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How Do Transitions Within End-Stage Renal Disease Impact Health-Related Quality of Life?

by

Chance Skylar Dumaine

A THESIS

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Abstract

Dialysis is used to sustain life for patients with end-stage renal disease (ESRD). While dialysis prolongs length of life, numerous studies have shown that dialysis patients have significantly reduced health-related quality of life (HRQoL). The degree of impairment seems to be partially related to dialysis modality [in-centre hemodialysis (IHD), peritoneal dialysis (PD), or home hemodialysis (HHD)], as patients on PD/HHD often have higher HRQoL scores than IHD patients.

Patients may change dialysis modalities a number of times during their life. Each change is accompanied by a “transition period” (period of time in which patients adapt to life on their new modality). These transition periods are often marked by high rates of anxiety, depression, morbidity, and mortality, and are periods when HRQoL may change rapidly. However, few studies have examined the magnitude of change in HRQoL during transition periods or what the drivers of change are. Such studies are necessary to ensure that patients are provided with the necessary supports during their modality transition to prevent declines in HRQoL.

In this pilot project, we tested the methodology of combining kidney disease-specific HRQoL questionnaires (Kidney Disease Quality of Life surveys) with semi-structured interviews in patients undergoing dialysis modality transitions. Patients completed KDQOL surveys prior to and 3 months after initiating a new dialysis modality and participated in semi-structured interviews to describe changes in HRQoL that occurred during the transition period.

Regardless of dialysis modality being initiated, mean HRQoL scores as measured by the five domains of the KDQOL-36 improved over the initial 3 months of the transition period. Scores in additional domains of the KDQOL-Short Form were more variable, with improvements in some domains but reductions in others. Patient interviews highlighted many factors that negatively impacted HRQoL which may be amenable to intervention.

Overall, combining the KDQOL tools with semi-structured patient interviews proved to be an effective method of studying changes in HRQoL that occur during modality transitions. Future

studies may consider implementation of this model on a larger scale in order to better understand transition periods and to test interventions to prevent declines in HRQoL.

Preface

The five chapters of this document represent a manuscript-based thesis in which Chapters III and IV will be submitted for publication in peer-reviewed journals in the field of nephrology.

Chapters I, II, and V (Introduction, Background, and Concluding Statements, respectively) will not be submitted for publication to peer-reviewed journals but are included to provide necessary context for Chapters III-IV.

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LIST OF ABBREVIATIONS

CKD	Chronic Kidney Disease
CMS	Centre for Medicare and Medicaid Services
DOPPS	Dialysis Outcomes and Practice Patterns Study
EQ5D	Euro-QoL 5-Dimension Questionnaire
ERA-EDTA	European Renal Association – European Dialysis and Transplant Association
ESRD	End Stage Renal Disease
FHN	Frequent Hemodialysis Network
FREEDOM	Following Rehabilitation, Economics and Everyday-Dialysis Outcome Measurements Study
HHD	Home hemodialysis
HRQoL	Health-related quality of life
IHD	In-centre hemodialysis
KDCS	Kidney Disease Composite Score
KDQOL	Kidney Disease Quality of Life
KDQOL-36	Kidney Disease Quality of Life-36 Questionnaire
KDQOL-SF	Kidney Disease Quality of Life-Short Form
MCID	Minimal clinically important difference
MCS	Mental component summary score
PCS	Physical component summary score
PD	Peritoneal dialysis
PRO	Patient-reported outcome
QoL	Quality of life
SARP	Southern Alberta Renal Program
SF-12	12 Item Short-Form Survey
SF-36	36 Item Short-Form Survey

There is more to living than not dying.

Cassandra Clare, *The Infernal Devices*

Chapter I: Introduction

Chronic kidney disease (CKD) is one of the most common chronic diseases in Canada, with an estimated prevalence of 12.5% (or approximately 3 million Canadians).¹ A significant proportion of patients with CKD progress to end-stage renal disease (ESRD) and require either dialysis or renal transplantation in order to sustain life. Unfortunately, the majority of Canadians with ESRD will require dialysis, either due to long wait lists for renal transplants or due to medical conditions that preclude them from being transplant recipients.²

In Canada, there are three dialysis modalities available for patients to choose from, the most common of which is in-centre hemodialysis (IHD).² IHD patients receive 4-hour treatments, thrice weekly, in a health care centre. Some hemodialysis patients receive treatment in their homes (“home hemodialysis”, or HHD); such patients are trained for 4-8 weeks in all aspects of their dialysis care, including how to operate a hemodialysis machine. Once the medical team deems them ready, they are discharged home to perform their own treatments. The third modality, peritoneal dialysis (PD), is also a home modality. The most recent estimates state that 44% of ESRD patients in Canada are treated with IHD, 11.5% with PD, and 3% with HHD; the remaining 41.5% are those who have received a successful kidney transplant.²

Dialysis modality is not static, and many patients will change modalities a number of times during their life, either due to medical necessity or due to a desire for a modality better suited to their lifestyle. In addition to the transition from pre-dialysis CKD to life on dialysis, patients with ESRD therefore experience a number of other “transition periods” which accompany modality changes. These transition periods are often tumultuous in terms of physical and mental health, particularly for patients forced into a transition because of medical necessity.³ There is growing recognition within the nephrology community regarding the importance of these transition periods, as well as a recognition that traditional models of care often fail to address factors that cause patients distress during these times.

The increased awareness regarding the importance of transition periods has occurred parallel to an increased emphasis on improving health-related quality of life (HRQoL) in ESRD patients. Dialysis patients have significant reductions across multiple domains of HRQoL compared to the

general population.⁴⁻⁶ Improving HRQoL has recently been recognized as a top priority for both dialysis patients and their caregivers, who cite improving HRQoL as more important than reducing infectious complications, cardiovascular disease, or even mortality.⁷⁻⁸ Impaired HRQoL has also gained increased attention as an independent marker for morbidity and mortality in dialysis patients.^{6, 9-10}

A growing body of literature over the past two decades has compared HRQoL in IHD, PD, and HHD patients to determine which modality offers patients the best quality of life. While studies often show conflicting results, a general trend is that PD and HHD patients (those on home modalities) often have higher self-reported HRQoL scores than IHD patients across a number of HRQoL domains.¹¹⁻¹⁴

Transition periods, however, remain a time period around which little is known regarding HRQoL. Most studies conducted regarding HRQoL have been cross-sectional studies of prevalent dialysis patients, and the longitudinal studies which have been published typically compare the change in HRQoL from modality initiation to 6 or 12 months, by which point in time patients are typically well established on their modality. Despite often having better HRQoL in the long-run, patients changing modalities often describe the initial transition period as fraught with both physical and mental/emotional challenges. This is an important, and understudied, area of research, and further studies are necessary to elicit the drivers of change in HRQoL during transition periods so that dialysis providers may develop effective interventions to combat declines in HRQoL.

In the following chapters, we present the results of a longitudinal, multi-methods, pilot project conducted at the University of Calgary in which a number of different modality transition periods (defined as the first 3 months on a new dialysis modality) were studied. Chapter II provides further background information on HRQoL, its importance in CKD and ESRD populations, the findings of previous studies comparing HRQoL between dialysis modalities, and the importance of transition periods in ESRD care. Chapter III presents the methodology and results of our pilot project, which utilized validated kidney-disease specific questionnaires (the Kidney Disease Quality of Life-36 Questionnaire and domains extracted from the Kidney

Disease Quality of Life-Short Form) and semi-structured patient interviews to study changes in HRQoL in 19 patients undergoing modality transitions. In Chapter IV, individual patient stories are used to highlight some of the challenges faced by patients undertaking modality transitions and to demonstrate some of the pearls and pitfalls clinicians should be aware of when using standardized HRQoL instruments in clinical practice. Finally, in Chapter V, we present the conclusions and recommendations for future research based on our findings. It is our hope that dissemination of these results helps to better inform large scale studies focused on maintaining and improving HRQoL during modality transitions.

Statement of Contribution

Each of the following chapters was initially drafted by Chance Dumaine. Jennifer MacRae, Pietro Ravani, and Maria Santana contributed to project design, data analysis, and sequential edits to the initial drafts in order to create this final manuscript.

CHAPTER I REFERENCES:

1. Arora P, Vasa P, Brenner D, et al. Prevalence estimates of chronic kidney disease in Canada: results of a nationally representative survey. *CMAJ* 2013;185 (9): E417-E423.
2. CIHI Snapshot: Treatment of End-Stage Organ Failure in Canada, CORR 2005-2014. *Canadian Institute of Health Information*.
https://www.cihi.ca/sites/default/files/document/2016_corr_snapshot_enweb.pdf. Accessed April 16th, 2018.
3. Hutchinson TA. Transitions in the lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing. *Palliat Med* 2005;19:270-7.
4. Evans R, Manninen D, Garrison L Jr, et al. The quality of life of patients with end-stage renal disease. *N Engl J Med* 1985;312:553-9.
5. Gorodetskaya I, Zenios S, McCulloch CE, et al. Health-related quality of life and estimates of utility in chronic kidney disease. *Kidney Int* 2005;68:2801-8.
6. Mapes D, Lopes AA, Satayathum S, et al. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 2003;64:339-49.
7. Janssen I, Gerhardus A, von Gersdorff G, et al. Preferences of patients undergoing hemodialysis: results from a questionnaire-based study with 4,518 patients. *Patient Prefer Adherence* 2015;9:847-55.
8. Urquhart-Secord R, Craig J, Hemmelgarn B, et al. Patient and caregiver priorities for outcomes in hemodialysis: an international nominal group technique study. *Am J Kidney Dis* 2016;68(3):444-54.
9. Hall RK, Luciano A, Pieper C, et al. Association of Kidney Disease Quality of Life (KDQOL-36) with mortality and hospitalization in older adults receiving hemodialysis. *BMC Nephrol* 2018;19:11.
10. Grincenkov FR, Fernandes N, Pereira Bdos S, et al. Impact of baseline health-related quality of life scores on survival of incident patients on peritoneal dialysis: a cohort study. *Nephron* 2015;129(2):97-103.
11. Wu AW, Fink NE, Marsh-Manzi JVR, et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *JASN* 2004;15(3):743-53.
12. Kutner NG, Zhang R, Barnhart H, et al. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 2005;20:2159-67.

13. Tennankore KK, Chan CT, Curran SP. Intensive home hemodialysis: benefits and barriers. *Nat. Rev. Nephrol* 2012;8:515-22.
14. Finkelstein F, Schiller B, Daoui R, et al. At-home short daily hemodialysis improves the long-term health-related quality of life (FREEDOM Study). *Kidney Int* 2012;82:561-69.

