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The Role of Social Support in Peritoneal Dialysis Management and Outcomes

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The Role of Social Support in Peritoneal Dialysis Management and Outcomes

by

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A THESIS

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Abstract

Peritoneal dialysis (PD) is an effective and cost-efficient renal replacement therapy that enables patients to maintain their independence at home. Unfortunately, technique failure is common and social support is necessary for PD success. The objective of this mixed methods study was to understand the significance and meaning of support in the PD context. Having a support person had a protective effect against technique failure between 3 and 12 months from the onset of PD. Social support was an important part of the PD experience, however, social support needs varied and were dependent on existing support networks and individual perspectives of support. To sustain patients on PD, the breadth of social support needs must be understood by healthcare providers and individualized to the patient/family.

Keywords: social support, peritoneal dialysis, home dialysis, end stage renal disease, competing risks, technique failure mixed methods, qualitative descriptive, observational cohort

Preface

Based on the work from this thesis, the following manuscripts have been prepared for future publication. For the papers below, Danielle Fox led the conceptualization, protocol design, implementation of the protocol, data analysis and initial draft of the manuscripts. Ms. Fox received substantial guidance from her thesis committee (Drs. Kathryn King-Shier, Robert Quinn, Matthew James and Lorraine Venturato) in all phases of research and thesis development. Ms. Alix Clarke also contributed to guiding Ms. Fox through the data analysis for the quantitative portion of this study. All authors contributed important intellectual content and provided critical reviews of the manuscripts.

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In the midst of a stressful week, an act of loving reassurance in the voice of my husband reminded me that my thesis was not an individual pursuit, but the work of a team. Within the next week, I had received a chat in the hallway from a committee member offering support, an email of encouragement from my supervisor, a productive meeting with the data analyst I was working with, a pep talk with granted time off from my manager, and a visit from my parents who not only looked after the lady of the house (my dog child Pippa), but filled my freezer with meals and replenished my confidence. This was over and above the usual loving kindness shown by my other family and friends. In my time of doubt, I was lovingly reminded that success was just around the corner.

In the last four years I have learned a lot about support and the impact that it has to outcomes, experience and well-being. I have also come to appreciate how rare it is to be completely supported. I feel exceptionally fortunate to have had my amazing ‘team’ alongside me, supporting me every step of the way. I am forever grateful.

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Dedication

This work is dedicated to my parents, Andrew and Lise-Marie Fox. Thank you for raising me with such love and devotion and for teaching me to value the important things in life.

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List of Abbreviations

PD	Peritoneal dialysis
HD	Hemodialysis
ESRD	End stage renal disease
DMAR	Dialysis Measurement and Reporting System
CI	Confidence interval
IQR	Interquartile range

Chapter 1 Introduction

The annual cost of caring for Canadians with end stage renal disease (ESRD) is estimated at 1.9 billion dollars (Zelmer, 2007). As the prevalence of ESRD continues to rise (Saran et al., 2015), it is imperative that appropriate, cost-effective treatments are implemented. The main treatment options for patients with ESRD are transplantation, dialysis, or conservative medical management with no dialysis (Vandecasteele & Tamura, 2014). There are more than 35,000 Canadians receiving dialysis (Yeates et al., 2012); the majority are treated with conventional in-center hemodialysis (HD) and home peritoneal dialysis (PD) (Devoe et al., 2016).

PD prevalence has traditionally ranged from 14% to 24% in Alberta, Canada and many eligible patients are not treated with PD (Alberta Health Services, 2016, para. 1). The ‘Starting dialysis on Time At home on the Right Therapy’ project has been implemented to “maximize the safe and effective use of PD, ensure patients are starting dialysis at the appropriate time, improve patient outcomes and experiences, and reduce costs to the healthcare system” (Alberta Health Services, 2016, para 4). PD and HD have similar patient outcomes (Yeates et al., 2012), though the total adjusted, one-year cost per patient on PD is \$33,932, compared to HD which is \$88,850 (Chui et al., 2012). In fact, Chui et al found that PD was “consistently the least costly modality at 1 and 3 years compared to HD” (p. 107), leading to a ‘PD-first’ approach in modality selection. Enhanced and timely modality education for patients with ESRD has been a focus of care in the hope of increasing PD usage in eligible patients (Blake, Quinn, & Oliver, 2013).

Patients on PD may discontinue due to a variety of reasons including technique failure, renal transplantation, and death. Patients who experience technique failure sustain

larger healthcare costs (Chui et al., 2012). It is imperative to explore reasons for loss of therapy in patients on PD to better understand how patients can be sustained on this comparatively less costly and equally effective modality.

Technique Failure

As demonstrated in Appendix A, inconsistencies exist between definitions, rates, reasons, and risks of PD technique failure. Recently, Lan et al. (2016) proposed a standardized definition of technique failure specifying it should be reported using a 30-day and 180-day no return to PD date, reporting death-censored technique failure separately, and specifying incident PD use (Lan et al., 2016). This definition does not appear to be accepted globally.

Risk for technique failure has been associated with increased age (Mehrotra, Story, Guest, & Fedunyszyn., 2012; Chidambaram et al., 2011); diabetes mellitus (Chidambaram et al., 2011; Shen, Mitani, Saxena, Goldstein, & Winkelmayr, 2013); coronary artery disease (Shen et al., 2013); high body mass index (Pajek et al., 2014; Shen et al., 2013); lower residual renal function (Pajek et al., 2014); previous HD treatment (Mehrotra et al., 2012; Chidambaram et al., 2011); male sex (Mehrotra et al., 2012); and being widowed, divorced, or separated (Shen et al., 2013). When assessing long- and short-term technique failure, specific reasons for technique failure are often consistent between studies. However, the frequency of individual causes of technique failure and time to technique failure vary. Few studies have defined specific reasons for technique failure and although some reasons are self-explanatory (e.g. peritonitis or catheter malfunction), many reported reasons are too broadly defined to fully comprehend the reason for failure. Social reasons for failure have been characterized as

social reasons (Lan et al., 2016), psychosocial reasons (Aguiar et al., 2016); Béchade et al., 2013; Goullouet), patient decision (De Sousa-Amorim et al., 2013; Gulcan et al., 2017; Workeneh et al., 2015), patient choice or not coping (Pakek et al., 2014), and unable to manage self-care (Lan, Clayton, Saunders, Polkinghorne, & Snelling, 2015). As social determinants of technique failure are potentially modifiable, it is important to better understand this phenomenon.

Other Reasons for Therapy Loss from PD

Other reasons for therapy loss from PD include renal transplantation, renal recovery, and death. Rates for these other reasons for loss from PD therapy also vary by study (Appendix B). Rates of renal recovery were low, and although some patients do recover renal function, the majority of patients with end stage renal disease do not (Appendix B). Renal transplantation is an economical treatment for ESRD and is associated with positive patient outcomes. Patients on PD have a decreased chance of receiving a renal transplant if they are older in age, have had coronary artery disease, congestive heart failure, diabetes mellitus, late referral to a nephrologist (Chidambaram et al., 2011); or had HD prior to PD (Béchade et al., 2013). Increased transplant rates on the other hand have been associated with male sex, (Chidambaram et al., 2011), younger age, lower Charlson Co-morbidity Index Scores, and lower prevalence of diabetes mellitus (De Sousa-Amorim et al., 2013). Unfortunately, renal transplantation is not always accessible in Canada due to long wait lists and strict eligibility criteria, and this varies by geographical location (Tonelli et al., 2006).

Overall mortality for patients on peritoneal dialysis has been associated with various risk factors including: continuous ambulatory peritoneal dialysis as initial

treatment (Béchade et al., 2013), HD prior to PD treatment (Béchade et al., 2013; Aguiar et al., 2016), diabetes mellitus (Gulcan et al., 2017; De Sousa-Amorim et al., 2013; Chidambaram et al., 2011; Aguiar et al., 2016), having three or more comorbid conditions (Gulcan et al., 2017); being 65 years of age and older (Gulcan et al., 2017; De Sousa-Amorim et al., 2013), having a history of congestive heart failure (De Sousa-Amorim et al., 2013; Chidambaram et al., 2011), having coronary artery disease (Chidambaram et al., 2011), and having had a late nephrologist referral (Chidambaram et al., 2011). Conversely, patients who performed the PD treatment themselves (Gulcan et al., 2017), were employed (Mehrotra et al., 2012), were 45 years of age and younger (Mehrotra et al., 2012), who used automated PD (Mehrotra et al., 2012), and who lived in an area with high per capita income (Mehrotra et al., 2012) had a lower mortality rate. Patients on PD may also choose to end renal replacement therapy for conservative management. Pajek et al. (2014) accounted for voluntary dialysis withdraw in their analysis and attributed it to 10% of total patient deaths between 2004-2010.

Healthcare Structure

The location and manner in which care is provided may also impact support availability and therapy outcomes. Gulcan and Keles (2014) reviewed PD treatment failure and found it was essential to account for system factors. They found lack of infrastructure, lack of PD supplier in place, lack of expert personnel, and absence of dialysis facilities were all considered system obstacles leading to technique failure. Fortunately, several strategies to prevent system-related failure were presented. These included optimizing PD facility dimensions and additional patient and physician training (Gulcan & Keles, 2014). Mehrotra et al. (2012) noted that centre differences were a

contributor to patient outcomes, particularly in the USA where 90% of patients were treated in large urban centres and technique failure and mortality increased in units in remote rural areas. This differs from Gulcan et al. (2017) who reported that French patients were treated in community hospitals in 56% of cases, non-profit centers in 16% of cases, private centers in 16% of cases, and academic centers in 12% of cases. With varying global healthcare structures, and potential impact on patient outcomes, it is important to identify where the treatment is being offered. Home care assisted PD has been incorporated into some programs in Canada (Chidambaram et al., 2011) and is one example of how system mechanisms were optimized to improve patient support. Family-assisted PD is also frequently discussed in the literature and it may lower technique failure rates (Béchade et al., 2013).

Social Support

Social support has been defined broadly as tangible or intangible assistance and protection given to others (Langford, Bowsher, Maloney & Lillis, 1997). Williams, Barclay and Schmied (2004) discussed social support and its relationship with stress and coping, which has been connected to psychological health, physiological health, and prevention of disease. Cohen and Wills (1985) believed social support to have a beneficial effect through two main models. The first, a buffering model, posited that support protected people from the influences of stressful events and emphasized social support during times of stress (Cohen & Wills, 1985). The second, a main-effect model posited that social resource had a benefit regardless of whether a person was under stress or not and thus, continuous social support was needed (Cohen & Wills, 1985). More recently, Kadirvelu, Sadasivan and Ng (2012) discussed the complexities associated with

the management of patients with chronic illness and the important role that social support plays.

Researchers suggest that social support has four main attributes including appraisal support, informational support, instrumental support and emotional support (Langford et al., 1997; Kadirvelu et al., 2012; House 1981). Kadirvelu et al. (2012) emphasised that it is not only important to understand and provide these attributes of support, but that it is also important to identify the components of a patient's social support network to enhance their confidence, mood, understanding of self-efficacy, and perceived social support.

Components of the social network

Social support networks for patients on PD include family members, healthcare providers, and peers or friends. Family members may include spouses (Sadala, Bruzos, Pereira, & Bucuvic, 2012; Cheng et al., 2013), children (Salada, Miranda, Lorencon, & de Campos Pereira, 2010) and grandchildren (Salada et al., 2010). Nurses and physicians are most commonly identified as the healthcare providers (Tong et al., 2013; Sadala et al., 2012), although it is known that other members of the healthcare team including dieticians, social workers, and pharmacists also support patients. Other components of the social network for patients on PD included friends or peers (Asti, Kara, Ipex, Erci, 2006; Tong et al., 2013) and paid caregivers (Cheng et al., 2013).

Family members, healthcare professionals, and institutional support were essential to patient survival and were necessary regardless of who performed the PD procedure (Sadala et al, 2012). Social networks are reduced when a patient undergoes PD because of the treatment and physical disabilities associated with PD (Asti et al., 2006), and

patients can experience social abandonment due to their illness (Tong et al., 2013).

Consequently, family and close friends become key players in offering social support to patients (Asti et al., 2006). Family support was also an important factor in determining PD eligibility (Oliver et al., 2010). Many patients on PD were very dependent on family for assistance (Sadala et al., 2012), and family members were considered partners in their treatment (Sadala et al., 2010). In a study ofpatients and caregivers both rated perceived social support as high, with the support score from family and friends accounting for more than two thirds of the total score (Asti et al., 2006).

