facilitator and barrier information from the quantitative studies available. As many were included into second-level screening (and thus read in their entirety), we note that many of the pre-defined and 'tested' facilitators and barriers were chosen without a sound theoretical basis or input from persons living this reality.

Two qualitative studies focused specifically on elderly participants' perspective of the facilitators and barriers to home dialysis specifically. This focus on older adults is important because as individuals age, they tend to have more negative attitudes towards home dialysis and to prefer in-center hemodialysis (Keating, Walsh, Ribic & Brimble, 2014; McLaughlin et al., 2003). This may be due to the decline of cognitive and physical abilities that occurs with aging, which was represented by the facilitator Burden of Care in our review. With 54% of new dialysis patients being over 65 years old and 28% of persons with ESRD being 75 years or older in Canada, it is important for healthcare providers to accurately assess cognitive and physical capacities prior to discussing home dialysis and to continue to monitor for changing abilities as one ages on dialysis (Seccareccia & Downar, 2012). Alternatively, evidence supports that younger individuals more commonly adopt home dialysis and, perhaps due to less comorbidities and a higher functional status, tend to adjust more quickly to home dialysis compared to older persons (Kaye & Levison, 1993; Quinn et al., 2011). Unfortunately, very few studies explore the perspective of the younger person and thus more work is needed in this area. Men were also overrepresented in the included studies (men=60.5 %, women= 39.5 %); however this sex distribution is in line with that reported in the literature (Iseki, 2008). Moving forward, it is important for researchers to consider facilitators and barriers specific to men and women. There are

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known differences in the way both sexes adapt to ESRD. For example, a study found that the women in their sample had better-developed coping skills and had adjusted more effectively to life with ESRD (Harwood et al., 2011).

In terms of demographic information, it is also important to note that we did not limit this review by country, however, most of the included studies were published in developed countries. Our synthesis thus best represents the facilitators and barriers to home dialysis in these countries. Studies have demonstrated that access to home dialysis in developing countries such as China may differ from those in richer countries (Yu & Yang, 2015). It was also interesting that only two studies reported the living situation of their participants. While this may be attributed to the qualitative design of the included studies, the living situation of individuals on home dialysis is very important as it ultimately represents the setting of their treatment. Our synthesis also presented conflicting information regarding the employment status of individuals on home dialysis. Some individuals were able to maintain employment while others were not. Studies profiling the living situation and employment status of individuals on home dialysis are therefore warranted.

Our sample of participants was composed predominantly of individuals on peritoneal dialysis. This was not surprising given that the prevalence of peritoneal dialysis use is higher than home hemodialysis, however it is important to consider their differences (MacGregor, Agar, Blagg, 2006; Qamar, Bender, Rault, Piraino, 2009). For example, home hemodialysis is associated with lower hospitalization rates and long-term survival because of its improved control over blood pressure and fluctuations in dry weight (Kumar, Ledezma, Idroos, Burchette & Rasgon, 2008; Marshall, Walker, Polkinghorne & Lynn,

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2014). Unfortunately, this modality also necessitates self-cannulation through a fistula, which imposes a heavy burden on caregivers (Cafazzo, Leonard, Easty, Rossos & Chan, 2009). As an ex post facto analysis, we compared the studies on home hemo- and home peritoneal dialysis. Two differences were noted: studies with a sample composed only of individuals on home hemodialysis reported more caregiver burden, as well more living space requirements (Giles, 2003; Polaschek, 2005). A recent systematic review (Walker et al., 2015) on the patient and caregiver perspectives of home hemodialysis identified the barriers unique to home hemodialysis; namely the fear of needling, feeling unqualified, of being alone, and of medicalizing the home. These were not reported in the studies included in our review, emphasizing the need for more research on home hemodialysis specifically.

Interestingly, the synthesis revealed an association between certain dyads of facilitators and barriers. For example, Burden of Care and Support were related. The participants' recounts suggested that by employing strategies to increase support for individuals on home dialysis, that the burden of their care was less. Furthermore, Disruption of Life appeared to be remedied by strategies that enhanced the Ability to Lead a Normal Life. Support was one of the most commonly cited and important facilitators to the uptake and continued use of home dialysis. Participants recounted that Support was needed throughout their journey, beginning with their initial choice of renal replacement therapy and continuing through their everyday troubleshooting concerns with their home dialysis machines. This finding adds to a growing body of evidence on how disinterest from family and/or lack of familial social support contributes to poor adoption of home dialysis (Zhang et al., 2010). Health-care providers must learn to assess the support needs of patients and to implement the use of other support resources, such as paid caregivers, when

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families are not meeting needs. Furthermore, our review suggests that health care provider support is also an important motivator for the uptake and continued use of home dialysis. This support comes in several forms including clear information sharing and education concerning their disease and any required surgical procedures, as well as the opportunity to engage in shared decision-making regarding the dialysis regimen.