Chapter II: Background

I. Health-Related Quality of Life: General Concepts

Introduction and Definitions

Medical therapies are often created with the intent of prolonging life. However, it has long been recognized that prolonging *length* of life does not always enhance *quality* of life and that some life-prolonging treatments may inadvertently worsen quality of life.¹ Recognition of this fact in the 1960s gave rise to the creation of a number of tools meant to measure and quantify quality of life as an outcome that could be studied in medical research.²⁻⁴ Over time, the term “health-related quality of life” evolved from these tools.

A number of definitions exist for both ‘quality of life’ (QoL) and ‘health-related quality of life’ (HRQoL). The World Health Organization defines QoL as “an individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. It is a broad range concept affected in a complex way by the person’s physical health, psychological state, level of independence, social relationships, personal beliefs, and their relationship to salient features of their environment”.⁵ This definition highlights two important facets of the concept of ‘quality of life’: first, QoL is a subjective assessment made by an individual about themselves, and second, QoL may be impacted, positively or negatively, by a number of different factors, only one of which is physical health.

The term “health-related quality of life” evolved out of a necessity to distinguish the impact of health, disease, and medical treatments on QoL; while the literature contains many definitions, the most pragmatic is that HRQoL is “those aspects of self-perceived well-being that are related to or affected by the presence of disease or treatment”.⁶ In colloquial terms, HRQoL is therefore an individuals’ subjective perception of the impact of a disease or disease treatment on their overall quality of life.

Measurements Tools

HRQoL can be divided into physical, mental, emotional, and social domains.⁷ Many tools used to assess HRQoL attempt to assess these domains separately from one another, as it is recognized that poor HRQoL in one domain does not necessarily infer poor HRQoL in other domains.⁸ Patients may also place different emphasis on these domains and the impact each has on overall HRQoL; for example, two patients may be assessed to have similarly low scores in ‘social’ domains of HRQoL, but the impact of this on overall HRQoL may be very minimal in one patient and very high in the other patient.⁸ An assessment of global HRQoL is therefore an important component to most measurement tools.

The tools used to measure HRQoL typically take the form of questionnaires.⁸ These questionnaires can be divided into generic and disease-specific forms.

Generic HRQoL questionnaires (such as the 36 Item Short-Form Survey or the Euro-QoL 5-Dimension Questionnaire) provide a measurement of HRQoL independent of any one disease or treatment; they may be applied to healthy populations or to patients with any disease.⁹⁻¹⁰ Generic HRQoL questionnaires are useful in comparing HRQoL between patients with different diseases or between a diseased population and a healthy population.⁸ Generic HRQoL tools, however, are limited in their ability to detect unique impairments or improvements in HRQoL that occur as the result of a specific disease or treatment.

Disease-specific HRQoL tools are generally more responsive to treatment-induced changes than generic tools and are preferred when tracking changes directly related to a specific disease or treatment.¹¹ A number of disease-specific HRQoL tools have been developed, including the Kidney Disease Quality of Life questionnaires for patients with chronic kidney disease and end-stage renal disease.¹²

Quantifying Clinical Importance of Changes in HRQoL

By definition, health-related quality of life is a ‘patient-reported outcome’ (PRO). PROs are defined as “any reports coming directly from patients about how they function or feel in relation to a health condition and its therapy”.¹¹ The recognition of the importance of PROs is evidenced

by the exponential growth in the number of clinical trials including PROs as an outcome over the past 30 years.¹³ However, despite a growing body of literature in this area, interpretation and clinical application of PRO data remains a challenge, primarily because it is often unknown when changes in PROs should be considered important enough to prompt changes in therapy.

The minimal clinically important difference (MCID) is defined as “the smallest difference which patients perceive as beneficial and which would mandate, in the absence of troublesome side effects and excessive cost, a change in the patient’s management”.¹⁴ In PRO-oriented research, defining MCID values is important to help distinguish ‘statistically significant’ changes from ‘clinically significant’ changes, which are often very different from one another; for example, a change in a PRO may be statistically significant but not clinically significant, clinically significant but not statistically significant, be significant in both ways, or be significant in neither way.

MCIDs can be calculated using many different methods, each of which has inherent limitations.¹⁵ A combination of anchor- and distribution-based methods may derive the most meaningful MCID values for PRO scales.¹¹ Anchor-based methods use patient input to associate the change in a numerical scale for a PRO to a subjective assessment of the change; in other words, the quantitative change on a PRO questionnaire is “anchored” to a qualitative assessment from each patient.¹⁵ Anchor-based methods are prone to a number of biases. For example, patients are typically asked about the degree to which their health status improved or worsened *after* they have completed a treatment of some sort; this creates opportunity for recall bias, in which patients may falsely recall their baseline state of health.¹⁵ Patients may also be biased by their expectations of the benefits the treatment would bring or be biased by comparing themselves to healthy counterparts rather than to their own selves prior to treatment.¹⁶ Patient factors such as age, education, and socioeconomic status may also influence patient responses and determination of MCIDs when using anchor-based methods.¹⁶ Despite these limitations, using anchor-based methods to determine MCID values is generally preferred, as it is the only method which directly captures patient preferences and values.¹³

Distribution-based methods rely on the statistical distribution of PRO outcome scores around the mean.¹⁵ Once the distribution is known, a number of approaches may be used to estimate the MCID; one commonly proposed method is to use half the standard deviation to approximate the MCID.^{11,17} Distribution-based methods are the least preferred for two reasons: first, there is no anchoring of the mathematically derived value to patient or clinician input, and second, distribution-based methods typically yield smaller values than anchor-based methods, suggesting a treatment is of benefit or harm to a patient when it may not actually be so.^{11,15} However, because of the risk of bias associated with anchor-based methods, some experts have advocated that a combination of anchor- and distribution-based methods should be used to derive MCID values for PRO scales.¹¹

Unfortunately, the determination of MCIDs has lagged behind the development of HRQoL assessment tools, and many HRQoL tools commonly used in medical research do not yet have defined MCID values. Interpretation of HRQoL data therefore remains a challenge in many fields. A recent systematic review by Jayadevappa et al assessed the MCIDs for 10 generic and 80 disease-specific instruments.¹¹ In their review, the authors highlight the urgent need to develop MCID values for both generic and disease-specific instruments in order to effectively use these tools to enhance patient care.

II. Methods of Measuring HRQoL in Kidney Disease Patients: Strengths and Limitations

As stated in Section I, HRQoL may be measured with either generic or disease-specific tools. Certainly, the most widely used generic tool that has been used to measure HRQoL in CKD/ESRD populations has been the 36-Item Short Form Survey (SF-36).⁹ The SF-36 is a self-administered questionnaire that measures general health status in eight domains: physical functioning, role-physical, bodily pain, general health perceptions, vitality, social functioning, role-emotional, and mental health. Each domain is graded on a scale of 0 to 100, with higher scores indicating better quality of life. The SF-36 also generates a physical component summary score (PCS) and mental component summary score (MCS); the mean score for both the PCS and MCS in the general population is 50, with a standard deviation of 10. The SF-36 has been validated in the general population and in a number of sub-populations, including those with chronic kidney disease and those on hemodialysis.¹⁸ As a generic HRQoL tool, the SF-36 may

be used to compare the health state of CKD/ESRD patients to those with other chronic diseases or to healthy populations. However, as with all generic tools, it has limited ability to track disease- or treatment-induced impairments and improvements longitudinally.

The most widely used disease-specific tools for patients with CKD/ESRD are the Kidney Disease Quality of Life (KDQOL) instruments (Figure 1).¹² The initial KDQOL Long Form was created for use in early clinical trials of anemia correction in dialysis patients; it contains a generic core (the SF-36) as well as 11 “kidney disease targeted scales”. The truncated KDQOL Short Form (KDQOL-SF) was created in response to reluctance to use the Long Form in clinical practice. While the KDQOL-SF measures the same domains/scales in fewer questions (80 rather than 134), the KDQOL tools were not widely adopted into clinical practice until the tool was significantly shortened (in 2002) into a 36-item questionnaire known as the KDQOL-36. The KDQOL-36 has been validated in a number of languages and populations worldwide, and is currently the HRQoL tool recommended by both the Center for Medicare and Medicaid Services in the United States and by an expert panel of the European Renal Association – European Dialysis and Transplant Association (ERA-EDTA).¹⁹⁻²³

The KDQOL-36 maintains a generic core (a shortened version of the SF-36 known as the SF-12) and three of the eleven “kidney disease targeted scales” of the KDQOL-SF (‘Symptoms/Problems’, ‘Effects of Kidney Disease on Daily Life’, and ‘Burden of Kidney Disease’). Like the SF-36, the SF-12 generates PCS/MCS scores, which have been shown to have a similar association with morbidity and mortality in ESRD patients regardless of whether they are derived from the SF-36 or SF-12.¹⁸ The three kidney disease targeted scales of the KDQOL-36 are scored from 0 to 100, with higher scores indicating better HRQoL; similar to the SF-36, the SF-12 PCS/MCS scores have a mean score of 50 (standard deviation 10) in the general population.

In the United States, dialysis facilities are required to perform an annual measurement of patient HRQoL using the KDQOL-36.²² In their recent review of patient-reported outcome measures in ESRD, Finkelstein and Finkelstein outline concerns with this method.²⁴ The first concern is that HRQoL may change dramatically over short periods of time in CKD/ESRD patients because of

their multiple comorbidities and complex treatment regimens; therefore, the authors point out, HRQoL should be assessed more often than annually to provide meaningful results. The second concern is that capturing HRQoL data solely with standardized questionnaires does not provide clinicians with a complete understanding of an individual's experience with kidney disease or dialysis; patient testimony is required to fully describe HRQoL. Finally, they state that a major challenge in monitoring HRQoL data is developing infrastructure and resources to manage shortcomings in HRQoL that come to light as a result of surveys. Solutions to these logistical challenges need to be studied as this field moves forward.

III. Importance of Health-Related Quality of Life in Patients with Kidney Disease

Patients with chronic kidney disease have a number of physical, psychosocial, and lifestyle disturbances that have been shown to impact health-related quality of life.²⁵ Studies suggest that HRQoL scores become progressively lower as kidney function declines, with the worst scores found in patients with end-stage renal disease who require dialysis.²⁶

The importance of assessing HRQoL in CKD and dialysis patients has been described for over a decade. In a 2005 review, Unruh et al described nine potential roles for routine HRQoL assessments in patients with kidney disease: describe a patient's health state; assess patient satisfaction with care; screen for disease; assess a patient's needs; set treatment goals; monitor disease progression; monitor treatment response; improve patient-physician communication; and standardize the interaction between physicians and patients.²⁵ They also point out that a standardized method of assessing HRQoL may allow patients to describe symptoms and concerns that they may be uncomfortable otherwise disclosing in a semipublic setting such as a hemodialysis unit or peritoneal dialysis training facility. However, routine assessments of HRQoL did not become part of clinical care until 2008, when an annual assessment of HRQoL was mandated for all dialysis patients in the United States.²²

Such routine assessments are critically important as health care systems attempt to provide patient-centred care. A 2015 survey of over 4000 German dialysis patients showed that quality of life, satisfaction with care, and safety of treatment were the three most important outcomes to patients.²⁷ Similarly, a 2016 study of 82 hemodialysis patients and their caregivers from

Australia and Canada examined patient/caregiver priorities and found that the top 5 were: ‘fatigue/energy levels’, ‘coping with therapy’, ‘ability to travel’, ‘dialysis-free time’, and ‘impact on family’, all components of health-related quality of life.²⁸ In this study, patients ranked these HRQoL parameters as more important than hospitalization rates, cardiovascular complications, or even mortality. Studies such as these have been instrumental in increasing awareness of the importance of monitoring HRQoL in this vulnerable patient population.