Prior work has shown that patients on PD describe healthcare as constantly available and caring and that communication with professionals was clear, objective and open (Sadala et al., 2010; Sadala et al., 2012). They desired holistic care, including attentive nursing care, and wanted health professionals to actively listen and provide opportunities for shared decision-making (Tong et al., 2013). Peer support from other patients on PD was described as very valuable (Tong et al., 2013) and they felt they could trust other patients to give them relevant and practical information on how to manage their therapy and share coping strategies with one another (Tong et al., 2013).

Appraisal support

Appraisal support “involves only transmission of information” (p. 25) that is used for self-evaluation (House, 1981). Fex, Flensner, Ek, and Söderhamn (2011) found patients on PD often felt supported by their family members who showed confidence in the patients’ abilities to manage their own care. Patients also developed confidence in self-care because of the interest and attention given by nurses, and that it was important for nurses to adapt their communication skills to the specific needs of the patient (Salada

et al., 2010). Although these processes were not defined as appraisal support, they increased the patient's ability to self-evaluate, a key attribute of appraisal support.

Informational support.

Informational support has been defined as “providing a person with information that the person can use in coping with personal and environmental problems” (House, 1981, p. 25). Information received from nurses was important to patients and they felt that nurses were essential in providing this support (Tong et al., 2013). However, patients also accessed information independently or when encouraged by peers (Tong et al., 2013). It was felt that actively accessing information enabled PD patients to be responsible for their own health (Tong et al., 2013).

Instrumental support.

Instrumental support involves “instrumental behaviors that directly help the person in need” (House, 1981, p. 25). Facility-delivered instrumental support is provided to patients on PD in various ways. In Canada, Oliver et al., (2010) discuss home care assisted PD where nurses provide daily dialysis set up as a means to support patients. Assisted PD is an appropriate option for patients who have barriers to PD such as comorbidities, physical disability, or psychosocial problems (Povlsen & Ivarsen, 2008), and can increase the likelihood of PD eligibility (Oliver et al., 2007; Castrale et al., 2010). PD home care support programs vary by location. In Alberta, Calgary is the only center that offers home care assisted PD and presently, only 17 spots are available to outpatient PD users. In France, home care assisted PD is fully covered (Castrale et al., 2010) and 45% of all patients on PD are assisted by a nurse (Verger et al., 2006). Duration of home care support can be used until the patient was able to take on the

therapy independently, as a temporary bridge to prevent caregiver burnout, or can be indefinite (Oliver et al., 2007).

Fex et al. (2011) found that some family members were very involved with the technical procedure, while others were not. Tong et al (2013) found that families provided much of the instrumental assistance in PD management. Instrumental support was also characterized by changing roles in the home, where family members took on more domestic duties while patients performed less strenuous ones (Fex et al., 2011). In addition, families provided other supports such as providing transport and managing diet (Griva et al., 2016).

Emotional support.

Emotional support involves offering caring, empathy, love, and trust (Kraus, 1986) and is an important perception of how support is conveyed (Langford et al., 1997). Self-care patients don't require assistance with PD therapy but seek support from their families in other ways. They function as advocates for them, coach them, and evaluate their health (Griva et al., 2016). Tong et al. (2013) found strong family support alleviated stress related to PD. In a study of family members of patients managing complex technology at home, including patients on PD, participants felt it was their mission "to give their psychological support by being there; being someone who listens and is engaged, and a source of security" (Fex et al., 2011, p. 342).

Clinicians can assist patients to overcome feelings of vulnerability around home dialysis, especially if they do not have a strong support network in the home (Walker et al., 2015). Nurse-led case management has been found to lead to higher quality of life, better emotional states and improved social functioning (Chow & Wong, 2010). Feeling

empathy from healthcare professionals has also helped patients using complex technology at home to feel supported, when needed (Fex et al., 2011).

Impact of Social Support on Patient Outcomes

Having higher levels of social support has been linked to better physical health in the general population (Uchino, 2006) and has been associated with lower levels of stress and burden in patients on PD (Tong et al., 2013). Regardless of whether family members help with the dialysis procedure, social support has been identified as an important element in the lives of patients on PD (Griva et al., 2016). Thong, Kaptein, Krediet, Boeschoten, & Dekker (2007) found that PD patients with a larger mismatch between expected and received levels of social support such as companionship, daily emotional support, and total support (p. 845), had higher mortality. In a qualitative synthesis of studies done with patients on PD, support led to positive adjustment that promoted control and freedom (Tong et al., 2013). Lack of support on the other hand “resulted in impaired self-esteem and an intensified sense of disablement” (Tong et al., 2013, p. 873). These feelings were not constant and would change throughout the course of PD therapy (Tong et al., 2013).

Plantinga et al. (2010) found social support scores were higher in PD than HD patients and were associated with greater satisfaction and reduced hospitalization, but no difference in technique failure or mortality. In Singapore, social support indicators were not associated with one-year survival (Griva et al., 2016). Alternatively, Szeto et al. (2008) found that in China, having social support was an independent predictor of technique survival in the first year, but did not affect the risk of hospitalization. Lastly, patients in the United States of America who were widowed, divorced, or separated were

31% more likely to fail PD, and social support was critical in maintaining them on therapy (Shen et al., 2013).

Though social support has been identified as an important factor in the lives of many patients on PD, few studies have examined how an absence of support may predict technique failure in Canada. Williams et al. (2004) identified 30 different definitions of social support and determined that researchers should derive a definition of social support in the context they are studying. Although some studies have researched social support in the PD context, few articles have thoroughly analyzed and developed this definition, especially in the Canadian context. In addition, quantitative studies evaluating social support as it relates to technique failure show inconsistent results, further emphasizing the importance of a study done in the Canadian context.

PD Sustainability

The main reasons for PD therapy loss include technique failure (e.g. permanent modality change to hemodialysis), transplantation, and death. Reasons for loss from PD therapy have been extensively explored and technique failure in particular is an economical concern for many renal programs. Unfortunately, there is great variability in findings, which may be due to variability in study locations (e.g., North America, Europe, Australia, New Zealand). It is thus important to understand rates and reasons for PD therapy loss in the context under study.

PD sustainability has been explored in two recent Canadian studies as highlighted in Appendix A. Perl et al. (2012) were only able to capture peritonitis and inadequate dialysis as reasons for technique failure, as other reasons for failure did not have clear definitions in the database. Alternate reasons for technique failure vary widely.

Chidambaram et al. (2011) examined sociodemographic factors influencing technique failure, unfortunately, no data were collected on how social support factors impact this problem. We did not identify any Canadian studies that explored social support in the PD population and the role of support as it relates to technique failure. A gap in the literature exists when adequately exploring reasons for transfer out of PD therapy in Canada, specifically with regard to detailed reasons for technique failure. As social support is a key factor for patients on PD and impacts patient outcomes, this phenomenon needs to be thoroughly defined and understood in the Canadian context.

Outline of Thesis Contents

Using a convergent, parallel mixed method design our objective was to understand the significance and meaning of support in the PD context. This was done through two studies which aimed to: (1) examine the association between support and technique failure in patients on PD in Alberta, and (2) explore how patients, their family, and nurses view social support.

Social support and technique failure are complex phenomena. Thus, in Chapter 2 we discuss the role of mixed methods research in healthcare and why a convergent parallel mixed methods design was important to conduct to meet our research aims. This manuscript-based thesis contains two manuscripts from two related studies. In Chapter 3 we report the findings of a retrospective observational cohort study, where we used a competing risk model to better understand the relationship between support and technique failure. In this chapter we also report our findings on reasons for technique failure and other reasons for therapy loss for patients on PD in Alberta. In Chapter 4 we briefly discuss why it was important to conduct the second study in this thesis. We

discuss the findings from the second study in Chapter 5, which was conducted using a qualitative descriptive design. We explored how patients, their families, and nurses view social support using the attributes of social support (emotional support, instrumental support, informational support and appraisal support) as an analytical framework. In Chapter 6, congruent with a convergent parallel mixed methods design (Creswell & Plano Clark, 2018), we conclude by synthesising our findings in a side-by-side comparison. In the conclusion, we identify the strengths and limitations of this thesis, implications for this work for renal programs and nursing practice, and future directions.

The proposal for this research was submitted and ethics approval was received from the Conjoint Health Research Ethics Board prior to study implementation. This study was undertaken in accordance with the Helsinki Declaration of 1964. All methods as outlined in the ethics application (REB17-1247) were followed.

Chapter 2. Defining Mixed Methods Research

Mixed methods research has been practiced by investigators from a variety of disciplines (e.g., social scientists, anthropologists and sociologists) since the early 20th century (Johnson, Onwuegbuzie, & Tuner, 2007). Mixed methods research capitalizes on the strengths of quantitative and qualitative methods to examine both the depth and breadth of a phenomenon to produce a more complete picture (Creswell & Plano Clark, 2018). In some instances, both quantitative and qualitative paradigms are required, when one alone would not suffice to answer certain research questions (Leech & Onwuegbuzie, 2009). Mixed methods approaches have not only been observed in research, but are intuitively present in clinical practice (Creswell & Plano Clark, 2018). For example, when choosing a PD prescription, the clinician considers quantitative clinical data points, such as laboratory values and other diagnostic measurements. Although these data are informative, the clinician would never make a decision without also considering qualitative factors, such as how the prescription needs to be modified to fit the patient's lifestyle, preferences, or the schedule requirements of the patient or support person performing the therapy. Used together, this information creates a PD prescription that not only meets the physiological needs of the patient, but that also considers the patient's social circumstances, making the therapy goals more achievable.

Definitions of mixed methods research have evolved over time (Creswell & Plano Clark, 2018). To gain consensus, Johnson et al. (2007) derived a general definition from leaders in mixed methods research. They defined mixed methods research as:

the type of research in which a researcher or team of researchers combines elements of qualitative and quantitative research approaches (e.g., use of

qualitative and quantitative viewpoints, data collection, analysis, inference techniques) for the broad purposes of breadth and depth of understanding and corroboration (p. 123)

Although a single definition continues to be disputed (Creswell & Plano Clark, 2018), it is clear that like quantitative and qualitative research methods, mixed methods research has become a distinct methodology (Johnson et al., 2007).

Mixed methods research has raised certain controversies and questions (Creswell, 2011). Opposing paradigms often seen in qualitative and quantitative methodology complicate the worldview that underpin mixed methods research. Quantitative research has traditionally aligned with a positivism paradigm known as a “singular reality, the one and only truth that is out there waiting to be discovered by objective and value-free inquiry” and constructivism/interpretivism with qualitative research where there is “no such thing as a single objective reality and that subjective inquiry is the only kind possible” (Feilzer, 2010, p. 6). Rather than using one paradigm, in mixed methods, paradigms should be used as a tool where one, or multiple paradigms, can be used depending on which is required to fit to the research question (Creswell & Plano Clark, 2018). The pragmatist paradigm is a practical approach, encouraging the use of the method that works best, including incorporating multiple views, theory generation, and theory verification when appropriate (Polit & Beck, 2012). For this reason, many mixed methods researchers use a pragmatism paradigm as a philosophical to guide mixed methods research (Creswell & Plano Clark, 2018; Feilzer, 2010). Its aim is to find the most appropriate method and to commit to uncertainty instead of “unvarying causal truths”, where “research is relative instead of absolute” (Feilzer, 2010, p. 13-14). The

most important question is not debating the qualitative/quantitative divide, but knowing whether the research methodology selected has allowed the researcher to answer the research question (Feilzer, 2010; Hanson, 2008).

Mixed Methods in Health Research

To effectively provide health services, there has been a drive to increase research that maintains a patient-centered approach and provides evidence to inform clinical decision making (Andrew & Halcomb, 2009). As the nature of health research is complex, identifying the most appropriate method, and mixing methods when appropriate, provides the most holistic evidence in health research (Andrew & Halcomb, 2009). It is imperative to understand when mixed methods are appropriate and select the appropriate methodology based on fit to the research question (Creswell & Plano Clark, 2018). “Research problems suited for mixed methods are those in which one data source may be insufficient” (Creswell & Plano Clark, 2018, p. 43). This is often the case in health settings, where many questions are too complex to be understood by either the qualitative or quantitative methods alone.