The findings of our scoping review also suggest that Burden of Care was one of the most commonly cited barriers to home dialysis. Contributors to this barrier included fear of the dialysis technology and increased burden of care on caregivers as well as lack of support. We found that the fear of making a mistake with the dialysis machine was a significant barrier to the continued use of home dialysis. This fear was also discussed in a Japanese study on the obstacles to peritoneal dialysis in Japan (Kawaguchi, 2007). In this study, the authors reported that the reluctance of individuals and their families to take on home dialysis was often because of the view that it was more dangerous and risky in terms of complications. As is done for persons living with other chronic and complex health conditions (Wild et al., 2007), these fears must be screened for and addressed in order to increase the proportion of individuals who adopt and remain on home dialysis.

A surprising finding was that the facilitator Personal Motivation was not well represented in the studies (n=3). Given our clinical experience working in a nephrology patient care setting, we would have expected to find strong evidence supporting the notion that individuals who are motivated to undertake home dialysis remain on it because of their personal attitude towards life, their responsibilities, or their hope to obtain a kidney transplant - often contingent on their ability to remain healthy by adhering to their home dialysis regimen. This clinical impression is also evident in the literature. For example,

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Ledebo (2008) reported that health practitioners worldwide identified personal motivation as the main reason why individuals continue to use home dialysis. It may be that health practitioners commonly perceive personal motivation as a facilitator of continued use and yet, it more accurately represents a catalyst to the choice of initiating home dialysis (Ledebo, 2008).

### **Limitations of the Study**

There are three limitations to consider when interpreting the findings of this study. First, as with all meta-synthesis studies, there is a possibility that we misrepresented the original experiences/interpretations. This can occur any time one synthesizes aggregated qualitative data from multiple sources (Sandelowski, Docherty & Emden, 1997; Walsh & Downe, 2005). To minimize this potential bias, we followed a rigorous Systematic Review methodology (Godfrey & Harrison, 2010), which involved double screening and data extraction. The research team also had expertise in review methods and ESRD patient care, which further enhances the validity of our results. Second, it is possible that the search strategy failed to identify all pertinent literature; however a library scientist with expertise in systematic reviews created the searches using both MESH headings and keywords. Finally, the database search was limited to studies written in French and English, which were published after 2004. Through the hand search, we identified two additional relevant studies (one published prior to 2004). While a 10-year timeframe is typical of reviews similar to the one presented here (Helfand & Balshem, 2009), it is possible that additional earlier studies exist.

### **Nursing Implications**

This study synthesizes existing evidence on the facilitators and barriers that must be

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addressed in order to increase the uptake and continued use of home dialysis. Nursing care should be focused on addressing the main barriers to home dialysis such as Burden of Care.

This can be done by encouraging peer support through the facilitation of peer discussion groups that address common issues, like troubleshooting and body image concerns.

Conducting small group, patient-centered education sessions on these topics may help mitigate concerns of individuals on home dialysis by taking into account their beliefs, fears and expectations (Hope, 2013). Knowing that support from caregivers decreases burden of care, nurses should try to include caregivers as much as possible to encourage support and to also address their fears and concerns. Another important, yet modifiable barrier to home dialysis, brought forward by this study is Disruption of Lifestyle. In order to decrease the perceived disruption of lifestyle on individuals on home dialysis and ultimately enable a more normal life, strategies and interventions that increase adaptive coping skills should be employed by nurses (Nearhos, Van Epps & Connor, 2013). These can include behavioural cognitive therapy and education in self-management and problem solving skills (Nearhos et al., 2013; Hener, Weisenberg, Har-Even, 1996).

## Conclusion

This study synthesized the facilitators and barriers to home dialysis from the patient perspective. Burden of care and the Disruption of Lifestyle were identified as important barriers that must be addressed in order to encourage the uptake and continued use of home dialysis. Although healthcare should be patient and family-centric and tailored to each person's needs, this review supports the need for overall efforts to increase support and minimize the disruption on everyday life. Interestingly, the perspectives of younger patients and those on home hemodialysis are not well represented. Future work is needed to further

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explore this gap in knowledge. Syntheses of the perspectives of health-care providers are also warranted in order to better understand their state of knowledge on the facilitators and barriers to the uptake and continued use of home dialysis.

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