HRQoL has also been shown to be an important clinical outcome as an independent predictor of morbidity and mortality. In IHD patients, reduced PCS scores on the SF-36 or KDQOL-36 have been shown to be predictive of hospitalization and mortality, while reduced MCS scores have been shown to be predictive of hospitalization.²⁹⁻³⁰ In peritoneal dialysis patients, reductions in either MCS or PCS are predictive of higher mortality.³¹

IV. Health-Related Quality of Life Across the Spectrum of Kidney Disease

While relatively few studies have examined the impact of non-dialysis dependent chronic kidney disease on HRQoL, a 2009 study of North American CKD patients (Stage III-V) showed that SF-36 scores were consistently lower in patients with chronic kidney disease than in healthy members of the general population.²⁶ This study also showed that SF-36 scores steadily declined in parallel with declining renal function. The scores seen in stage III-V CKD patients were higher than scores seen in hemodialysis and peritoneal dialysis cohorts, but lower than scores of patients with stage I-II CKD. This study, as well as other similar studies, show that while much focus is given to poor HRQoL in patients with ESRD, reductions in HRQoL begin quite early in chronic kidney disease and that HRQoL progressively worsens as renal function declines.³²

A number of studies have examined HRQoL in IHD patients. A 2004 publication by DOPPS (Dialysis Outcomes and Practice Patterns Study) showed that regardless of geographic region, IHD patients have significantly lower SF-36 scores than the general population.²⁹ A subsequent publication re-examined this data and showed that for the SF-36 PCS, independent predictors of worse scores included age (with progressively worse scores for each decade beyond 30 years old), female sex, being unemployed, serum albumin less than 35 g/L, and having any of:

cerebrovascular disease, cardiac disease, peripheral vascular disease, diabetes, lung disease, or psychiatric disease.³³ For the SF-36 MCS, independent predictors of worse scores included an annual income less than \$10 000, not having post-secondary education beyond high school, and psychiatric disease. The kidney disease-specific domains of the KDQOL-SF were also examined; for these domains, psychiatric disease was the strongest predictor of poor scores, but unemployment, lack of post-secondary education, lower income, living alone, living in a nursing home, and a number of physical comorbidities (cerebrovascular disease, cardiac disease, peripheral vascular disease, diabetes, lung disease) were also significantly associated with lower scores. Of note, a number of clinical parameters often followed in dialysis units (serum albumin, hemoglobin, dialysis adequacy as determined by eKt/V, vascular access type, predialysis blood pressure, and body mass index) had no independent association with kidney disease-specific HRQoL scores. Subsequent studies have consistently shown poor HRQoL for in-centre hemodialysis patients compared to the general population. Depression, lack of employment, symptoms of kidney disease/dialysis-related symptoms, post-dialysis fatigue, and loss of residual renal function have all been shown to significantly reduce HRQoL in IHD patients.³⁴⁻⁴⁰

Whether peritoneal dialysis results in better HRQoL has been a long-standing question in the nephrology community. Two large prospective cohort studies (CHOICE and DMMS Wave 2) each showed that after 1 year of therapy, patients on peritoneal dialysis had similar overall HRQoL when compared to IHD patients.⁴¹⁻⁴² However, dialysis modality seemed to impact scores in specific HRQoL domains, with PD patients reporting higher scores with regards to financial well-being, ability to travel, dietary restrictions, dialysis access, effects of kidney disease on daily life, burden of kidney disease, and satisfaction with care. In-centre hemodialysis patients reported better scores in domains related to sleep, body image, and sexual functioning. Since the publication of CHOICE and DMMS Wave 2, a number of observational studies with similar findings have been published. A 2017 meta-analysis synthesized 7 studies which had used the KDQOL-SF or KDQOL-36 to compare HRQoL in HD versus PD patients.⁴³ The only statistically significant difference found was in the “Effects of Kidney Disease” domain score, which was superior in patients on peritoneal dialysis. Overall, studies comparing IHD and PD emphasize the fact that both modalities have intrinsic pros and cons that impact HRQoL in different ways.

The impact of dialysis modality on HRQoL may be related to time on dialysis; a 2008 study compared HRQoL of 77 IHD patients to 58 PD patients who were divided in a binary fashion into those on dialysis for less than or greater than 4 years.⁴⁴ While no significant differences were seen between those on PD for less than 4 years, those on PD for greater than 4 years, or those on IHD for less than 4 years, patients on IHD for longer than 4 years had lower HRQoL scores in domains indicative of physical health, social relationships, and environment. IHD patients also had significantly higher anxiety/insomnia scores than PD patients regardless of time interval, and those on IHD for longer than 4 years had the poorest overall mental health. The authors therefore surmised that HRQoL may be comparable in the first few years of therapy regardless of modality, but that patients on IHD may fare worse than PD patients if they remain on dialysis for longer periods of time, an important consideration as dialysis is a lifelong therapy for many patients.

An extensive body of literature has been published in the last decade regarding patient outcomes on home hemodialysis (HHD). Tennankore et al nicely summarize the findings of major studies conducted prior to 2012 and state that 5 observational cohort studies published between 1998 and 2010 all showed improved HRQoL with HHD compared to IHD.⁴⁵ They also summarize two randomized controlled trials which evaluated the impact of HHD on HRQoL. The first (conducted in Alberta, Canada) compared in-centre conventional hemodialysis to home nocturnal hemodialysis and showed that HHD patients had statistically significant improvements in the “Effects of Kidney Disease” and “Burden of Kidney Disease” domains of the KDQOL-SF.⁴⁶ The second, the Frequent Hemodialysis Network (FHN) Nocturnal Trial, did not show an improvement in SF-36 scores for home nocturnal dialysis patients compared with conventional dialysis patients; however, the FHN Nocturnal Trial has been criticized because the majority of “conventional” dialysis patients were not dialyzing in-centre, but were actually performing thrice weekly dialysis at home.⁴⁷ In actuality, the study showed that patients experienced an increase in SF-36 PCS scores after conversion from IHD to HHD, regardless of whether they were doing HHD nocturnally or on conventional schedules. The overall conclusion by Tennankore et al was that the existing body of evidence suggests improved (and certainly not worsening) HRQoL with HHD compared to IHD. The results of the 2012 FREEDOM Study (the largest cohort study to

date examining the impact of HHD on HRQoL) seem to substantiate this conclusion, showing that conversion to HHD resulted in statistically significant improvements in SF-36 scores by 4 months.⁴⁸ Whether or not HRQOL is superior on HHD than on PD remains unclear, as few studies have compared these two modalities using validated HRQoL measurements.

V. Transition Periods in End-Stage Renal Disease

During the life of a patient with kidney disease, a number of important transitions may occur. Not only do patients experience a transition from living with chronic kidney disease to life on dialysis, but patients may change dialysis modalities a number of times during their life. Consider, for example, a patient who initiates in-centre hemodialysis as their initial dialysis modality when their CKD reaches the point of ESRD (transition #1). After some time on IHD, the patient may decide they wish to change to peritoneal dialysis in order to maintain employment and to make travel easier (transition #2). As the patient's residual renal function declines, PD may no longer be able to provide adequate dialysis, and the patient may transition back to IHD as PD fails (transition #3). Wanting to maintain their autonomy and continue dialyzing at home, the patient may decide to train for and undertake home hemodialysis (transition #4). Finally, after years on HHD, health problems may force the patient to return to IHD (transition #5). This patient has experienced 5 important transition points in their life as a dialysis patient; such a course is common for many patients with ESRD. Some of these transitions may be patient-initiated (such as #2 or #4) but many transitions occur, often urgently, out of medical necessity (such as transitions #1, #3, and #5). While transitions ideally occur over a gradual period of time, allowing for patient education and counselling, studies would suggest that many transitions are unplanned and occur urgently because of medical decompensation.⁴⁹

Transition points in ESRD care pathways have been described as challenging times when patients embark on a completely new way of life, challenging their coping mechanisms and forcing them to re-evaluate their identities as well as their relationships with themselves, others, and with their disease and treatment.⁵⁰ These transition periods have been described as physically and emotionally turbulent, “marked by periods of emotional upheaval and doubts about the future”.⁵¹ A qualitative study of 36 patients initiating hemodialysis identified three major constructs that patients describe during a transition period: “redefinition of self”, “quality

of supports”, and “meanings of illness and treatment”.⁵¹ Negative descriptors such as “helpless”, “dependent”, “humiliated”, and “inadequate” were commonly seen when patients described themselves during a transition period. These negative feelings towards self often manifest as depression and anxiety during transition periods, with a 2003 study finding 44% of patients initiating dialysis met criteria for depression.⁵²

In addition to being times of mental and emotional stress, transition points are often periods of physical stress as well. Many transitions in ESRD care are triggered by declining health, and patients may be suffering a number of symptoms related to uremia or inadequate dialysis at the time of transition. In keeping with this, transition periods have been shown to be one of the periods where patient morbidity and mortality are highest.⁵³⁻⁵⁴

Despite growing recognition that transition periods are times of immense difficulty for patients, relatively little is known about methods to ease physical and emotional strain during transitions. As evidenced by a 2010 publication by the European Renal Best Practice Advisory Board, clinicians often focus on *medical* complications during transition periods rather than *psychological* complications, and some experts have suggested psychosocial and spiritual factors should be attended to more by dialysis staff during transition states.^{50,55} Some authors have even suggested that “transitional care units” should be standard of care; in these units, patients would receive more individualized care for the initial weeks to months of dialysis, allowing a more intensive focus on their individual motivations and goals.⁵⁶⁻⁵⁷ Such individualized care is challenging in current dialysis facilities, where resources for patient-specific supports are often limited by time and budgetary constraints.