Social Support and Mixed Methods

Social support and PD technique failure are complex phenomena that require multiple methods to comprehensively describe. Data retrieved from the Dialysis Measurement Analysis and Reporting System (DMAR) provides an understanding of support available for a patient starting PD at baseline. DMAR is a web-based platform that captures high-quality, expert-reviewed data on all patients initiating dialysis in Alberta, Canada. These high-quality data also provide a deeper understanding of characteristics of the PD population and enables an understanding of the relationship

between baseline support and technique failure. However, social support is complex and to truly understand the depth and breadth of support, further investigation was needed.

The depth of understanding needed is not possible without also using qualitative methodology. Using qualitative methodology allowed patients receiving PD to share their stories. This in turn, provided valuable insights into what social support meant for this population, and how social support needs must be individualized and may change over time.

As neither method would have been sufficient to understand the research question, a convergent parallel mixed methods design was used to collect quantitative and qualitative data. Using a single-phased approach, qualitative and quantitative data were analyzed separately and then the results were compared using a side-by-side comparison approach (Creswell & Creswell 2018). The convergent mixed method design allowed for different, yet complementary, data to be collected (Morse, 1991) and for the development of a comprehensive view of the phenomenon (Creswell & Plano Clark, 2011). Equal importance was ascribed to collecting both quantitative and qualitative data in this circumstance. Congruent with a convergent mixed-methods research design, the questions were designed to ensure that parallel concepts were answered so that they were addressed in both the qualitative and quantitative work (Creswell & Plano Clark, 2011).

Chapter 3: The Impact of Support on Peritoneal Dialysis Technique Failure: A Competing Risk Analysis

Abstract

Objective. The objective of this study was to examine the association between the availability of support and the risk of technique failure in patients starting PD in Alberta, Canada.

Design. Retrospective, observational cohort study.

Methods. Data was retrieved from the Dialysis Measurement Analysis and Reporting (DMAR) system on all incident patients on PD in Alberta, Canada between January 1, 2013 and December 31, 2018. The method of Fine and Gray was used to determine the cumulative risk of technique failure over time, while a Cox proportional hazards model was used to determine the association between the availability of a support person at baseline and technique failure.

Results. One hundred and sixty-nine patients experienced permanent technique failure at a median time of 7 months ($IQR = 2-26$). Other causes of loss from PD included transplant ($n = 65$), death ($n = 56$), transfer to palliative care ($n = 10$), recovery of renal function ($n = 12$), and transfer out of the program ($n = 13$). The raw cumulative incidence of technique failure at 24 months was 28% overall (25% for those with support and 31% for those without). The impact of support on technique failure was significant between 3 and 12 months.

Conclusion. Having a support person available in the home is associated with a significantly lower hazard of technique failure between 3 and 12 months.

Introduction

As the prevalence of end stage renal disease (ESRD) increases (Saran et al., 2015), patient appropriate, cost-effective renal replacement therapies are necessary. Peritoneal dialysis (PD) is often promoted as it costs less than hemodialysis (HD) and has a number of potential benefits: PD has similar patient outcomes, is associated with preservation of residual renal function, can preserve vascular access sites, increase patient flexibility, and may enhance quality of life (Karopadi, Mason, Rettore, & Ronco, 2013; Theofilou, 2011; Moist et al., 2000; Chaudhary, Sangha, & Khanna, 2011; Chui et al., 2012). With initiatives aimed at increasing PD use (Finkelstein et al., 2008; Chaudhary et al., 2011; Lacson et al., 2011; Morfin, Yang, Wang & Schiller, 2017), there is concern that more marginal candidates may be put on PD, who may be at higher risk of failing.

Predictors of technique failure have largely focused on demographic and medical factors, with few studies examining social factors such as the availability of support (Shen, Mitani, Saxena, Goldstein, & Winkelmayr, 2013). Program- or family-assisted PD, whereby patients are provided instrumental support to set-up and administer therapy, is associated with a reduced risk of technique failure (Lobbedez, Verger, Ryckelynck, Fabre, & Evans, 2012). Having a support person has also been shown to be a significant predictor of the likelihood that patients will be considered eligible for, and choose, PD (Oliver et al., 2010). While instrumental support is important, social support encompasses much more than providing physical assistance to help deliver the therapy (Griva et al., 2016; Tong et al., 2013). We hypothesized that the availability of support from family or friends, regardless of who actually performs the dialysis procedure, may have a role in reducing the risk of technique failure.

Objective

The objective of this study was to examine the association between the availability of support and the risk of technique failure in patients starting PD in Alberta, Canada.

Methods**Study design and data source.**

This retrospective, observational cohort study utilized data from the Dialysis Measurement Analysis and Reporting (DMAR) system. DMAR is a web-based platform that captures high-quality, expert-reviewed data on all patients initiating dialysis in Alberta, Canada. Data are entered by trained front line staff following clear definitions and a standardized coding scheme, with all queries being addressed prior to data analysis. Alberta has 7 PD centers and 32% of patients initiating dialysis receive PD within 6 months (Alberta Health Services, 2018).

Participants and settings.

To be eligible for the DMAR database, patients must have (1) received at least one outpatient dialysis therapy; (2) a diagnosis of ESRD documented by a nephrologist; or (3) have an acute kidney injury that required at least 28 days of dialysis. The cohort was further restricted to adults 18 years or older, who had received at least one outpatient PD therapy in Alberta, Canada between January 1, 2013 and December 31, 2018. Patients enrolled prior to October 1, 2016 were restricted to the Calgary zone. After October 1, 2016 the data system was expanded to include all patients starting dialysis in the province. Patients were followed from their first dialysis treatment (i.e. incident patients) and were excluded if they did not meet the above criteria or did not have more than 90

days of potential follow-up prior to the end of study date. Participants were followed with outcomes updated every three months until the first of: death, transplant, recovery of renal function, transfer out of the program, loss to follow-up, or end of study date (December 31st, 2018).

Exposure: Support.

In the DMAR database, support is captured at baseline and is defined as the presence of “an individual(s) who was able, willing, and available to provide support for PD in the patient’s residence” including their spouse, other family members, paid caregivers and other support. This study was primarily focused on the availability of a support person, thus program support (i.e. home care assisted PD) was not included as ‘having support’. Only one center in Alberta had a home care assisted PD program and only 18 people were receiving home care assisted PD at any one point in time (Hermann, L, personal communication, May 13, 2019). Having home care assisted PD available at baseline was included as a confounding variable. A sensitivity analysis was conducted excluding patients who had received home care assisted PD at any point during PD therapy.

Primary Outcome: Technique failure.

We were interested in permanent technique failure, so technique failure was ultimately defined and reported as a transfer to hemodialysis for a period of at least 90 days. In previous studies, only 11% of participants meeting this criterion returned to PD after 12 months, compared to 24% using a 30-day definition that is commonly used (Lan et al., 2016). If a patient recovered renal function, received a transplant, died or transitioned to palliative care within the 90 days after a transfer to HD, they were

included as “technique failure” as it would be unlikely that they would return to PD. All other exit reasons that occurred during this time were not considered permanent technique failure. These included last update date/end of study date, transfer out of the program, and other reasons for loss. Eighteen reasons for technique failure are reported in the DMAR database. They were grouped into eight categories of technique failure: PD infectious complications, inadequate dialysis, PD catheter-related problems, other PD complications, social reasons, medical reasons, other, and unknown.

Baseline covariates of interest.

Baseline characteristics were retrieved from the DMAR database that were either clinically relevant or associated with support and/or technique failure in the literature. These included age, gender, body mass index (BMI), diabetes mellitus, cardiovascular disease (congestive heart failure, coronary artery disease and other cardiac disease), peripheral vascular disease, polycystic kidney disease, albumin, started dialysis as an inpatient, receipt of HD before PD, receipt of at least 4 months of pre-dialysis care, the presence of a medical, physical, cognitive or social barrier to PD, and the availability of home care assistance for PD.

Statistical analysis.

For continuous variables, differences in baseline characteristics between groups were calculated using the Mann-Whitney U test and we reported the median and interquartile ranges, as they were not normally distributed. Categorical variables were analyzed using Pearson’s chi-squared test, and we reported frequencies and percentages. All variables had less than 1% missing values, with the exception of BMI and albumin, which were missing in 5% and 2% of patients, respectively. For these cases imputation

was used (Kang, 2013). We estimated the probable value based on weight and gender for BMI, and based on age group (18-44, 45-64, 65-75 and >75) for albumin. Logistic regression was used to check for multicollinearity between variables. We did not observe any significant collinearity, as evidenced by variance inflation factors in the range of 1.03-1.81.

A Cox proportional hazards model was used to determine the causal relationship between the availability of a support person at baseline and technique failure. Death (which included transfer to palliative care), transplant, recovery of renal function, transfer out of the program, loss to follow-up, and the end of follow-up were included as censoring events. We checked the exposure variable for a violation of the proportional hazards assumption using graphical and statistical techniques, which demonstrated non-proportionality. As a consequence, we broke follow-up time into 3 periods (0-3 months, 3-12 months, and 12+ months).

The method of Fine and Gray (Fine and Gray, 1999) was then used to determine the cumulative risk of technique failure and the relationship between support and technique failure, accounting for competing risks. Transplant, death (including a transfer to palliative care) and recovery of renal function were considered competing events, with all other exit reasons being right-censored. A violation of the proportional hazards assumption was again observed and we introduced a three-category variable for time (0-3, 3-12 and 12+ months).

Both models were adjusted for age, gender, body mass index (BMI), diabetes mellitus, cardiovascular disease (congestive heart failure, coronary artery disease and other cardiac disease), peripheral vascular disease, polycystic kidney disease, albumin,

started dialysis as an inpatient, receipt of HD before PD, receipt of at least 4 months of pre-dialysis care, the presence of a medical, physical, cognitive or social barrier to PD, and the availability of home care assistance for PD. We were unable to analyze the relationship between support and specific reasons for technique failure, as the number of patients experiencing the individual reasons for technique failure were small. Most technique failure events occurred within the first two years, thus we focused on reporting the cumulative risk of events within this time period. All analyses were conducted using STATA statistical software, Version 14 (StataCorp LLC, 2019).

Results

Patient characteristics.

Between January 2013 and December 31st, 2018, 683 incident patients received outpatient PD and were eligible to be included in the study. Of these, 59% had a support person available to them in the home. Support people included spouses (71%), other family members (26%) and other support (4%). No participants were identified as having a paid support person, and 22 participants had a support person in more than one category. Patient characteristics at dialysis initiation are shown in Table 1. Individuals with support at baseline were more likely to be older, have cardiovascular disease, a lower albumin level, have a medical, physical cognitive or social/residential barrier to self-care PD, have home care assisted PD available, and to be on home care assisted PD.

Events during PD.

The median follow-up time for study participants from first PD use date to study exit date was 15 months (*IQR* = 8-26). One hundred and sixty-nine patients experienced permanent technique failure at a median time of 7 months (*IQR* = 2-26). Other causes of

loss from PD included transplant ($n = 65$), death ($n = 56$), a transfer to palliative care ($n = 10$), recovery of renal function ($n = 12$), and transfer out of the program ($n = 13$) (Table 1).

Four patients received a transplant, 5 died and 1 transitioned to palliative care ($n = 1$) within the 90 days after a transfer to hemodialysis and were included as technique failure. Those with a last update date/end of study date ($n = 17$), who transferred out of the program ($n = 4$), and who had other reasons for loss ($n = 1$) during this time were censored. The most common reasons for technique failure were inadequate dialysis (29%), infectious complications (18%) and other PD complications (12%). Social reasons accounted for 11% of events and included patient-initiated switches to HD or inability to cope ($n = 13$), the need for increased care ($n = 3$), and psychosocial/social/financial reasons ($n = 3$). The overall, raw cumulative incidence of technique failure was 13%, 17% and 28% at 6, 12 and 24 months respectively. The cumulative incidence curves for technique failure, transplant, and death (including transfer to palliative care) according to the presence or absence of support are reported in Figures 1 to 3.

The impact of support on technique failure was significant between 3 and 12 months, where those with support had a lower probability of developing technique failure (adjusted relative hazard of technique failure: 1.02, 95% CI:0.57-1.80 for 0 to 3 months; 0.44, 95% CI: 0.25-0.78 for 3 to 12 months; and 1.27, 95% CI:0.71-2.26 for greater than 12 months). A sensitivity analysis excluding participants who had received home care assisted PD at any point during PD therapy ($n = 40$) revealed similar results.

Using the method of Fine and Gray to account for competing risks, the adjusted subdistribution hazards of technique failure for these times were: 0.90, 95% CI [.52, 1.54]

for 0 to 3 months; 0.40, 95% CI: [.23, .69] for 3 to 12 months; and 1.72, 95% CI [.98, 3.05] for greater than 12 months.

Table 1. *Patient Characteristics at Dialysis Initiation*

Baseline Characteristic	Support Available (<i>n</i> = 402)	No Support Available (<i>n</i> = 281)	p-value
Age, median (IQR)	59 (48-70)	56 (45-66)	.01
Male, n (%)	256 (64)	186 (66)	.50
Body mass index, median (IQR)	26.69 (23-30)	27.18 (23 – 32)	.19
Diabetes, n (%)	215 (53)	133 (47)	.16
Cardiovascular disease (any), n (%)	153 (38)	82 (29)	.02
- Congestive heart failure	46 (11)		
- Coronary artery disease	87 (22)	22 (8)	.12
- Other cardiac	82 (20)	48 (17)	.14
		34 (12)	< .01
Peripheral vascular disease, n (%)	35(9)	17 (6)	.20
Polycystic kidney disease, n (%)	20 (5)	18 (6)	.42
Albumin, median (IQR)	33 (29-36)	36 (31-39)	< .01
Started dialysis as inpatient, n (%)	95 (24)	73 (26)	.48
Received HD before PD, n (%)	85 (21)	74 (26)	.11
Pre-dialysis care \geq 4 months, n (%)	349 (87)	237 (84)	.36
Medical barrier to self-care PD, n (%)	108 (27)	96 (34)	.04
Physical barrier to self-care PD, n (%)	76 (19)	26 (9)	< .01
Cognitive barrier to self-care PD, n (%)	72 (18)	25 (9)	< .01
Social/residential barrier to self-care PD, n (%)	24 (6)	29 (10)	.04

Home care assisted PD available, n (%)	282 (70)	80 (28)	< .01
Received home care assisted PD, n (%)	9 (3)	31 (8)	.01

Note: HD = hemodialysis; Medical barrier to self-care PD = abdominal aortic aneurysm, abdominal scarring, ascites, bowel cancer, bowel obstruction, colostomy, diarrhea, diverticulitis, future abdominal surgery, gastroparesis, hernia ileal conduit, ileostomy, incontinence, inflammatory bowel disease, insomnia, ischemic gut, nephrotic syndrome, obesity, polycystic kidneys, other; Physical barrier to self-care PD = decreased hearing/deafness, decreased manual dexterity, decreased strength to lift PD bags, decreased vision/blindness, frailty, poor hygiene, reduced mobility, other; Cognitive barrier to self-care PD = anxiety, aphasia/dysphasia, dementia, language barrier, learning disability, mild cognitive impairment, noncompliance, psychiatric disorder, other; Social/residential barrier to self-care PD = employment, primary caregiver, small living space, other; Home care assisted PD available = has home care assisted PD available in their area, but did not necessarily receive home care assisted PD

Table 2. *Reasons for Therapy Loss*

Reason for Loss	Support Available (<i>n</i> = 208)	No Support Available (<i>n</i> = 117)
Technique Failure, n (%)	48% (101)	58% (68)
Death, n (%)	20% (41)	13% (15)
Palliative care, n (%)	4% (8)	2% (2)
Transplant, n (%)	21% (44)	18% (21)
Recovery, n (%)	4% (8)	3% (4)
Transfer, n (%)	3% (6)	6% (7)

Note: Death = death and a transfer to palliative care; Transfer = transfer out of the program

Table 3. *Reasons for Technique Failure*

Technique Failure Reason	0-3 Months (n = 53)		3-12 Months (n = 51)		> 12 Months (n = 65)	
	Support Available	No Support Available	Support Available	No Support Available	Support Available	No Support Available
PD Infectious Complications, n (%)	1 (3)	1 (5)	5 (24)	7 (23)	12 (24)	4 (25)
Inadequate dialysis, n (%)	4 (13)	5 (23)	1 (5)	9 (30)	22 (45)	8 (50)
PD catheter related problem, n (%)	7 (23)	3 (14)	4 (19)	1 (3)	1 (2)	0
Other PD complication, n (%)	8 (26)	7 (32)	2 (10)	3 (10)	1 (2)	0
Social Reason, n (%)	5 (16)	2 (9)	2 (9)	4 (13)	4 (8)	2 (13)
Medical Reason, n (%)	5 (16)	2 (9)	3 (14)	6 (20)	2 (4)	2 (13)
Other, n (%)	1 (3)	2 (9)	3 (14)	0	4 (8)	0
Missing/unknown, n (%)	0	0	1 (5)	0	3 (6)	0

Note: PD = peritoneal dialysis

Figure 1. Unadjusted, cumulative incidence of technique failure over time.

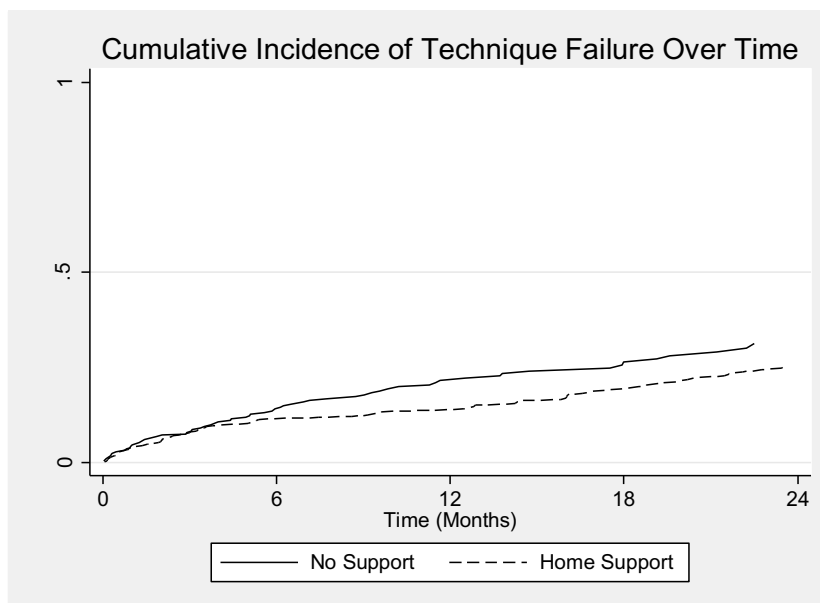


Figure 2. Unadjusted, cumulative incidence of death over time.

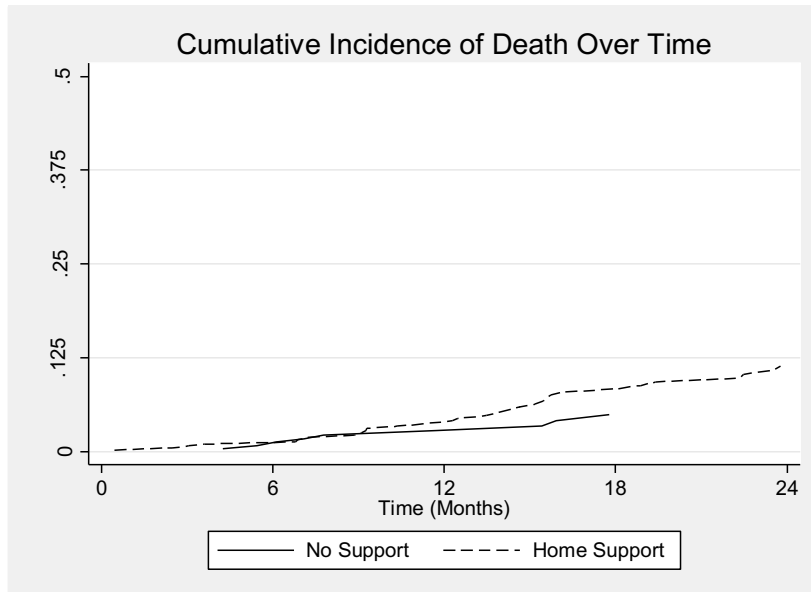


Figure 3. Unadjusted, cumulative incidence of transplant over time.

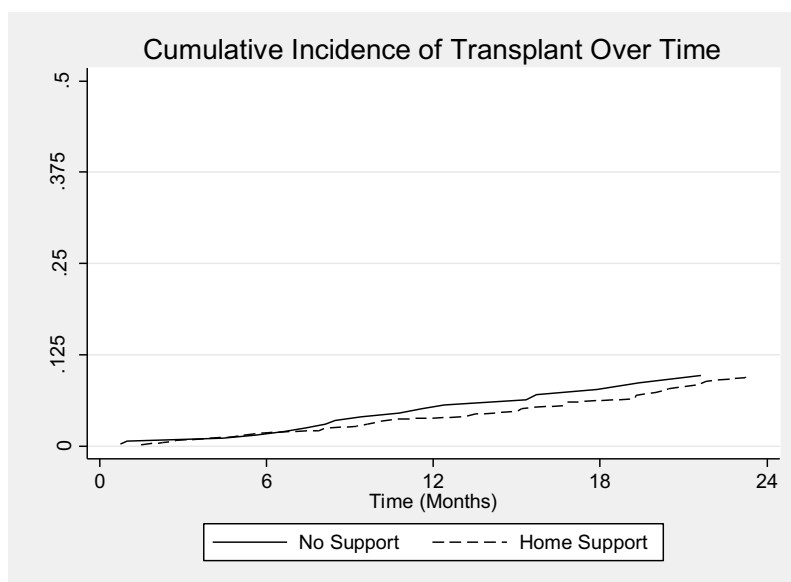
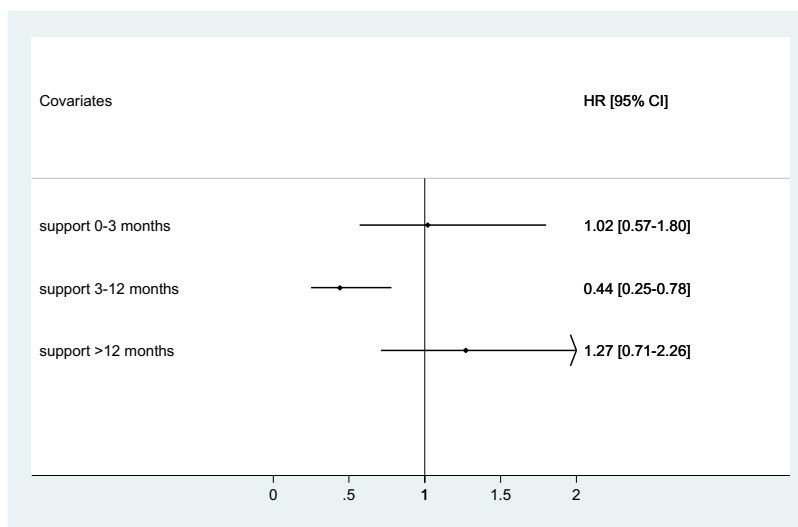


Figure 4. Hazard ratio for the effect of support on risk of technique failure in patients on PD.



Discussion

This study of incident patients on PD examined the association between the availability of a support person in the home when initiating dialysis and technique failure in Alberta, Canada. We found that support was associated with a significantly lower hazard of technique failure between 3 and 12 months, despite the fact that patients with support were older and had more comorbidities and barriers to self-care PD. Technique failure was most often due to inadequate dialysis and PD infectious complications. The raw cumulative incidence of technique failure at 24 months was 28% overall (25% for those with support and 31% for those without).

Having support is important for people on PD as it is associated with an increased likelihood of being eligible for PD and choosing PD (Oliver et al., 2010), and is integral to psychosocial outcomes (Tong et al., 2013). Two studies have quantitatively explored the relationship between support and technique failure. Lobbedez et al. (2012) found home care assisted PD, with support provided by the program or family, reduced the risk of technique failure with a cause-specific relative hazard of 0.85, 95% CI [.77, .95].

Those who received home care assisted PD in this study were older and had a higher Charlson Comorbidity Index. We observed similar results, although the effect was most pronounced between 3 and 12 months and was not significant at other time points. They did not reveal a violation of the proportional hazards assumption. Szeto et al. (2008) also found that social support independently predicted technique failure in prevalent Chinese patients ($n = 165$) on PD that were followed for one year. Although they found statistical significance the effect size was small (HR close to 1), compared to our study. Although Szeto et al. (2008) used a validated tool to measure social support, follow-up was short

and was captured only on prevalent patients. The observed differences may reflect the fact that we conducted our analysis on a larger cohort of incident patients that had longer follow up time. The Lobbedez study was based on registry data rather than primary clinical data (Lobbedez et al., 2012). Finally, other studies used different definitions of support compared to our study, which focused on having a support person available in the home.