Providing high-quality patient-centred care is also difficult in current models because few studies have examined the change in HRQoL that occurs during transition periods in a way that allows targeted interventions to be created. Most studies assessing HRQoL have done so over a 6 to 12 month period, which may be too long to truly be defined as a “transition” period. Additionally, most studies that have focused on changes in HRQoL during a modality change have focused on the transition from IHD to either PD or HHD; little has been written about the unique challenges that are faced by patients switching from a home modality back to IHD or between PD and

HHD. Further studies are needed to determine the factors that positively and negatively impact HRQoL during different modality transitions so that ESRD programs may develop targeted interventions to address these factors.

Figure 1: The Kidney Disease Quality of Life (KDQOL) Tools

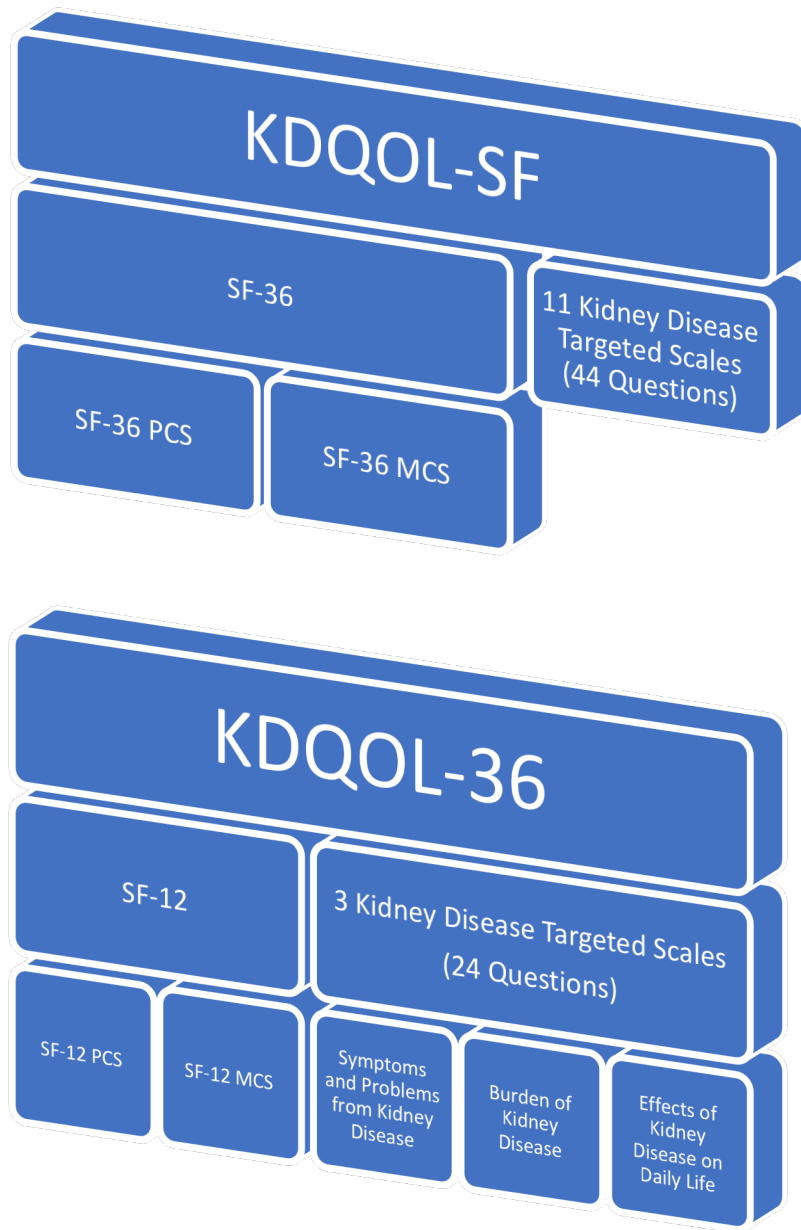


Figure 1: The components of the Kidney Disease Quality of Life Short Form (KDQOL-SF) and Kidney Disease Quality of Life-36 (KDQOL-36). SF-36 = Short-Form 36; PCS = physical component summary score; MCS = mental component summary score; SF-12 = Short-Form 12.

CHAPTER II: REFERENCES

1. Kaplan RM, Bush JW. Health-related quality of life measurement for evaluation research and policy analysis. *Health Psychology* 1982;1:61-80.
2. Elkinton JR. Medicine and the quality of life. *Ann Intern Med* 1966;64:711-14.
3. Spitzer WO. State of science 1986: quality of life and functional status as target variables for research. *J Chronic Dis* 1987;40:465-71.
4. Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics* 2016.;34(7):645-49.
5. World Health Organization. ‘Introducing the WHOQOL instruments’. *WHOQOL: Measuring Quality of Life*. Retrieved April 16, 2018 from <http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>.
6. Ebrahim S. Clinical and public health perspectives and applications of health-related quality of life measurement. *Soc Sci Med* 1995;41:1383-94.
7. Office of Disease Prevention and Health Promotion. ‘Healthy People 2020’. *Health-related quality of life and well-being*. Retrieved April 16, 2018 from <https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being>.
8. Lin XJ, Lin IM, Fan SY. Methodological issues in measuring health-related quality of life. *Tzu Chi Medical Journal* 2013;25:8-12.
9. RAND Corporation. ‘Surveys’. *36-Item Short Form Survey (SF-36)*. Retrieved April 16, 2018 from https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html.
10. EQ-5D. ‘EQ-5D Instruments’. *About EQ-5D*. Retrieved April 16, 2018, from <https://euroqol.org/eq-5d-instruments/>.
11. Jayadevappa R, Cook R, Chhatre S. Minimal important difference to infer changes in health-related quality of life – a systematic review. *J Clinical Epidemiol* 2017;89:188-98.
12. RAND Corporation. ‘Surveys’. *Kidney Disease Quality of Life (KDQOL) Instrument*. Retrieved April 16, 2018, from https://www.rand.org/health/surveys_tools/kdqol.html.
13. Johnston BC, Ebrahim S, Carrasco-Labra A, et al. Minimally important difference estimates and methods: a protocol. *BMJ Open* 2015; 5(10): e007953.
14. Jaeschke R, Singer J, Guyatt GH. Measurement of health status. Ascertaining the minimal clinically important difference. *Control Clin Trials* 1989;10(4):407-15.

15. McGlothlin AE, Lewis RJ. Minimal Clinically Important Difference: Defining What Really Matters to Patients. *JAMA Guide to Statistics and Methods* 2014;312:13.
16. Cook CE. Clinimetrics Corner: The Minimal Clinically Important Change Score (MCID): a necessary pretense. *J Man Manip Ther* 2008;16(4):E82-83.
17. Norman GR, Sloan JA, Wyrwich KW. Interpretation of changes in health-related quality of life: the remarkable universality of half a standard deviation. *Med Care* 2003;41(5):582-92.
18. Loosman WL, Hoekstra T, van Dijk S, et al. Short-Form 12 or Short-Form 36 to measure quality-of-life changes in dialysis patients? *Nephrol Dial Transplant* 2015;30:1170-76.
19. Ricardo AC. Validation of the Kidney-Disease Quality of Life Short Form 36 (KDQOL-36™) US Spanish and English Versions in a Cohort of Hispanics with Chronic Kidney Disease. *Ethn Dis* 2013;23(2):202-209.
20. Yang F, Wang VW, Joshi VD, et al. Validation of the English Version of the Kidney Disease Quality of Life Questionnaire (KDQOL-36) in Haemodialysis Patients in Singapore. *Patient* 2013;6:135-41.
21. Chow SKY, Tam BML. Is the kidney disease quality of life-36 (KDQOL-36) a valid instrument for Chinese dialysis patients? *BMC Nephrol* 2014;15:199.
22. Schatell D, Witten B. Measuring Dialysis Patients' Health-Related Quality of Life with the KDQOL-36™. *KDQOL COMPLETE*. 2012. Retrieved April 16, 2018, from <https://kdqol-complete.org/pdfs/kdqol-36.pdf>.
23. Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015; 30(10): 1605-14.
24. Finkelstein FO, Finkelstein SH. Time to rethink our approach to patient-reported outcomes measures for ESRD. *Clin J Am Soc Nephrol* 2017;12:1885-88.
25. Unruh ML, Weisbord SD, Kimmel PL. Health-Related Quality of Life in Nephrology Research and Clinical Practice. *Semin Dial* 2005;18(2):82-90.
26. Mujais SK, Story K, Brouillette J, et al. Health-related Quality of Life in CKD Patients: Correlates and Evolution Over Time. *Clin J Am Soc Nephrol* 2009;4(8):1293-1301.
27. Janssen I, Gerhardus A, von Gersdorff G, et al. Preferences of patients undergoing hemodialysis: results from a questionnaire-based study with 4,518 patients. *Patient Preference Adherence* 2015;9:847-55.

28. Urquhart-Secord R, Craig J, Hemmelgarn B, et al. Patient and caregiver priorities for outcomes in hemodialysis: an international nominal group technique study. *Am J Kidney Dis* 2016;68(3):444-54.
29. Mapes D, Lopes AA, Satayathum S, et al. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 2003;64:339-49.
30. Hall RK, Luciano A, Pieper C, et al. Association of Kidney Disease Quality of Life (KDQOL-36) with mortality and hospitalization in older adults receiving hemodialysis. *BMC Nephrol* 2018;19:11.
31. Grincenkov FR, Fernandes N, Pereira Bdos S, et al. Impact of baseline health-related quality of life scores on survival of incident patients on peritoneal dialysis: a cohort study. *Nephron* 2015;129(2):97-103.
32. Gorodetskaya I, Zenios S, McCulloch CE, et al. Health-related quality of life and estimates of utility in chronic kidney disease. *Kidney Int* 2005;68:2801-8.
33. Lopes AA, Bragg-Gresham JL, Goodkin DA, et al. Factors associated with health-related quality of life among hemodialysis patients in the DOPPS. *Qual Life Res* 2007;16:545-57.
34. Erickson KF, Zhao B, Ho V, et al. Employment among patients starting dialysis in the United States. *Clin J Am Soc Nephrol* 2018;13:265-73.
35. Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. *Adv Chronic Kidney Dis* 2007;14:82-99.
36. Claxton RN, Blackhall L, Weisbord SD, et al. Undertreatment of symptoms in patients on maintenance hemodialysis. *J Pain Symptom Manage* 2010;39:211-18.
37. Weisbord SD, Fried LF, Mor MK, et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007;2(5):960-7.
38. Bossola M, Pepe G, Marzetti E. Health-related quality of life of patients on chronic dialysis: the need for a focused effort. *Semin Dial* 2017;30(5):413-6.
39. Rayner HC, Zepel L, Fuller DS, et al. Recovery Time, Quality of Life, and Mortality in Hemodialysis Patients: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis* 2014;64(1):86-94.
40. Poulsen CG, Kjaergaard KD, Peters CD, et al. Quality of life during initial hemodialysis therapy and association with loss of residual renal function. *Hemodial Int* 2017; 21(3): 409-21.