We found that the availability of support was protective between 3 and 12 months, but not at other time points after the initiation of dialysis. This differs from Lobbedez et al. (2012) who reported that they did not reveal a violation of the proportional hazards assumption in their study. The most common reasons for early technique failure (< 3 months) in our study were catheter malfunction and other complications of PD. This is consistent with other studies that have looked at early technique failure and found catheter malfunction to be a leading cause (Béchade et al., 2013; Descoeudres et al., 2008). Support may have less impact on these reasons for technique failure, which would clinically explain the insignificant result during this time. For patients on PD after 12 months, our results may indicate that if a patient has not failed in the first year, they are less likely to have a cause of technique failure that can be modified by support (e.g. inadequate dialysis).

Support people do a lot more than instrumental tasks for people on PD including developing confidence with self-care (Sadala, Miranda, Lorençon & de Campos Pereira, 2010) and improving treatment- and medication-adherence, as well as nutrition (Plantinga et al., 2010). Psychosocial factors, such as social support, may be modifiable (Tong et al., 2013) and enhancing social support may improve clinical outcomes for

people on PD (Szeto et al., 2008; Tong et al., 2013). It is thus important to not only have someone available to perform the PD procedure (i.e. instrumental support) when needed, but to have someone available to provide social support in other ways. Caregivers of patients on PD also report an increase in caregiver burden over time and a deterioration in psychological health (Kang et al., 2019). Clinically, we know that support needs for people on PD are greater when starting therapy, as PD begins to fail, or as patients develop more complex medical needs. It is possible that during these times support needs become greater and may explain the lack of a protective effect of support between 0 and 3 months and after 12 months. Implementing support interventions at appropriate times may not only have an impact on technique failure, but qualitative work in this area shows it may also have impact on improving the PD experience (Fox, Quinn, James, Venturato, & King-Shier, 2019). This would emphasize the need to not only focus on support during 3 to 12 months, but to implement support interventions that are individualized to the unique and changing needs of patients on PD and their caregivers.

Our overall cumulative risk of technique failure at two years (0.28) was similar to studies done by Pajek et al. (2014) and Lobbedez et al. (2012) (self-care cohort), who reported cumulative risks of 0.24 and 0.21, respectively. The reported risk of technique failure in other studies were not directly comparable due to methodological and reporting differences (Workeneh, Guffey, Minard & Mitch, 2015; Chidambaram et al., 2011; Perl et al., 2012; Lan et al., 2015). This is especially true of studies that used traditional survival analysis (e.g. Kaplan-Meier) to determine technique failure risk. This method would be inappropriate as traditional survival analysis are known to overestimate event probabilities in the presence of competing risks (Beuscart et al., 2012; Noordzij 2013).

This may result in observed higher rates of technique failure in studies that did not use competing risk methodologies.

Interestingly, we found no baseline characteristics to be associated with technique failure other than support. This differs from other studies which have reported technique failure to be associated with increased age (Mehrotra, Story, Guest, & Fedunyszyn., 2012; Chidambaram et al., 2011), diabetes mellitus (Chidambaram et al., 2011; Shen et al., 2013), coronary artery disease (Shen et al., 2013); high BMI (Pajek et al., 2014; Shen et al., 2013), lower residual renal function (Pajek et al., 2014), previous HD treatment (Mehrotra et al., 2012; Chidambaram et al., 2011), male sex (Mehrotra et al., 2012), and being widowed, divorced, or separated (Shen et al., 2013). Paradoxically, in our study, the people with support were older and had more comorbidities, and yet failed less often. The majority of studies that report an association between baseline characteristics and technique failure do not account for support. Therefore, we do not know the effect that including support would have had on these results. It is also possible that our study was underpowered to detect further associations. We also lacked data on certain baseline characteristics (e.g. residual renal function) which may have impacted our results. However, as we had a relatively large sample size (compared to other non-registry-based PD studies), we feel that our results warrant consideration into the impact of support as a protective factor against technique failure. Having support may also lessen the impact of other covariates that are associated with technique failure, thus accounting for support would be an important variable to consider in future studies exploring technique failure.

This study has several limitations. First, support was only captured at baseline and not tracked throughout the course of PD therapy. The support needs of patients may vary,

especially in this medically vulnerable population. Little is also known about the support needs of patients on PD and although many patients have support, the nature of the support people provide to PD patients is largely unknown. Second, although DMAR captures high quality, expert-reviewed data, it is still at the discretion of the person inputting the data to interpret reasons for technique failure. Assigning a single cause of technique failure may be inappropriate in some cases, as causes of technique failure can be multifactorial. For example, if someone did not have adequate support and had poor PD technique, this may lead to technique failure due to peritonitis. However, when implementing strategies to prevent the failure, increasing support would be the modifiable factor that would need to be taken into consideration. Finally, although many authors have reported findings on technique failure, there is great variability in not only findings, but also in definitions used (Lan et al., 2016), making it difficult to accurately compare rates and reasons across studies.

In summary, technique failure remains a concern for many PD programs. While certain demographic characteristics and comorbidities have been explored as potential predictors of technique failure, few studies have explored social predictors, including the impact of having a support person available to assist with home dialysis. Our study found that having support is associated with a reduced risk of technique failure between 3 and 12 months.

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Waiver

May 28th 2019

Signed waiver indicating co-authors of unpublished manuscripts agree to have the manuscript included in the thesis.

The signatories below agree that the, yet unpublished, manuscript entitled ‘The Impact of Support on Peritoneal Dialysis Technique Failure: A Competing Risk Analysis’, may be included in this thesis.

Dr. Kathryn King-Shier.

Dr. Robert Quinn

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Ms. Alix Clarke

Chapter 4: The Need for a Mixed Methods Approach

Conducting the quantitative portion of this study, we were able to gain insights into the relationship between having available support in the home and technique failure. We were also able to identify who was available to support the patient in the home at baseline and reasons for technique failure and therapy loss from PD. This being said, it is important to mix methods when appropriate to gain a more holistic perspective (Andrew & Halcomb, 2009). This was especially pertinent in this context where complex phenomena were under study. Specifically, using a convergent parallel mixed methods design, we wanted to collect different, yet complementary data that can provide breadth when understanding social support in PD. As we had prior insight into the data that were available in the DMAR system, we anticipated certain limitations that we hoped to mitigate using qualitative methods.

DMAR could only capture specific information on the support networks for patients initiating renal replacement therapy. Although we were able to understand the number of patients receiving PD that had support, and who those support people were, this was exclusive to support people that were available in the home. Support networks for patient on PD also include people outside the home including healthcare providers (Tong et al., 2013; Sadala et al., 2012) and friends and peers (Asti, Kara, Ipex, Erci, 2006; Tong et al., 2013), and it was important to get this perspective.

Using DMAR data we also had the ability to determine if there was an association between support and technique failure, however it was also important for us to know and understand what this support entailed. The depth of this understanding was important to

get from a holistic perspective, using the four domains of support (emotional, instrumental, informational and appraisal) as an analytical framework (House, 1981).

From a clinical perspective, we suspected that many patients would have available support in the home, but many would not. As PD is being promoted in many renal programs (Alberta Health Services, 2018), we needed a deeper understanding of what the support needs of both populations were to inform future initiatives. Thus, the second study in this thesis was a qualitative descriptive study which aimed to answer our research question from a different perspective.

Chapter 5: Social Support in the Peritoneal Dialysis Experience: A Qualitative Descriptive Study

Abstract

Aim. To explore how patients, family members, and nurses from a PD clinic in Western Canada view social support.

Design. Qualitative, descriptive study.

Methods. Patients ($n = 15$), family members ($n = 6$) and nurses ($n = 11$) were interviewed between January and May 2018. Conventional content analysis was undertaken using four attributes of social support (i.e., emotional support, instrumental support, informational support and appraisal support) as an analytic framework.

Results. Themes related to the four attributes of social support were identified: addressing emotional needs and managing emotion (emotional support); support with PD and life tasks (instrumental support); accessing information, receiving information and learning (informational support); and affirmation/external reassurance and self-confidence (appraisal support). The social support needs of patient and family members varied and were dependent on their existing support networks and individual perspectives of support.

Conclusion. Home-based PD has potential benefit to patients and healthcare systems. However, receiving PD requires support. It is imperative that healthcare providers are clear about what ‘support’ entails, the breath of what it entails, and how it is best offered to make decisions about individual patients and PD programming.

Impact. All elements of social support identified by study participants are important, and it is imperative that social support be individualized to the patient. Having a better

understanding of the breadth of social support needs may help healthcare providers who support people receiving PD and inform stakeholders when making decisions about PD programing.

Introduction

People with end stage renal disease can either pursue conservative (palliative) management or renal replacement therapy (kidney transplantation, hemodialysis, or peritoneal dialysis). Though transplant is preferred, there are a limited number of organs available rendering the majority of patients treated with some form of dialysis. Hemodialysis and peritoneal dialysis (PD) are equivalent with regard to clinical outcomes (Karopadi, Mason, Rettore, & Ronco, 2013), but PD is much less costly to provide (Chui et al., 2013). Some authors have reported that receiving PD renders higher patient satisfaction (Rubin et al., 2004) and patient autonomy than hemodialysis (Sinnakirouchenan & Holley, 2011). However, PD carries a self-care burden on patients and families. Social support may not only impact PD sustainability, but may also improve the PD experience. Unfortunately, little work has been done to characterize the social support needs of patients receiving PD.

Background

Social support is broadly defined as “assistance and protection given to others” (Langford, Bowsher, Maloney & Lillis, 1997, p. 95), and has four defining attributes: emotional support, instrumental support, informational support and appraisal support (Langford et al., 1997; Kadirvelu, Sadasivan, & Ng, 2012; House, 1981). Having social support has been associated with improved psychological and physiological health (Uchino, 2006), and plays an integral role in the self-management of complex chronic diseases (Kadirvelu et al., 2012). House (1981) defined the four attributes of social support. Emotional support involves “providing empathy, caring, love and trust” (p. 24); instrumental support involves “instrumental (practical) behaviors that directly help the

person in need” (p. 25); informational support entails “providing a person with information that...(they) can use in coping with personal and environmental problems” (p. 25); and appraisal support is the “transmission of information” (p. 25) by someone which is, in turn, used for self-evaluation. Though variations of these definitions have been offered over time, these variations have occurred based on the context in which they have been studied (Williams, Barclay, & Schmied, 2004).

As the number of patients with kidney failure rises (Saran et al., 2015), many renal programs are implementing strategies to increase the use of comparatively less costly home renal replacement therapies such as PD (Alberta Health Services, 2018). Social support is important for patient receiving PD (Griva et al., 2016; Tong et al., 2013), and in sustaining PD therapy (Shen et al., 2013), with patients with support valuing “the control, independence, self-efficacy, and social freedom attributable to PD” (Tong et al., 2013, p. 885). Few studies have comprehensively explored social support in the context of PD.

Given that PD is largely a self-managed therapy and social support is a modifiable factor associated with its success, it is imperative that an in-depth exploration of the role of social support be undertaken.

The Study

Study aim.

Our aim was to explore how patients, family members, and nurses from a PD clinic in Western Canada view social support.

Design.

We used a qualitative descriptive design (Kim, Sefcik, & Bradway, 2017) to comprehensively explore the role of social support as viewed by patients receiving PD, their family members, and nurses. Qualitative description was used to examine and describe people's perceptions without any expectation of theorizing (Neergaard, Olesen, Andersen, & Sondergaard, 2009; Sandelowski, 2000).

Sample participants.

Participants were recruited through an outpatient PD clinic in Western Canada. This clinic serves approximately 240 patients who reside primarily in an urban center and surrounding rural areas. Participants were recruited through the use of an intermediary who called eligible participants to inform them about the study. Interested participants then called the research line. Patients were purposively sampled to include those with a variety of experiences and characteristics. Family members of participating patients, licensed practical nurses that support the home care cycler assist program, and registered nurses working in the PD clinic were also interviewed. All participants were English speaking and ≥ 18 years of age. Potential participants were not asked to participate if they had a cognitive deficit. Recruitment continued until data saturation occurred, or no new data were revealed (Polit & Beck, 2012).

Data collection.

Recruitment and data collection took place between January and May 2018 using telephone-based (Musselwhite, Cuff, McGregor & King, 2007), individual interviews (patients, family members, and cycler assist nurse) and focus groups (PD nurses). Demographic data were gathered from all participants. Data collection took place using

semi-structured interview techniques with open-ended questions. Individual interviews and focus groups lasted 30 – 45 minutes. The primary interview questions remained consistent over the course of the study, however, probing and follow up questions changed over time as themes began to emerge.

Ethical considerations.

This study protocol received approval from the Conjoint Health Research Ethics Board of the University of Calgary and was undertaken in accordance with the Helsinki Declaration of 1964.

To limit the perception of coercion (given some investigators are affiliated with the PD program), an intermediary was used for participant recruitment, and participants were reminded that they could withdraw their consent at any point during the qualitative data collection. No participants withdrew their consent.

Data analysis.

Interviews and focus groups were digitally recorded, then transcribed verbatim by a transcriptionist who signed a confidentiality agreement. Conventional content analysis was used to analyze the data (Hsieh & Shannon, 2005). First, transcripts were read and organized. A combination of inductive and deductive coding was used, with the components of emotional, instrumental, informational and appraisal support as a guiding framework for analysis. Patterns within the coding framework were identified and recorded using a color-coded system and written memos. Labels were assigned to the emerging patterns, then the patterns were grouped into themes and categories. A codebook was developed to organize themes and their definitions. Findings were then

represented in the form of a synthesis of themes and categories that emerged from the data.

Table 1. *Demographic Characteristics of Patients and Family Members*

	Patients (<i>n</i> = 15)	Family Members (<i>n</i> = 6)
Male (%)	11 (73%)	2 (33%)
Median Age (IQR)	70 (47-82 years)	68 (42-73 years)
Median Time PD (IQR)	24 (11-37)*	13 (11-24 months) [†]

Note: IQR = interquartile range

*median time receiving PD

[†]median time caring for a patient receiving PD

Table 2. *Demographic Characteristics of Nurses*

	Nurses (<i>n</i> = 11)
Male (%)	1 (9%)
Median Years in Nursing (IQR)	25 (13-39)
Median Years in PD (IQR)	10 (6-13)

Note: IQR = interquartile range

Rigor.

Purposive sampling identified participants from various backgrounds with varied experiences and perspectives (Polit & Beck, 2012). Interviews continued until data saturation occurred to enhance transferability (e.g., external validity, generalizability) of

results (Sandelowski, 1986). The research team was comprised of methodological and PD content experts who were involved throughout the research process, in interview question development and theme generation. Careful probing was used during the interviews to obtain rich and comprehensive data (Polit & Beck, 2012). Rigorous data analysis occurred using a team approach and consensus building enhanced internal validity (findings are characteristics of the variables under study) (Sandelowski, 1986).

Findings

The majority of patient participants were male while the majority of family members were female (see Table 1). The majority of nurses were female and had worked with patients receiving PD for a mean of 9 years (see Table 2).

Emotional support.

Two themes were associated with emotional support. One was ‘addressing emotional needs’ and the other was ‘managing emotion’. Addressing emotional needs encompassed ensuring the patient’s emotional needs were identified, while managing emotion referred to how emotional needs were identified and attended to.

Addressing emotional needs.

Addressing emotional needs was important for the majority of participants, and many felt that more focus could be placed on this element of care. One patient said, “I’ve got absolutely no complaints at all about the medical treatment I’ve received and the professionalism... Yet nobody in over 3 years... has said ‘Well, how are you?’” Another patient spoke of how she wished for more emotional support from her healthcare provider. She said,

Their (providers') purpose is instrumental and the emotional support is incidental. Nobody ever talked to me and ... (asked) 'How does it feel to live with something that you know if you don't follow this therapy, you will die?' ... 'What's that like for you?'

It was important that the emotional needs of not only the person receiving PD, but also their family be addressed. One wife said, "There are things (that need) to be asked, you know... 'As a support person, how are you doing? Are you doing okay?'"

Some participants placed less emphasis on others addressing their emotional needs as they felt they could ask for assistance when necessary. One patient said, "I'm not sure if I've needed emotional support. I mean...I look at what's going on with my health as, kind of as an adventure..."

The importance of how and by whom emotional support was addressed was also identified. Some nursing staff felt that patients may get the majority of their emotional support from family, and given their time-constraints, would at times, prioritize clinical care over emotional care. One nurse said, "I think the family gives more emotional support than the staff...(However), I think those patients whose spouses or children are providing the dialysis...the nurse is the biggest support for the caregivers."

Nurses identified that they are in an ideal position to provide emotional support. One said, "We're the ones that are there every day to support (the patient)... having us there to provide that help was incredibly good for (the patient's) emotional support... some of these people don't have anyone on a daily basis."

How others asked ‘the question’ was also important; one family member identified how difficult it was to respond to others’ questions, in the face of having a ‘terrible’ situation.

They always ask me ‘How is he?’, ‘How’s he doing?’.... So what do I say?...Like what do you say when somebody is on dialysis? There’s nothing to say!

Managing emotion.

Having kidney disease and receiving dialysis brought negative emotions from both patients and family members including depression, fear, anxiety, worry and feeling overwhelmed. One patient recalled, “When I was first diagnosed with this disease, I was so down that I, could not think of anything but why, why, why?” A man expressed great concern about his wife when he said, “I don’t know, I try to be with her all time the best I can but it’s hard for her sometimes. It’s hard for me too... I hate to leave her alone.”

Patients talked about the different ways they managed these emotions including religious activities, talking to counsellors and having other people in their social network ‘be there’ for them. A patient spoke about the influence his parents had on his outlook. He said, “They basically helped me believe in myself and believe there is a higher power from what I thought.” Another patient identified the benefits of seeing a counselor. She said, “(The therapist) helps with, the emotional and mental state of dealing with chronic illness... I’m just seeing her just to keep...my mental health in check.”

Instrumental support.

There were two major tasks that required instrumental support: PD tasks and life tasks. PD tasks included setting up or undertaking the PD therapy and life tasks included domestic duties such as house and yard work.

PD tasks.

PD therapy. The majority of patients and family members spoke about the need for help with PD therapy (e.g., dialysis set up and take down, assistance with dialysate bag selection and therapy management). The amount of PD therapy support received varied, where certain patients required full support and others needed only small amounts of support (e.g., PD dressing changes). One patient described all that his wife did for him. He said, “She gets the machines ready, she disposes of bags, she orders all my medication...I would sink without her.” A wife described a small, but necessary task that she provided for her husband. She said, “When he showers he has trouble changing the dressing for his catheter and I do that all the time for him.”

Supply management. Supply management included ordering supplies, picking up supplies from the clinic, and moving supplies. Many patients and family members spoke about the supply delivery method and how beneficial it was to have someone move the supplies for them. Some participants identified they lived in confined spaces and needed to be resourceful to organize their supplies. They often felt overwhelmed by the amount of supplies and medicalization of their home. Some participants identified the challenges of being home for supply delivery if working or if they had appointments. One wife described a situation when there was some confusion about where supplies should be left. She said, “All of those boxes (were left) out on the front step. And they, they weigh a lot... I know because I moved a lot of them...he (husband) couldn’t even help me.”

Problem solving. There was great variability in the amount of complications or concerns that patients and family members identified, and in the knowledge and confidence that participants had in being able to troubleshoot independently. One wife

identified, “If (my husband) had any problems during the night and the machine was not functioning correctly I got up and you know, either figured it out myself ... or I read the manual and if I couldn’t (fix the problem, I called the support line) to get instruction.” A patient described his ability to independently problem solve. He said, “I’ve learned a lot about my body. And, and I know for instance that if, if my blood pressure is high then there’s one or two things it’s likely to be, I don’t even phone the PD clinic about that, I just remedy the situation.”

Some patients and family members identified that issues would often occur when the clinic was closed, meaning that they would need to call support lines. Though most issues were solved, some participants identified that success depended on who was on the other end of the telephone. One wife described her experience:

Well everything goes wrong on the weekend ...It never goes wrong during the work week, it’s always on a Friday night or something....So we persevere...You can phone...(the support line) and maybe you’ll get a good person that’s smart enough to help you understand what you’re talking about.

Transportation. Many patients required support with transportation, whether it be driving back and forth to appointments, picking up medications/supplies or going for blood work. Rural-living patients, in particular, reported high transportation costs, and limited services available for transportation. There were limited options for any patient who could not drive or did not have a family member or friend available to drive them. Taxicabs are expensive in this city. Patients felt that public transportation was often not an option as they may not have the energy or feel well enough to use it. One nurse identified that accessible transportation services for people unable to use public transit, is

inconvenient for many patients. She described, “They give you like a 5 hour window so they’ll pick you up but then you may be driving three other spots before you actually get where you wanna go.”

Recreational travel. A few patients spoke of the benefits of using PD as it made travel easier. However, it was clear that there were travel challenges. For example, one patient was concerned that the dialysis machine would be difficult to lift on the plane (“Yeah, you can travel, but can you lift the machine?”), while another identified that airport personnel did not always appreciate the need for medical supplies and extra care for the safety of the machine. It was clear that assistance and understanding were required from others (including airport workers) when travelling. Regardless of these problems, some patients still felt the ability to travel was a positive attribute of PD.

Other. Patients and family members also spoke about the different ways they assisted or received assistance with PD related tasks, not necessarily related to the PD set up itself. These included organizing medications; booking, managing and attending appointments; and maintenance of the PD environment including cleaning. One son said,

I was managing ... what kind of medicine she needed and where to get it from...(Then) I was thinking, if someone don’t have this kind of support, it will be a challenge...

One family member talked about the importance of being available during the dialysis therapy. He said, “You know, once she’s on she’s tied down...(If she thinks ‘oh I forgot this’) she can’t just run and get it, so she just hollers at me.”

Life tasks.

Domestic duties. The majority of patients talked about the many life-related tasks with which they required support. These included cooking and grocery shopping, assistance with yard work, and cleaning. Support was often needed for food preparation including learning the renal diet and cooking renal friendly meals. One wife spoke of how she did many of the domestic tasks prior to her husband starting PD, while other family members discussed how their roles changed once PD was initiated. One patient spoke about the changing needs. She said,

I can't vacuum anymore, I just can't do it. I can do the rug, then I have to sit down...I can load my dishwasher but if I try to unload it, I almost pass out into it. And that's just, you know, part of the disease.

One nurse identified that PD takes a great time commitment. She identified that even well, independent patients, who might be working outside the home, may be challenged to find the time to undertake their PD and perform their regular life-related tasks without support.

Financial. Financial concerns were identified by some patients. These included concerns about inability to work, as well as costs such as parking at medical appointments. One patient shared, "When I was doing the training, they gave me a parking pass. Now, I don't get the parking pass, I have to pay for the parking and it's expensive."

These concerns were stressful and some patients felt that they needed to borrow money or rely on others for financial support. A few participants spoke about how financial concerns were difficult to discuss with healthcare providers. One patient said,

Like you're asking a little too much because it's like you know, we're taking care of your life, you, you're asking about money? You know, so it's not a question I was comfortable asking, or would've been comfortable asking about.

Those that had no financial concerns spoke of ways that they were either able to pay for services to make life-related tasks easier, while others wished there were more offered supports available to assist in this area. One participant spoke of being able to pay for a grocery delivery system that eased the burden of having to grocery shop and cook. She said, "You pick a few recipes, they have all the ingredients that they deliver to your house and then you just cook the meal. So we've been trying that and that's actually more helpful."

Informational support.

Providing information to participants was influenced by three main factors: how participants accessed information; how they received information; and mechanisms of learning.

Accessing information.

Patients and family members accessed information through a variety of means: clinic/healthcare provider, online, industry, counselors, and support groups. One patient simply said, "I pick up a lot of reading... anything about kidney, ... I read it." Participants also spoke about 'double checking' information received elsewhere (e.g., renal dosing of medications) with the renal clinic staff.

Receiving information.

Some participants felt the information available to them met their learning needs, while others did not. Participants wanted to receive honest and factual information and it was important that information was not distorted. One patient described,

I don't like sugar coating...I've had this disease for like 16 years of my life and I know it's eventually gonna kill me. I just, I want all the gory details as far as it's going to, for that person to tell me. I'd rather know than just stay in the dark.

Patients and family members felt it was important for information to be personalized, rather than receiving generalized information. One participant spoke of this process as a conversation based on his individual needs. He said, "Getting information for me is not just a straightforward answer, yes or no, it's just more less a conversation of you know, here's... what I'm asking right now and there's some details that need to be exchanged to make the answer a little different." A few patients and family members spoke of being reluctant learners or at times being too overwhelmed or feeling too unwell to receive or retain information. One patient said, "My experience was that the nurses were very reliant on me to describe my symptoms... And you know, brain fog is such a huge part of this disease that sometimes I needed that guided interview."