41. Wu AW, Fink NE, Marsh-Manzi JVR, et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *JASN* 2004;15(3):743-53.
42. Kutner NG, Zhang R, Barnhart H, et al. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 2005;20:2159-67.
43. Zazzeroni L, Pasquinelli G, Nanni E, et al. Comparison of quality of life in patients undergoing hemodialysis and peritoneal dialysis: a systematic review and meta-analysis. *Kidney Blood Press Res* 2017;42(4):717-27.
44. Ginieri-Cocossis M, Theofilou P, Synodinou C, et al. Quality of life, mental health and health beliefs in haemodialysis and peritoneal dialysis patients: investigating differences in early and later years of current treatment. *BMC Nephrol* 2008;9:14.
45. Tennankore KK, Chan CT, Curran SP. Intensive home hemodialysis: benefits and barriers. *Nat. Rev. Nephrol* 2012;8:515-22.
46. Culleton BF, Walsh M, Klarenbach SW, et al. Effect of frequent nocturnal hemodialysis vs conventional hemodialysis on left ventricular mass and quality of life: a randomized controlled trial. *JAMA* 2007;298(11):1291-99.
47. Rocco MV, Lockridge RS Jr, Beck GJ, et al. The effects of frequent nocturnal home hemodialysis: the Frequent Hemodialysis Network Nocturnal Trial. *Kidney Int* 2011;80:1080-91.
48. Finkelstein F, Schiller B, Daoui R, et al. At-home short daily hemodialysis improves the long-term health-related quality of life (FREEDOM Study). *Kidney Int* 2012;82:561-9.
49. Boissinot L, Landru I, Cardineau E, et al. Is transition between peritoneal dialysis and hemodialysis really a gradual process? *Perit Dial Int* 2013;33(4):391-7.
50. Hutchinson TA. Transitions in the lives of patients with end stage renal disease: a cause of suffering and an opportunity for healing. *Palliat Med* 2005;19:270-7.
51. Gregroy DM, Way CY, Hutchinson TA, et al. Patients' perceptions of their experience with ESRD and haemodialysis treatment. *Qual Health Res* 1998;8:764-83.
52. Watnick S, Kirwin P, Mahnensmith R, et al. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003;41:105-10.
53. Pulliam J, Li N-C, Maddux F, et al. First-year outcomes of incident peritoneal dialysis patients in the United States. *Am J Kidney Dis* 2014;64(5):761-9.

54. Lukowsky LR, Kheifets L, Arah OA, et al. Patterns and predictors of early mortality in incident hemodialysis patients: new insights. *Am J Nephrol* 2012;35(6):548-58.

55. Covic A, Bammens B, Lobbedez T, et al. Educating end-stage renal disease patients on dialysis modality selection: a clinical advice from the European Renal Best Practice (ERBP) Advisory Board. *NDT Plus* 2010;3: 225-33.

56. Morfin JA, Yang A, Wang E, et al. Transitional dialysis care units: a new approach to increase home dialysis modality uptake and patient outcomes. *Semin Dial* 2018;31:82-7.

57. Bowman B, Zheng S, Yang A, et al. Improving incident ESRD care via a transitional care unit. *Am J Kidney Dis* 2018; XX(XX):1-6. Published online ahead of print: doi: 10.1053/j.ajkd.2018.01.035

Chapter III: Pilot Project

Introduction

Patients with end-stage renal disease (ESRD) have reduced health-related quality of life (HRQoL) compared to the general population.¹ In-centre hemodialysis (IHD) patients have particularly low HRQoL scores, while patients treated with peritoneal dialysis (PD) or home hemodialysis (HHD) often report higher HRQoL across a number of domains.²⁻⁴ Studies that examine HRQoL changes with a dialysis modality transition typically assess change after 6-12 months. While such studies provide valuable information regarding the long-term impact of modality changes, they fail to capture changes in HRQoL that occur during the early transition period. Transition periods may be times when patients enjoy improvements in both physical and mental health; however, they are more often tumultuous and marked by depression, anxiety, morbidity, and mortality.⁵⁻⁹

Given the lack of awareness of the potential stress associated with dialysis transitions, many dialysis facilities are ill prepared to aid patients struggling during these times. To increase our understanding of how transition periods impact HRQoL, we conducted a multi-methods pilot project in patients undergoing various transitions between pre-dialysis chronic kidney disease (CKD), IHD, PD, and HHD. Here, we report on the methodology and results of our pilot project.

Methods

Study Design and Setting

This was a multi-methods study conducted in the Southern Alberta Renal Program (SARP) in Alberta, Canada. Patients undertaking a modality transition (initiation of dialysis for the first time or changing dialysis modalities) between the months of July and September, 2017, were invited to participate. Changes in HRQoL during the first 3 months of treatment on the new modality were examined using both quantitative and qualitative methods of data collection. Within the quantitative arm, patients completed Kidney Disease Quality of Life-36 (KDQOL-36) surveys (supplemented with additional domains from the KDQOL-Short Form survey) at baseline and 3 months.¹⁰ Within the qualitative arm, patients participated in semi-structured

interviews 3 months after transition to their new modality and described specific factors that had contributed to positive and negative changes in HRQoL during the transition period. This study was approved by the Conjoint Health Research Ethics Board at the University of Calgary.

Participants

All adult patients (older than 18 years of age) with ESRD undertaking a modality change during our recruitment period were approached and asked to participate in this study. Patients with acute kidney injury who were expected to have recovery of renal function within 3 months, patients undergoing a temporary modality change anticipated to last less than 3 months, and non-English speaking patients were excluded from study participation. Participation in each component of the study was voluntary and all participants provided informed consent.

Data Sources

The KDQOL-36 assesses HRQoL in two generic domains [physical component summary score (PCS) and mental component summary score (MCS)] and three kidney disease-specific domains (“Symptoms/Problems”, “Burden of Kidney Disease”, and “Effects of Kidney Disease on Daily Life”).¹⁰ Each kidney disease-specific domain is scored from 0 to 100, with higher scores representing better HRQoL. The PCS and MCS are similarly scored but scores may be compared to those of the general American population (mean score 50 and standard deviation of 10).

The KDQOL-36 has been validated in both pre-dialysis CKD patients and dialysis patients and is the recommended tool for assessing HRQoL by both the Centre for Medicare/Medicaid Services in the United States and the European Renal Association – European Dialysis and Transplant Association.¹¹⁻¹² Three additional domains of interest (Sleep, Social Support, Work Status) and one question assessing overall health on a 0 to 10 Likert scale (“Overall, how would you rate your health?”, where 0 is worst possible and 10 is best possible) were extracted from the KDQOL-Short Form (KDQOL-SF); each domain, as well as the overall health status question, are also reported as values from 0 to 100, with higher scores representing better HRQoL.¹⁰ (Copies of the KDQOL instruments are available through RAND Corporation at https://www.rand.org/health/surveys_tools/kdqol.html).

The script utilized for semi-structured patient interviews was created with the assistance of an expert in collecting patient-reported outcomes measures (MS) and was structured to supplement and expand upon the domains interrogated by the KDQOL instruments. A copy of the interview script may be found in Appendix A.

Data Collection

Participants completed baseline KDQOL surveys either on their first day of IHD or their first day of PD/HHD training. IHD patients completed follow-up surveys in the IHD unit 3 months after their initial dialysis treatment, while PD/HHD patients completed follow-up surveys in clinic 3 months after their last day of training (within SARP, average training times are 3-4 days for PD and 4-6 weeks for HHD); patients were also given the option of completing follow-up surveys via e-mail. All survey responses were anonymized and entered into the Microsoft Excel KDQOL-36 scoring template provided by RAND corporation, which converts raw entry data to a score from 0 to 100. The additional domains from the KDQOL-SF were scored manually using instructions provided by RAND.

At the time of obtaining informed consent, patients agreed to be contacted by telephone for semi-structured interviews; interviews were conducted after 3 months on their new modality (same timeline as the 3-month follow-up surveys). Patients who could not be contacted by telephone after attempts on 3 different dates were approached at either their next dialysis treatment (IHD patients) or next clinic visit (PD and HHD patients) and asked to participate in in-person interviews. Patients who declined in-person interviews were not contacted subsequently and were removed from this arm of the study.

All interviews were conducted by the lead author (CD), who had no relationship with the participants prior to the study, but who had met with and received informed consent from all patients at the study onset. Interviews ranged in length from 6 to 58 minutes depending on patient responses. All interviews were audio recorded, transcribed in full, and verified against audio recordings for accuracy.

Sample Size

This study was undertaken as a pilot project to test the methodology of combining the KDQOL surveys with our semi-structured interview. Given the lack of knowledge about effect sizes and their variability (i.e., association between transition and change in score), an effect-driven sample size calculation was not completed. The number of study participants was determined by the number of patients initiating/changing dialysis modalities during the designated recruitment period.

Data Analysis

Baseline characteristics of study participants were summarized with basic descriptive statistics. Participants were divided into three subgroups based on whether they were transitioning to IHD, PD, or HHD. Mean scores for each of the KDQOL domains were calculated for each group at baseline and at 3 months. Hypothesis testing was not conducted.

Interviews were also subdivided based on the modality being transitioned to (IHD, PD, or HHD). Scripts were sent to two independent reviewers and multiple readings were undertaken to gain content familiarity. A deductive coding process was utilized by each reviewer in order to organize interview data into candidate themes reflective of the domains of the KDQOL instruments. Candidate themes were then compared between the two reviewers to ensure consistency, and final themes were selected by the primary author (CD) and one co-author (JM). The reviewers and authors collaboratively selected quotes that were felt to be representative of each theme and which reflected whether the change in HRQoL (as related to that theme) had been positive or negative.

Results

Sixty-nine patients undertook modality changes during the recruitment period. Twenty-five were excluded based on the pre-specified exclusion criteria. Of the 44 patients eligible for the study, 30 consented to participate. Figure 1 shows the number of patients lost to follow-up. At three months, 19 patients remained in the study: 3 in the IHD group, 9 in the PD group, and 7 in the HHD group. All 19 completed KDQOL surveys at baseline and 3 months, and fifteen patients participated in semi-structured interviews.

Table 1 shows the demographics of the study participants as a whole, as well as within each of the 3 subgroups. The mean age of the cohort was 54.0 +/- 18.1 years, with patients transitioning to HHD tending to be younger (mean age 47.6 +/- 19.0 years versus 54.7 +/- 16.8 years for PD patients and 58.5 +/- 17.4 years for IHD patients). While approximately three-quarters of the participants in this study were male, a greater proportion of PD patients were male (84.6%) compared to the IHD (75.0%) or HHD (61.5%) groups. Dialysis vintage ranged from 0 months (incident patients) to one patient who had been on dialysis for over 7 years. The most common cause of ESRD in this patient population was glomerulonephritis (40.0%), followed by diabetic nephropathy and polycystic kidney disease (16.7% each). While all patients in the study had been diagnosed with hypertension and approximately one-third had diabetes, other comorbidities were uncommon.

Quantitative Results

Figures 2-4 show mean baseline and 3-month scores for each domain of the KDQOL-36 within each modality. Each of the five domains improved over the initial 3 months regardless of the transition modality. Within each domain, scores were lowest at baseline and 3 months for patients transitioning to IHD. Patients transitioning to home hemodialysis had the highest baseline and 3-month scores for most domains. For IHD and HHD patients, the largest improvements were seen in the “Symptoms/Problem List” domain, while for PD patients the largest improvement was seen in the “Effects of Kidney Disease on Daily Life” domain.

Figure 5 shows the changes in the additional domains extracted from the KDQOL-SF (Sleep, Social Support, Work Status and self-rated overall state of health). Sleep scores improved within all 3 groups, with the largest change seen in HHD patients. Social support scores improved for IHD and HHD patients, but declined for PD patients. IHD patients demonstrated the largest improvement in both “Work Status” and “Overall Health Rating” scores.

Qualitative Results

Eight major interview themes were selected to supplement the domains of the KDQOL tools. These were: “physical health and well-being”, “mental health and well-being”, “interactions with family and friends”, “symptoms of kidney disease/dialysis”, “sleep”, “ability to work”, “ability

to participate in hobbies, recreation, and travel”, and “general changes in quality of life”. Key quotes that exemplify these themes may be found in Tables 2-4.

Patients transitioning to IHD tended to describe the transition period in negative terms (Figure 6), particularly if they were transitioning from PD. The major drivers of poor HRQoL during the transition period were a loss of independence, increased restrictions on diet/fluid intake, reduced energy (compared to PD), prolonged post-dialysis recovery times, increased depressive symptoms, reduced interactions with family and friends, increased dependence upon family members, feelings of burdening their loved ones, and post-dialysis leg aches; the only positive change noted by patients changing from PD to IHD was no longer having the responsibility for self-care. The transition period was described in quite different terms by the patient who transitioned to IHD from pre-dialysis CKD; this individual described improved sleep, improved energy levels, reduced pruritus, and improved productivity at work.

Patients transitioning to PD (all of whom were from pre-dialysis CKD or IHD) tended to describe an improvement in HRQoL during the transition period (Figure 7). Patients transitioning from CKD described a general feeling of better health, an appreciation of the independence PD allowed them, and improved energy and mood levels. There were negative aspects of the transition for some patients, particularly in patients utilizing nocturnal PD, who noted reduced free time in the evening as a result of PD. Patients on nocturnal PD also frequently mentioned sleep disturbances, especially initially, and a number of patients commented on the negative impact that post-operative lifting restrictions had on their ability to get tasks done at home or at work. While many patients expressed appreciation that PD allowed them to maintain employment, patients with physically laborious jobs often stated that they had not been adequately warned of the physical limitations that came along with PD and stated they had been led to believe they would be able to work at their full pre-dialysis capacity, which was often not the case.

The two patients transitioning from IHD to PD had similarly positive experiences with the transition and frequently compared HRQoL on PD to that on IHD. Both commented on the increased time gained with family members as a result of doing dialysis at home rather than in-

centre, and one mentioned that doing PD rather than IHD resulted in financial savings, as they no longer had to pay for parking at the dialysis centre or for fuel to commute to and from IHD. However, these patients also echoed the concerns that patients transitioning from CKD to PD had discussed (especially sleep disturbance and the impact of post-operative lifting restrictions on daily activities). Both patients expressed they were glad they had made the change to PD, even though the modality came with its own set of challenges.

Patients transitioning to HHD tended to have the most positive transition period in our study (Figure 8). Of these patients, 1 transitioned from IHD, 2 from PD, and 3 from CKD. Regardless of where they transitioned from, patients frequently expressed an appreciation for the flexibility in their dialysis schedules, the liberation in dietary and fluid restrictions, improvement in energy levels, improved mental health, reduced anxiety from their disease, increased optimism, improved relationships with family and friends, reduction in uremic or dialysis-related symptoms, and increased ability to work and participate in other life activities. While two patients (one from IHD and one from CKD) expressed a desire for a machine that allowed them to travel, one patient transitioning from PD (a modality that typically allows patients greater ease of travel) stated that they felt more able to travel on HHD due to improved overall health and not having to transport PD supplies while traveling. The only negative aspects of the HHD transition period noted were worsening sleep quality (if performing nocturnal HHD) and an increased workload in self-managing their disease. Similar to patients transitioning to nocturnal PD, patients often reported that the disruption in sleep was temporary and improved throughout the transition period. Patients uniformly expressed that while HHD was indeed more work, the benefits of HHD far outweighed any negative impact this had on their quality of life.

Discussion

Numerous studies have compared health-related quality of life between patients on IHD and those on PD or HHD.²⁻⁴ These studies tend to be cross-sectional in nature (examining HRQoL in a cohort of prevalent dialysis patients) or compare HRQoL at the time of dialysis initiation to HRQoL after 6-12 months. While these studies allow us to assess the HRQoL of patients well-established on their dialysis modality, they fail to capture the changes in HRQoL that may rapidly occur as patients transition to a new modality. Transition periods have been described as

physically and emotionally turbulent times for patients, and increased understanding of the positive and negative drivers of change during transition periods is necessary to inform the development of interventions to assist patients and their families.⁵

In this pilot project, we tested the methodology of combining kidney-disease specific HRQoL questionnaires (KDQOL instruments) with semi-structured patient interviews in order to gain better insight into the impact modality transitions have on HRQoL. In this small patient cohort, we saw that the first three months of dialysis were associated with improvements in HRQoL as measured by the KDQOL tools. This pilot project was not powered to detect statistically significant changes; as such, further studies are needed to examine whether these changes were statistically significant.

Whether or not the changes observed were clinically significant is difficult to ascertain. The “minimal clinically important difference” (MCID) is defined as the smallest change in a patient-reported outcome that patients feel are clinically important and which should prompt changes in patient management.¹³ Unfortunately, the MCID values for the kidney disease-specific domains of the KDQOL tools have not been well elucidated, and this is an area which deserves further study. The generic components of the KDQOL-36 (PCS and MCS scores) have been studied in more depth as part of the larger Short Form-36; a 2016 study stated that in patients with conservatively managed Stage 5 CKD, the MCID is 5.7 for the PCS and 9.6 for the MCS.¹⁴ These values are much larger than previous studies, which have stated that changes of 3-5 points in either domain are clinically significant; however, such studies were not conducted specifically in patients with kidney disease.¹⁵ Using MCID values of 5.7 and 9.6 for the PCS and MCS, respectively, we see that while clinically significant changes occurred in the PCS for IHD and HHD patients, but no clinically significant changes in the MCS occurred. If an MCID value of 4.0 (the median of the 3-5 range suggested to be clinically important by other studies) is used, we see clinically important changes in the PCS for all 3 groups and in the MCS for patients transitioning to PD and HHD. These findings demonstrate that the value chosen for the MCID of each domain can greatly impact the interpretation of HRQoL research. Further studies are required to better understand the MCID values for the KDQOL-36, KDQOL-SF, and other tools commonly used to assess HRQoL in CKD/ESRD patients.

Of the 44 patients eligible for participation in our study, only 30 (68%) chose to participate; to better understand how patients who consented for participation differed from those who did not, demographics of the two groups were compared (Table 5). Overall, the two cohorts appear to be similar in most respects, with the notable exception of dialysis vintage. Those who did not consent for the study had a lower dialysis vintage (mean 2.8 months, range 0-13 months) than those who did consent for the study (mean 13.0 months, range 0-86 months). This may indicate that patients who have been exposed to dialysis for a longer period of time are more cognizant of the negative impact dialysis may have on HRQoL and are more willing to participate in a study attempting to improve HRQoL. Those who did not consent also seemed to have slightly more comorbidities, particularly diabetes and coronary artery disease; it may be that increased burden of comorbid disease results in patients being less eager to participate in tasks which may be seen as onerous (such as completing surveys and participating in semi-structured interviews).

Comparing our Interview Findings to Other Qualitative Studies of HRQoL in ESRD Patients

Few studies have used qualitative methodology to study HRQoL in ESRD patients, and to our knowledge, no studies have specifically examined changes in HRQoL that occur during the initial months of a modality transition. However, qualitative studies of prevalent dialysis patients do show themes common to those discussed by patients in our study. A 2016 review by Reid et al synthesized the findings of qualitative studies that had examined the experiences of prevalent IHD patients.¹⁶ Many of the descriptive themes in the review mirror sentiments expressed by our patients. Patients commented on a “changing identity” when commencing hemodialysis; feelings of vulnerability, dependency upon both the dialysis treatment and caregivers, and a loss of social relationships were major contributors to this theme. “Effect on family roles and relationships” was also a common theme amongst IHD patients who expressed frustration at needing to relocate, at the reduced time and energy available because of dialysis, and feelings of being a burden on their family members. Patients also commented on “changing social world” as a result of dietary and fluid restrictions, time spent on dialysis, and post-dialysis fatigue which limited their ability to engage in previously enjoyed social activities. Despite the majority of patients in this review being prevalent dialysis patients, many of the negative impactors on quality of life discussed in this review were already noted by our IHD patients

within the first 3 months of therapy, suggesting that the negative impact of IHD on HRQoL begins almost immediately.

In 2017, Tannor et al conducted focus groups with 36 prevalent IHD and PD patients in Cape Town, South Africa.¹⁷ Similar to our findings, insomnia was a common theme amongst PD patients in the South African cohort. These patients also frequently noted treatment-related limitations, such as dietary and fluid restrictions, difficulty maintaining employment as a result of dialysis, impaired social interactions, and difficulty traveling. Again, in keeping with concerns raised by our home modality patients, South African PD patients expressed frustration with difficulties finding employment or with reduced productivity at work due to fatigue and other limitations.

PD patients in the Tannor study also found that limited interactions with other patients was a downside to home modalities, a sentiment echoed by one of our HHD patients who suggested that a peer-support group would be beneficial to home modality patients. In contrast, IHD patients in the Tannor study frequently discussed enjoying support from fellow patients in the dialysis unit; this was not discussed by any of our IHD patients. The fact that our patients did not comment on peer support networks may reflect that our dialysis patients were new to their modality, while the patients in the Tannor study were prevalent (mean of 2.2 years for the PD patients and 6.0 years for the IHD patients). It may be that the benefits of peer support (or the detrimental effects of lack of peer support) become more important with longer durations on renal replacement therapy.