Nurses spoke about how they would write information down for patients and deliver information in different ways in order for them to receive it appropriately. One nurse described this saying, "You may have somebody who is very by the book and will follow step 1B after 1A, but... you might have somebody that jumps around, and as much as possible... I'll try and work with that... I think it must be patient driven."

Availability. Some patients and family members felt it was important for healthcare providers to be available to provide information in a timely manner and when needed. One patient felt that scheduled appointments were particularly important as they provided dedicated time to the patient, instead of impromptu phone calls where the nurse may be rushed. It was also important to have informational resources available when needed. One patient talked about her experience of missing information. She said, “That was a piece of information that I missed in my training was what exercises would’ve been useful to maintain...as much abdominal strength as I could in a safe way.”

Timing. Some patients and family members felt that they received too much information at the beginning and offering information in smaller, spread out sessions would be optimal. One wife described the importance of this timing, stating, “I almost was overwhelmed with the amount of information that I got right at the beginning... but I know that’s important so I don’t know if there’s any way that you could sort of break it in a little bit more gently for some people.”

Although spreading out information delivery was important, patients and family members generally wanted information given to them prior to an event happening, so they could feel prepared. Yet, some could feel overwhelmed by it all. One wife talked about how she received all the information and training initially and delivered this information gradually to her husband over time. She said, “You have to have somebody with the patient to help him at the beginning and then pass the information slowly to him.”

Learning.

Teaching/mentoring. Teaching was an important element of the learning process for patients, family members and nurses. One patient identified the importance of how information was conveyed. He said, “They might’ve went to school for it, but they just don’t know how to come out and exactly tell you what you’re doin’ wrong.”

Nurses spoke about enabling the patient or family member to lead their learning by identifying what they want or need to know at the time. One nurse spoke of this process saying, “Like having them kinda lead the way because... maybe what we’re thinking isn’t what they’re thinking. And if there’s a disconnect, you’ve sorta lost them the rest of the training.”

A few patients also spoke of the benefits of peer mentorship. These patients wanted to receive information and talk to people that had been through similar experiences to help contextualize or solidify their own learning.

Learning environment. The learning environment was important for some patients and family members as they felt that learning in the clinic where all supplies and support were available, did not mirror their home environment. A few participants thought it would be helpful to have a healthcare provider come to their home initially to assist them to set up and ensure that they were comfortable performing the procedure in their own environment. One patient said, “I think it would be better even if they did... a home visit even once or twice to just show you exactly what to do... Not that they don’t do it in the clinic, but the clinic and home are two different environments.”

Appraisal support.

There were two ways in which patients received information that was useful for self-evaluation. The first was receiving affirmation and external reassurance which provided comfort to the patient. The second was confidence building through various means including providing encouragement.

Affirmation/external reassurance.

Many patients and family members received affirmation which helped them feel reassured and relieved. This reassurance came from a variety of sources, including the clinic's multidisciplinary team, family and their faith. One patient said, "I prayed and God gave me the assurance that everything was gonna be okay. And I've had peace with it ever since."

Affirmation and reassurance also enabled patients and family members to feel more settled and made it easier to make decisions. One family member said, "We were very, very nervous about... the whole situation because you're relying on a machine at home...we're not medical people, ...but they were very comforting,... they would not let you go or do anything... if you weren't comfortable or did not understand."

One patient acknowledged the challenge that it must be for healthcare providers to assist patients in this way. He said, "It's a hell of a challenge for you medical people to make people like me who are intimidated and, and scared of it and everything else, to make us feel comfortable."

Self-confidence.

Patients and family members had different levels of confidence and it was important for their support people and the healthcare team to provide encouragement to

build their confidence. One patient said, “They’re totally reassuring and just kinda gives you confidence that yeah, this is gonna be okay.”

Encouragement helped people to be more confident to problem solve, enabled them to feel more comfortable, and provided inspiration to persevere through difficult times. One nurse discussed how trust helped to build confidence and enabled patients to in turn self-manage their care. She said, “They trust our knowledge, ...they see how things have worked out when they have had situations... that have been resolved and they begin to say ‘Oh, yes!’ Then we in turn know, they have capabilities to address their own problems.”

Discussion

We conducted a qualitative descriptive study to explore how patients, family members, and nurses from a PD clinic in Western Canada viewed social support. Using the attributes of social support outlined by House (1981; emotional support, instrumental support, informational support and appraisal support) as an analytic framework, we identified themes that give a comprehensive description of the role of social support for people on PD. PD places a high onus of responsibility on the patient and family to manage their therapy, with patients often requiring high levels of support.

Though instrumental support with PD therapy is clearly very important, our study offers evidence that social support encompasses many other elements that need to be incorporated into care to create a holistically supportive environment. Researchers have identified that various elements of support enhance PD success. For example, support offered by healthcare providers can enable patients receiving PD to develop confidence with self-care (Sadala, Miranda, Lorençon & de Campos Pereira, 2010), while family

members can provide psychological support by engaging and being available to the patient (Fex, Flensner, Ek, & Söderhamn, 2011). However, no researchers have examined the breadth of potential social support needs in this vulnerable population.

The support networks of patients receiving PD vary, and they will have different support needs. It is important to include both patients and support people as partners in treatment (Sadala et al., 2010). There is variability in the extent that caregivers are involved when providing support to patients receiving PD (Beanlands et al., 2005), or the availability of programs to provide PD home assistance (Oliver et al., 2007; Castrale et al., 2010). Thus, it is important to consider the breadth of the potential support network when working with patients (Tong et al., 2013; Sadala, Bruzos, Pereira, & Bucuvic, 2012; Cheng et al., 2013). Interestingly, some participants in our study who initially identified that they had no support with their PD therapy, in fact had support people that assisted them in other ways. This is in keeping with a study by Beanlands et al. (2005) that revealed other types of support (e.g., managing the diet, transportation to appointments) are also required. It is crucial that an understanding of patients existing (and potential) support networks be understood so targeted support services can be put in place.

Participants in this study had varying perspectives on what support they needed and who should provide that support. The ‘objective’ number of support people available to participants, was not necessarily associated with how supported the participants felt. To improve social support for patients receiving PD, further work needs to be done to understand what underpins individual views and experiences so care delivery can be

adapted to meet unique patient and family needs. Using a framework which encompasses the variety of potential sources of social support (House, 1981) might better enable healthcare providers to make these assessments.

Limitations

Given that social support needs are context specific, there are unique attributes of each PD program that may impact the transferability of these findings to other practice settings. However, we comprehensively explored social support in the context of PD, thus it may still provide important insights to programs that are structurally different.

Conclusion

Patients family members and nurses identified that receiving PD requires support that crosses the four domains of social support (emotional support, instrumental support, informational support and appraisal support). It is imperative that healthcare providers are clear about what ‘support’ entails and the breadth of support needs for people on PD.

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Waiver

May 28th 2019

Waiver indicating co-authors of unpublished manuscripts agree to have the manuscript included in the thesis.

The signatories below agree that the, yet unpublished, manuscript entitled ‘Social Support in the Peritoneal Dialysis Experience: A Qualitative Descriptive Study’, may be included in this thesis.

Dr. Kathryn King-Shier.

Dr. Robert Quinn

Dr. Matthew James

Dr. Lorraine Venturato

Chapter 6: Conclusion

PD has many benefits, but it requires the patient to participate in their care. Many patients with and without barriers to self-care have someone in the home who supports them with their PD therapy. Using a convergent, parallel mixed method design our objective was to understand the significance and meaning of support in the PD context. This was done through two studies which aimed to: (1) examine the association between support and technique failure in patients on PD in Alberta (observational cohort study), and (2) explore how patients, their family, and nurses view social support (qualitative descriptive study). Data from the quantitative analysis revealed that patients with support were more likely to have barriers to self-care PD, among other comorbidities. At 24 months the raw probability of experiencing technique failure was 25% for patients with support and 31% for patients without. Having a support person available in the home also reduced the risk of technique failure between 3 and 12 months. Data from the qualitative analysis revealed the many different elements that need to be incorporated into care to create a holistically supportive environment. These included themes related to the four attributes of social support: addressing emotional needs and managing emotion (emotional support); support with PD and life tasks (instrumental support); accessing information, receiving information and learning (informational support); and affirmation/external reassurance and self-confidence (appraisal support). The social support needs of patient and family members varied and were dependent on their existing support networks and individual perspectives of support. Indeed, data from the quantitative and qualitative studies have shown the importance of support in the PD context.

Synthesis of Findings

The quantitative data revealed that over half of patients on PD had someone available to support them in the home with the PD therapy at baseline. The most commonly identified support people in both the quantitative and qualitative analyses were spouses, followed by other family members. The qualitative data revealed that although having a support person available to provide assistance with PD therapy varied, even those who identified as having no support with the PD therapy had many support people available that provided support in other ways. Support people were integral to meeting the social support needs of patients on PD and included friends, various community networks and associations, and healthcare providers.

Having social support not only impacted the patient experience, but having a support person upon the initiation of renal replacement therapy was associated with a reduced risk of technique failure between 3 and 12 months. As the quantitative analysis was limited by only having support metrics at the initiation of renal replacement therapy, the qualitative element of this work allowed for a complementary, in-depth understanding of the varying support needs of participants and identified how these needs differed between participants and over the course of therapy. Together, these findings present an important perspective on the role of support on technique failure.

The quantitative analysis revealed that having support was protective against technique failure between 3 and 12 months following the initiation of PD. This could potentially be explained by the reasons for technique failure at these time points, where those experiencing technique failure before 3 months and greater than 12 months were more likely to experience technique failure for reasons that support may have less impact

on (e.g. catheter malfunction and inadequate dialysis). This being said, the qualitative work also helped to explain these findings. We found that the timing of support was important for patients on PD, with both patients and their support people requiring a great deal of support, especially when initiating the therapy. Patients on PD during this time were often both unwell and overwhelmed by the amount of information and responsibility that accompanied independently managing the PD therapy. This may also be true for later in the therapy, where participants may be likely to fail for reasons such as membrane failure, becoming too ill to continue PD, lessening the effect of support. Indeed, it is possible that during these time points the support needs of both patient and caregiver surpass what an available support person can provide in the home.

Two social support models originally described by Cohen and Wills (1985) could help to explain these results. The first is described as a buffering model, where support is protective against stressful events, and the second, a main-effect model, where social resource are beneficial regardless of stress (Cohen & Wills, 1985). These models emphasize both the need for support through stressful events, and the need for continuous support (Cohen & Wills, 1985), and were found to be true for participants in this study. Certainly, continuous support was necessary for many people on PD, but was especially important during times of stress. Support people in the home were largely available for continuous support, as well as during times of substantial stress (including when starting therapy, and when complex medical needs change). The role of caregiver burnout in this relationship, and the effect of significant and prolonged demands placed on caregivers and patients should also be considered. These matters were not primarily addressed in our study overall, but indeed emerged as a sub theme in the qualitative data.

Although support people continued to provide support to the patient during these times of high stress, the qualitative data revealed that they would also rely on outside support (e.g. healthcare providers) during this time. The effect of having a support person available may have been diminished by the amount of responsibility by both the patient and their support person, who required increased support during these times. Indeed, 3 to 12 months post initiation of PD may present a point of stability for patients. Support needs change throughout therapy and are different for each patient. Additional support may be necessary at times where the support needs of both patients on PD and their support people are high.

Instrumental support in the form of home care assisted PD has been identified as a solution to overcome barriers for patients starting PD (Oliver et al., 2007). When we excluded participants who had received home care assisted PD in a sensitivity analysis, we found that having a support person available in the home (who likely provided support in multiple ways), continued to have a protective effect against technique failure. This emphasizes the importance of incorporating other types of support, not just instrumental. It is crucial to incorporate holistic support structures that provide patients with a variety of support that is individualized to their unique needs and is incorporated at the appropriate time.

Strengths and Limitations

There are strengths and limitations to this work. Using mixed methods research, we were able to comprehensively explore the phenomenon of social support as it relates to both PD experience and outcomes, which a single study would not have been able to adequately explore. Accessing data from the DMAR system, allowed us to use data on all

incident patients starting PD in Alberta during the time period of interest. Using this cohort enhanced the generalizability of our findings to patients on PD in Alberta. This being said, we were limited to conducting an analysis using data collected for other purposes, so there were important data elements that were not available to us. Limitations of these data included not capturing detailed information on the types of support that support people provided to patients on PD. Information on support was also only captured at baseline, and we know that the support needs of patients on PD change throughout therapy. Fortunately, this information was garnered through conducting the qualitative descriptive portion of this research. Through this process we were able to explore the role of support people and the social support needs of patients on PD in greater depth. However, our sample size was small, the data were only collected at one site, and so these findings may not be as generalizable to other patients on PD in Alberta. However, we feel we have been able to present comprehensive findings on a previously understudied phenomenon.