Many of the potential interventions listed by Tannor et al parallel those generated by discussions with our cohort: counselling home modality patients that the timing of dialysis can be altered to facilitate social outings and events, vocational training and support for patients on home modalities who wish to work in reduced capacities, and support groups for dialysis patients to engage with and encourage one another.

A 2015 review of HHD patient perspectives revealed a number of themes raised by our HHD patients: ‘increased demands placed on caregivers’, ‘re-establishing a healthy self-identity’,

‘gaining control and freedom’, ‘freedom and normality’, ‘experiencing improved health’, and ‘ownership of decisions’.¹⁸ This review also found caregivers frequently worry about their partners, a finding that is in keeping with our HHD and PD patients who noted family members often had anxiety about allowing them to be independent. Walker et al showed HHD patients often express feelings of social isolation; again, this was not expressed by our patients newly transitioning to HHD. Similar to our findings, HHD patients have concerns regarding the financial burden and stress related to utility costs and loss of income during training periods.

Potential Impact of Study Findings

Our findings highlight several key items that should be addressed during periods of transition. For example, patients transitioning to any dialysis modality (but especially to IHD) should be informed about the increased risk for depression and anxiety amongst dialysis patients and that these issues often worsens during times of transition. Opening the conversation regarding mental health disease may help patients feel less alone and help empower them to discuss symptoms of mental health disease with their health care providers, leading to increased recognition and earlier treatment. A number of other educational opportunities for patients transitioning to home modalities include sleep hygiene and how to combat sleep disturbances as patients transition to nocturnal modalities, how to safely modify the timing and length of dialysis prescriptions in order to accommodate social events and other activities, and realistic goal-setting on returning to work .

Our findings have important implications for follow-up and management of patients who have recently transitioned. Increased screening and treatment of mental health disease is required for all patients undergoing modality transition; this is emphasized in an EDTA position paper.¹⁹ Clinicians tend to focus on the physical complications and neglect the emotional complications of modality transition when in fact, both aspects of care should have equal weight. Increasing access to social workers and other mental health care professionals is an initial step in rectifying this issue. Establishing peer support groups or mentorship programs for new dialysis patients and family members as was suggested by one patient could reduce emotional duress. Systematic screening for new dialysis-related symptoms (for example, post-dialysis leg pain and sleep disturbances) is needed, as these are under-recognized and undertreated. Consideration to refer

to vocational training programs may enable patients to continue working. Home hemodialysis programs should also consider advocating for patient compensation during dialysis training periods and/or for subsidized utility costs, as financial struggles due to home hemodialysis are a significant patient concern.

Limitations

While our study yields important findings regarding changes in HRQoL during transition periods, there are some important limitations. This study was purposed as a pilot project to test the efficacy of combining the KDQOL questionnaires with our semi-structured interviews. As a pilot project, our recruitment period was short, yielding a small number of patients. Larger patient numbers would allow for hypothesis testing to determine whether statistically significant changes in KDQOL scores occurred and would ensure thematic consistency across groups within the qualitative arm of our study. The lack of well-defined MCID values for the KDQOL questionnaires is also an important limitation, as it makes it impossible to comment upon the potential clinical significance of our findings.

Certain modality transitions were absent (HHD to IHD) or under-represented (CKD to IHD had only 1 patient) in our study. It is clear that a patient's experience during a modality transition is heavily influenced by their baseline; it is difficult, for example, to compare the experience of a patient initiating IHD as their initial dialysis modality to that of a patient transitioning to IHD after several years on PD. Increased representation for all transition types would help to shed more light on shared experiences.

Finally, the fact that non-English speakers were excluded from our study is an important limitation, as it stands to reason that lacking the ability to fully communicate with care providers may have a profoundly negative impact on quality of life during the transition period.

Conclusions

During the first three months of a new dialysis modality, health-related quality of life appears to improve across all domains measured by the KDQOL-36 (and selected domains of the KDQOL-SF) regardless of dialysis modality. Determining the clinical significance of these changes is

difficult, as this assessment is dependent upon the value chosen for the minimal clinically important difference; however, even conservative estimates of the MCID show clinically significant improvements in the physical component summary scores of IHD and HHD patients. Through the use of semi-structured interviews, we identified a number of drivers of both positive and negative changes in HRQoL, including a number of factors which may be amenable to intervention. Further studies are required to develop and examine the efficacy of interventions purposed to maintain or improve HRQoL during modality transitions. While our pilot study begins to lay the groundwork towards an increased understanding of transition periods, larger studies using both quantitative and qualitative methodology are required to better understand the shared experiences of patients undergoing modality transitions.

CHAPTER III REFERENCES:

1. Unruh ML, Weisbord SD, Kimmel PL. Health-Related Quality of Life in Nephrology Research and Clinical Practice. *Semin Dial* 2005;18(2):82-90.
2. Wu AW, Fink NE, Marsh-Manzi JVR, et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *JASN* 2004;15(3):743-53.
3. Kutner NG, Zhang R, Barnhart H, Collins AJ. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 2005;20:2159-67.
4. Tennankore KK, Chan CT, Curran SP. Intensive home hemodialysis: benefits and barriers. *Nat. Rev. Nephrol* 2012 8:515-22.
5. Hutchinson TA. Transitions in the lives of patients with end stage renal disease: a cause of suffering and an opportunity for healing. *Palliat Med* 2005;19:270-7.
6. Gregroy DM, Way CY, Hutchinson TA, et al. Patients' perceptions of their experience with ESRD and haemodialysis treatment. *Qual Health Res* 1998;8:764-83.
7. Watnick S, Kirwin P, Mahnensmith R, et al. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003;41:105-10.
8. Pulliam J, Li N-C, Maddux F, et al. First-year outcomes of incident peritoneal dialysis patients in the United States. *Am J Kidney Dis* 2014;64(5):761-9.
9. Lukowsky LR, Kheifets L, Arah OA, et al. Patterns and predictors of early mortality in incident hemodialysis patients: new insights. *Am J Nephrol* 2012;35(6):548-58.
10. RAND Corporation. 'Surveys'. *Kidney Disease Quality of Life (KDQOL) Instrument*. Retrieved April 16, 2018, from https://www.rand.org/health/surveys_tools/kdqol.html.
11. Schatell D, Witten B. Measuring Dialysis Patients' Health-Related Quality of Life with the KDQOL-36™. *KDQOL COMPLETE*. 2012. Retrieved April 16, 2018, from <https://kdqol-complete.org/pdfs/kdqol-36.pdf>.
12. Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015; 30(10): 1605-14.
13. Jaeschke R, Singer J, Guyatt GH. Measurement of health status. Ascertaining the minimally clinically important difference. *Control Clin Trials* 1989;10(4):407-15.
14. Erez G, Selman L, Murtagh FEM. Measuring health-related quality of life in patients with conservatively managed stage 5 chronic kidney disease: limitations of the Medical Outcomes

Study Short Form 36: SF-36. *Qual Life Res* 2016;25:2799-809.

15. Samsa G, Edelman D, Rothman ML, et al. Determining clinically important differences in health status measures: a general approach with illustration to the Health Utilities Index Mark II. *Pharmacoeconomics* 1999;15: 141-155.

16. Reid C, Seymour J, Jones C. A thematic synthesis of the experiences of adults living with hemodialysis. *Clin J Am Soc Nephrol* 2016;11(7):1206-18.

17. Tannor EK, Archer E, Kapembwa K, et al. Quality of life in patients on chronic dialysis in South Africa: a comparative mixed methods study. *BMC Nephrol* 2017;18:4.

18. Walker RC, Hanson CS, Palmer SC, et al. Patient and caregiver perspectives on home hemodialysis: a systematic review. *Am J Kidney Dis* 2015;65(3):451-63.

19. Covic A, Bammens B, Lobbedez T, et al. Educating end-stage renal disease patients on dialysis modality selection: a clinical advice from the European Renal Best Practice (ERBP) Advisory Board. *NDT Plus* 2010; 3: 225-233.

	Entire Cohort (n=30)	IHD (n=4)	PD (n=13)	HHD (n=13)
Age in Years, mean (SD)	54.0 (18.1)	58.5 (17.4)	54.7 (16.8)	47.6 (19.0)
Male, n (%)	22 (73.3%)	3 (75.0%)	11 (84.6%)	8 (61.5%)
Dialysis Vintage in Months, mean (range)	12.2 (0-86)	27.3 (0-86)	3.1 (0-14)	18.7 (0-80)
Cause of ESRD, n (%):				
<i>Diabetic Nephropathy</i>	5 (16.7%)	-	3 (23.1%)	2 (15.4%)
<i>Hypertensive Nephropathy</i>	3 (10.0%)	-	2 (15.4%)	1 (7.7%)
<i>Polycystic Kidney Disease</i>	5 (16.7%)	2 (50.0%)	1 (7.7%)	2 (15.4%)
<i>Glomerulonephritis</i>	12 (40.0%)	1 (25.0%)	6 (46.2%)	5 (38.5%)
<i>Obstructive Nephropathy</i>	1 (3.3%)	-	-	1 (7.7%)
<i>Multiple Myeloma</i>	1 (3.3%)	1 (25.0%)	-	-
<i>Amyloidosis</i>	1 (3.3%)	-	-	1 (7.7%)
<i>Nephronophthisis</i>	1 (3.3%)	-	-	1 (7.7%)
<i>Lithium Toxicity</i>	1 (3.3%)	-	1 (7.7%)	-
Comorbidities, n (%):				
<i>Hypertension</i>	30 (100%)	4 (100%)	13 (100%)	13 (100%)
<i>Diabetes</i>	9 (30.0%)	1 (25.0%)	4 (30.8%)	4 (30.8%)
<i>Coronary Artery Disease</i>	4 (13.3%)	1 (25.0%)	2 (15.4%)	1 (7.7%)
<i>Congestive Heart Failure</i>	3 (10.0%)	-	1 (7.7%)	2 (15.4%)
<i>Malignancy</i>	3 (10.0%)	1 (25.0%)	1 (7.7%)	1 (7.7%)

Table 1: Demographic information for the 30 patients who consented to study participation. Demographics are shown for the entire cohort as well as for each of the subgroups. Additional comorbidities were screened for (peripheral vascular disease, cerebrovascular disease, chronic obstructive pulmonary disease) but were not present in any patients in this cohort.