Implications for Nursing Practice

To provide holistic support to patients on PD, as healthcare providers we must aim to not only individualize support interventions, but provide interventions that meet support needs in different categories. The outpatient PD clinics in Alberta only employ registered nurses as PD case managers. Although they collaborate with the healthcare team, they are the primary case managers of patients on home PD. The findings from this research may assist PD nurses to more holistically support people on PD by giving them a deeper understanding of the support needs of the population they serve. This insight

should encourage PD nurses to not only identify these needs, but put supports in place that mitigate some of the barriers to successfully managing PD therapy.

Program Implications

Alberta is a leader in nephrology research and has the support of Alberta Kidney Care, the Alberta Kidney Disease Network and the Kidney Health Strategic Clinical Network. The findings from this research will be informative for the Starting dialysis on Time At home on the Right Therapy (START) project, where a primary aim is to improve patient outcomes and experiences with home therapies and reduce cost to the healthcare system provincially (Alberta Health Services, 2016). Technique failure is a serious concern, which negatively impacts patient outcomes and is fiscally demanding on the healthcare system. The importance of home therapies has already been made a priority for Alberta renal programs and the reduction of technique failure would be an important avenue to maintain sustainability of PD. This research has established essential information regarding rates and reasons of therapy loss and identified specific areas of technique failure occurring in the PD patient population. Social support has been identified as an important phenomenon in home therapies (Griva et al., 2016; Tong et al., 2013) and we now have a greater understanding as to how it may predict and impact technique failure and the patient experience in the Alberta context. This information can be used to assist when creating future program-related priorities and goals to sustain patients on PD in Alberta. Without this study, sustainability decisions and interventions would have been based on prior studies, the findings of which may have less relevance to patients with ESRD in Alberta. Through understanding reasons for PD therapy loss and the role of social support within this clinical phenomenon, it is our hope that targeted

interventions will be developed to ensure patients who are eligible for PD and want the therapy, are understood and appropriately sustained and supported on their modality of choice.

Future Work

Now that a deeper understanding of the social support needs for patients on PD has been identified, the implementation of future work to improve care is needed. An in-depth understanding of the social factors that lead to PD technique failure will inform future shared decision-making, enable clinicians to identify risk factors prior to the start of therapy and throughout therapy, and to put appropriate supports in place to mitigate them. This work may also help renal programs to lobby for additional resources and support further work to improve the patient-experience. Ideally a validated tool to measure social support for patients managing home dialysis therapies would be developed. This tool could enable tracking of the available supports and the individualized social support needs of patients on PD, facilitating the coordination of care for healthcare providers. With this information, patient- and family-centered interventions and resources could be offered where needed. This work would be crucial to the ‘Starting dialysis on Time At home on the Right Therapy’ project, where a primary aim is to improve patient outcomes and experiences with home therapies and reduce cost to the healthcare system (Alberta Health Services, 2016). In addition, the enthusiasm of the PD clinic staff regarding this project may help facilitate future project goals.

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APPENDIX A: TABLE 1. REASONS FOR TECHNIQUE FAILURE

Author/ Year/ Country	Sample	Definition of technique failure	Technique failure rate	Technique survival	Identified reasons
Aguiar et al., 2016 Portugal	n = 184	Transfer to HD	34 (18.5%) 1992-2001: 8 (10.1%) 2002-2012: 26 (24.8%)	Unadjusted 1yr (85.9%); 3 yrs (64.7%); 5 yrs (56.5%) Median: 39 months	Infection (peritonitis and access related): 10 (29.41%) Other infections: 5 (14.71%) Inadequate dialysis (ultrafiltration/dose inadequacy): 13 (38.24%) Catheter (mechanical complications): 3 (8.82%) Psychosocial factors: 3 (8.82%)
Béchade et al., 2013 France	n = 9675	Early:< 6 months on PD and transfer to HD with > 2 months on HD	615 (6.36%)		Catheter Dysfunction 111 (18.05%) Psychosocial Reasons 101 (16.42%) Miscellaneous reasons related to PD 95 (15.45%) Peritonitis 94 (15.28%) Miscellaneous reasons unrelated to PD 82 (13.33%) Dialysis Inadequacy 73 (11.87%) Ultrafiltration failure 48 (7.80%) Malnutrition 11 (1.79%)
Chidambaram et al., 2011 Canada	n = 5162	Transfer to HD for > 2 months	1323 (25.63%)	Unadjusted 1 yr (87.3%); 2 yr (77.5%); 5 yr (58.2%)	
De Sousa- Amorim et al.,	n = 667	Transfer to HD	149 (22.33%) 1980-1990: 47 (24.5%)	Median: 82 months	Patient decision 44 (29.5%) Wall problems: 16 (10.73%) Insufficient dialysis: 2 (1.34%)

2013 Spain			1991-2000: 44 (21.7%) 2001-2010: 58 (21.3%)		Catheter malfunction: 2 (1.34%) Various causes: 14 (9.39%)
Guillouet et al., 2016 France	n = 5406	Early: < 6 months on PD and transfer to HD with > 2 months on HD	415 (7.68%)		Catheter dysfunction: 82 (19.76%) Dialysis inadequacy: 58 (13.98%) Psychosocial problems: 47 (11.33%) Peritonitis: 40 (9.64%) Ultrafiltration failure: 39 (9.40%) Malnutrition: 6 (1.45%) Other related to PD: 143 (34.46%)
Gulcan et al., 2017 Turkey	n = 322	Transfer to HD	n = 249 (all PD discontinuation including TF; death; transplantation)	1 yr (91%); 3 yr (67%); 5 yr (57%)	Peritonitis: (48.8%) Ultrafiltration insufficiency: (18.6%) Patient's request: (17.4%)
Lan et al., (2015) Australia and New Zealand	n = 4781	First HD session Outcomes: < 6 months and < 12 months on PD	n = 1699 (35.53%) < 6 months: 515 (30.31%) < 12 months: 864 (50.85%)		Peritonitis: 720 (42%) Inadequate dialysis: 248 (15%) Abdominal complications/surgery: 213 (13%) Unable to manage self-care: 114 (7%) Dialysis leak: 126 (7%) Tunnel/exit-site infection: 61 (4%) Patient preference: 53 (3%) Other: 58 (3%) Unspecified: 22 (<1 %) Not known: 8 (<1%) Planned transfers: 7 (< 1%) Sclerosing peritonitis: 3 (< 1%)
	n = 16612				

Lan et al., (2016) Australia and New Zealand		Transfer to HD or death Transfer to HD reported based on time on HD as > 30 days; > 60 days; > 90 days; > 180 days; > 365 days	10,274 (61.84%) to 11,467 (69.02%) depending on time on HD	Median: 2.0 years (30 days on HD) 2.4 years (365 days on HD)	(30 days) (60 days) (90 days) (180 days) (365 days) Death: 4535 (40%); 4670 (42%); 4788 (43%); 4922 (46%); 4954 (48%) Infection: 3166 (28%); 3104 (28%); 2938 (27%); 2677 (25%); 2502 (24%) Inadequate dialysis: 1206 (11%); 1216 (11%); 1206 (11%); 1173 (11%); 1083 (11%) Mechanical: 1380 (12%); 1070 (10%); 976 (9%); 853 (8%); 756 (7%) Encapsulating Peritoneal Sclerosis: 19 (<0.2%); 19 (<0.2%); 19 (<0.2%); 20 (<0.2%); 16 (<0.2%) Social: 907 (8%); 903 (8%); 890 (8%); 865 (8%); 819 (8%) Other: 115 (1%); 105 (1%); 100 (1%); 87 (1%); 78 (1%) Not reported: 139 (1%); 130 (1%); 120 (1%); 98 (1%); 66 (1%)
Mehrotra et al., 2012 United States of America	n = 58700	Transfer to HD	29% 6% > 90 days on PD	Median: 49 months	
Pajek et al., 2014 Slovenia	n = 286	Permeant transfer to HD (patient not included if ever changed back to PD) and death	n = 95 (33.22%)	Median = 1.80 years (time to TF, transplant or death)	Peritonitis: 40 (42.10%) Choice or not coping: 15 (15.79%) Leak or mechanical problems: 14 (14.74%) Inadequate solute removal: 10 (10.53%) Ultrafiltration failure: 6 (6.32%) EPS or EPS suspicion: 4 (4.21%) Other: 6 (6.32%)

Perl et al., 2012 Canada	n = 13120	Transfer to HD ≥ 90 days	4318 (33%)	1995 – 2000: 1.9 years 2001 – 2005: 2.2 years 2006 – 2009: 1.7 years	Hazard Ratio (95% Confidence Interval) Inadequate PD: 1995-2000: 1; 2001- 2005: 1.21(1.00, 1.46); 2006-2009: 0.69 (0.54, 0.90) Peritonitis: 1995-2000: 1; 2001-2005: 1.21 (0.99, 1.48); 2006-2009: 0.95 (0.83, 1.10) Other: 1995-2000: 1; 2001-2005: 0.68 (0.60, 0.77); 2006-2009: 0.95 (0.83, 1.10)
Pulliam et al., 2014 United States of America	n = 1677	First year outcomes: < 12 months on PD and transfer to HD with ≥ 30 days on HD	350 (20.87%)		
Shen et al., 2013 United States of America	n = 1387	Transfer to HD for ≥ 30 day	≥ 30 days: 537 (39%) ≥ 7 days: (47%) ≥ 1 day (49%)	Median: 2.7 yrs	
Workeneh et al., 2015	n = 128	Discontinuation of PD > 6weeks	59%	Median: 781 days (2.1 yrs)	Peritonitis (30%) Catheter Dysfunction (18%) Ultrafiltration failure (16%) Patient choice (16%) Hernia/other surgical complications (6%) CVA (1%) Hydrothorax (1%)

APPENDIX B: TABLE 2. OTHER REASONS FOR THERAPY LOSS FROM PD

Author/Year	Sample	Transplant	Mortality	Other
Aguiar et al., 2016 Portugal	n = 184	Total: 54 (29.3%) 1992-2001: 28 (35.4%) 2002-2012: 26 (24.8%)	Survival 1 yr (86.4%); 3 yrs (72.8%); 5 yrs (66.8%)	
Béchade et al., 2013 France	n = 9675 Six month results	215 (2.2%)	809 (8.4%)	Recovered renal function = 146 (1.51%) Lost to follow up: 44 (0.45%)
Chidambaram et al., 2011 Canada	n = 5162		n = 2798 (54.20%) Survival: 1 yr (81.9%); 2 yrs (69.9%); 3 yrs (46.9%)	
De Sousa-Amorim et al., 2013 Spain	n = 667	Total: 232 (34.8%) 1980-1990: 80 (41.7%) 1991-2000: 70 (34.5%) 2001-2010: 111 (40.8%)	Total: 199 (29.8%) 1980-1990: 80 (41.7%) 1991-2000: 70 (34.5%) 2001-2010: 49 (18%)	Recovered renal function: 14 (2.1%) Transferred out: 38 (5.7%)
Gulcan et al., 2017 Turkey	n = 322	n = 28 (8.70%)	n = 135 (41.93%) 5 yr survival = 62%	

Lan et al., 2015 Australia and New Zealand	n = 4781	n = 495 (10.35%)	n = 875 (18.30%)	Renal recovery n = 52 (1.09%)
Pajek et al., 2014 Slovenia	n = 286 Median follow up time: 24.2 months	76 (26.57%)	102 (35.66%)	Lost to follow up: 4 (1.39%)
Perl et al., 2012 Canada	n = 13120		4158 (31.69%)	
Pulliam et al., 2014 United States of America	n = 1677	6.90%	1 yr crude mortality: 9%: 6.5% death; 2.5% Withdrawal	Recovered renal function: 1.6% Transferred out: 5.4% Hospitalized: 56%
Mehrotra et al., 2012	n = 58700	12%		
Tonelli et al., 2006	n = 7034	10.6% (deceased donor) 5.8% (living donor)	46%	Lost to follow up: 0.5%
Workeneh et al., 2015 United States of America	n = 128	12 (9.4%)	6 (12%)	Changed PD units: 8 (6.3%)