Table 2: Exemplar quotes from patients transitioning to in-centre hemodialysis

<i>Theme</i>	<i>Quote</i>
Physical Health and Well-Being	<p>“When I’m on hemodialysis, I’m <i>always</i> tired. If I wasn’t on dialysis, I wouldn’t be tired...I just don’t have the energy anymore.”</p> <p>“Before I started hemo, I couldn’t get out of a wheelchair, I couldn’t get out of a chair. Somebody had to help me into bed and out of bed and get my clothes on and have a shower...but I’m getting stronger. Basically, I’m almost back to what I was before [on PD], but I am a lot weaker still. But I think there are a lot of other reasons for that.”</p> <p>“I always used to be stronger [on PD]. I could go get the groceries, go to the pharmacy to get our pills, go do things we had to do....I was always quite independent...I still do some of it, but I need help.”</p> <p>“I had more energy back then [on PD]. And I was peeing back then. As soon as they pulled me off and put me back on hemo, it sort of stopped.”</p>
Mental Health, Well-Being, and Self-Perception	<p>“I know that there is a part of me that is never going to get better....I pretty much accept things as they are. It’s life.”</p> <p>“Lower energy. Getting depressed. You just don’t even know what you can do. I was hoping I would go from hemo to PD to transplant. But now that PD has failed, I feel like I’m starting all over again”.</p> <p>“Somedays I get home and I’m in a good mood, but other days I’m just mopey and feeling sorry for myself. Basically, I’m just feeling fed up. I just want it done. Get these tubes out of me.”</p>
Interactions with/Impact on Family and Friends	<p>“As far as support, everyone has just been great. You know, my daughter goes to work a half hour early in the morning and stays a half hour later at night so that she can take an hour at lunch to take me to dialysis. She’s just been such a huge help.”</p> <p>“They’re afraid to let me do anything. I have to tell them, ‘You know, I can do some things. I <i>need</i> to do something’....nobody has asked the doctor if I should just sit on my chair all the time. And you know, I don’t want to just sit on my chair.”</p> <p>“We used to go out for supper and then go to [a friend’s] place and play games and stuff, and come home at 1 o’clock at night</p>

	<p>and think nothing of it. ...but I started to find my legs were bothering me....it was just too much. So I finally said we couldn't come anymore.”</p> <p>“My friends, I don't really see them anymore. They just kind of drifted out of the picture.”</p> <p>“[My fiancée] does all the cooking. When she cooks, my levels are always fine, because she always watches. I just do what's easy and I don't always think about watching my potassium....she has to put up with a lot, taking care of me and being responsible for the cooking...she'd like it if we could travel together, and so would I. But it's just not in the cards right now I guess.”</p>
Symptoms of Kidney Disease/Dialysis	<p>“I find that most days after dialysis, I have a lot of soreness in my legs....they call it restless legs, but mine are sore. It's not that they have to move. It's that they ache.”</p> <p>“My legs get achey after dialysis, usually from my knees down...it's not cramps. It's different from cramping. It's aches.”</p>
Quality of Sleep	<p>“I was getting up a lot in the middle of the night to go to the bathroom before dialysis....not so much after I started. I was peeing less.”</p> <p>“On PD, I hooked up and went to bed, and then I got up in the morning. Very seldom was I awake all night. But with this [IHD], I can be awake a lot.”</p>
Ability to Maintain Employment	<p>“I had more energy at work [when on IHD] because I was sleeping better.”</p>
Participation in Hobbies, Activities & Travel	<p>“Now when you want to do something, you have to say ‘Well, let's wait and see where I am in the morning’. Whereas with the peritoneal dialysis, I could just do. Sometimes I'd be tired, but I'd be able to do it.”</p> <p>“And being trapped in Calgary. Because I can't go anywhere. Well I can, for maybe two days, but I have to be back right away. And I have to go somewhere where there's a machine”.</p>

<p>Overall Changes to HRQoL</p>	<p>“I’d like to drink because I’m thirsty all of the time. I drink a couple of cups, 2 or 3 cups a day, but I’d like if it was more.”</p> <p>“The big thing is the time involved in getting here, getting the four hours of treatment, and going home.”</p> <p>“I got in an accident once... a car came up behind me and slid on the ice right into me... it’s one of those things, I wouldn’t have been on the road that day if it wasn’t for needing to get to dialysis.”</p> <p>“It [transitioning from PD to IHD] is just what happened. And I wish it hadn’t. I’d love to still be on peritoneal dialysis. But I have a feeling they’re not going to put me back. So, I guess I will be doing this for the rest of my life, and I don’t know how long that’s going to be.”</p> <p>“It’s not the best, but I guess it’s all I’ve got right now until hopefully a transplant comes along. Six to ten years is a long time to wait though. But I guess I’m stuck with this for now.”</p>
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Table 3: Exemplar quotes from patients transitioning to peritoneal dialysis

<i>Theme</i>	<i>Quote</i>
Physical Health and Well-Being	<p>“It was [the doctor’s] opinion that I should not lift any more than 5 or 10 pounds maximum. Prior to my PD surgery, I had a hernia surgery done, so I was told that if I lifted something heavy again, the hernia could come back and it would cause more problems. Therefore, I would not be able to do my PD anymore at night and I would have to go back on hemodialysis”.</p> <p>“I have a lot more energy and a lot more drive, I think, since I switched from the hemo to the peritoneal.”</p> <p>“I can do many things that I could not do before....I used to not be able to go up the stairs without shortness of breath....now I walk to [the grocery store]. It is about 3 kilometres from my house. We walk there now....prior to dialysis, when I was pulling up my blanket in my bed, I would already get shortness of breath.”</p> <p>“I feel like my energy is lower than it was before. When I was on hospital dialysis, I felt like I had a little more energy.”</p> <p>“I find myself more sluggish with all the fluid in with the PD. I’m back to work now and I just feel sluggish.”</p> <p>“Mobility, I guess, would be the biggest negative about the PD...mobility restrictions from a lot of the fluid in there.”</p>
Mental Health, Well-Being, and Self-Perception	<p>“I used to worry about the future and what would happen to me. I thought I should go back to the Philippines because I did not have much life left. But since dialysis, I feel better.”</p> <p>“Sometimes I get irritated by things. It’s a big change in lifestyle and I guess that’s what’s getting me down more than anything else. But it’s getting better. The PD is helping.”</p> <p>“I’m a fairly adaptable person. The catheter and dealing with the fluids, none of that bothers me. I mean, it’s just learning another chore. It’s like brushing my teeth.”</p> <p>“I went into hemodialysis with a fairly positive attitude and I think that continues now. Kidney transplant would probably be a more ideal situation, but yeah, you adapt to the situation.”</p>

<p>Interactions with/Impact On Family and Friends</p>	<p>“It’s nice that I get to be at home with my family more. Before [on IHD] I was missing a lot of time with them because of my treatments.”</p> <p>“I don’t visit with friends as much because I go to bed earlier.”</p> <p>“Life has slowed down a bit since I got on PD....like quite a bit. Interactions down 90%...even if you have friends over, well friends go home sooner than they would have before.”</p> <p>“My wife, and sometimes even my children, they don’t want me to participate in things that they think are not proper for me...for example, sometimes washing dishes, my wife tells me that if I get myself wet, especially where the tube is coming out of my belly...it might start an infection and I might get in trouble. Therefore she tells me not to touch anything.”</p>
<p>Symptoms of Kidney Disease/Dialysis</p>	<p>“The itchy skin is gone....it was driving me crazy [before PD].”</p> <p>“It [PD] makes me itchy always. I feel like I lay down at night, then I start scratching and scratching and I put lots of lotion on already, but it didn’t work.”</p> <p>“I get heartburn like you wouldn’t believe, with all the fluid in there....I’ll have chewed up half a dozen Tums just to get to the end of the day. Twenty-four hours a day I got heartburn. Nighttime is usually the worst.”</p>
<p>Quality of Sleep</p>	<p>“At the beginning...I turned and tossed in the bed, and the tube would get twisted and cut off the flow and then the machine would start making all kinds of noises, so that was a bit of a challenge. But slowly I’m getting used to it.”</p> <p>“I still haven’t adjusted to the night, because when the cyclor changes and starts to drain like a vacuum, I just sort of wake up...but I am adjusting and it’s getting a little better over time.”</p> <p>“I seem to be urinating quite a bit more...the urine is just pouring through there now. I’m up at least four times per night... and the heartburn doesn’t help either”</p> <p>“I get way more sleep [on PD]. I’m at a stage in my life now...I need as much rest as I can get. So, if anything, it maybe helped slow me down quite a bit, being on PD.”</p>

<p>Ability to Maintain Employment</p>	<p>“I’m back to work now, and as far as working goes, with my specific job, I don’t have a problem with it....I can go to work and I can provide for my family. I can do that....if I had to do hemo well...I couldn’t do what I do for a living.”</p> <p>“I’m not working...with the limitations on lifting and all kinds of stuff, and because of the type of work that I used to do...I’m not an office worker, so it’s a bit difficult for me to do something that I’ve never done before. I would have to change to something completely different and most of the time, I don’t have the mood or energy for that.”</p> <p>“I was a farmer, so I’m quite physical, but I can’t really do that kind of work anymore like I used to. If I had had a difference source of employment, I probably could have been just fine. If I was somebody that was happy sitting the whole time, I probably could function way better...if you need to be physically active in your job, it’s still not ideal.”</p>
<p>Participation in Hobbies, Activities & Travel</p>	<p>“I used to brush my teeth and then be gasping for breath. Now that doesn’t happen. Now I play ping pong on Sunday nights. And billiards downstairs. I want to do everything.”</p> <p>“I play more games now. I play a lot of cards again. I play Bingo. The only problem is I cannot go to places overnight because of dialysis in the evening. Sometimes we are invited to stay at friends’ houses overnight, for a late dinner, but I always have to say ‘I have my dialysis later’.”</p> <p>“We are going out to do things more often. It’s more of a schedule where you can fit a variety of things in during the day, like visiting friends, going out for lunch, that kind of thing. So it tends to make the day a little more enjoyable for me.”</p> <p>“It ruins my social life, because I have to wake up at 7 o’clock [to do a manual exchange] and then do it again at 11 o’clock and 3 in o’clock in the afternoon and then 7 o’clock at night, so I don’t go nowhere.”</p>
<p>Overall Changes to HRQoL</p>	<p>“For the most part my quality of life has been better since I’ve been on PD....I’m a long way from being healthy, but compared to what I was feeling like before, there’s no comparison”.</p>

	<p>“With not working and not bringing any income to the family...not going to the hospital saves us money on things like parking and gas. So that’s a positive change for me.”</p> <p>“I get up in the morning and I’m done with dialysis...I don’t have to think about it or worry about it. I don’t have to spend four or five hours going on the road to the hospital and getting my treatment then coming back. So I think there are more positives with peritoneal dialysis compared to hemodialysis”.</p> <p>“It’s allowed me to keep going, so I’ve made it work. It’s working. I haven’t had to talk to the PD unit in almost a month.”</p>
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Table 4: Exemplar quotes from patients transitioning to home hemodialysis

<i>Theme</i>	<i>Quote</i>
Physical Health and Well-Being	<p data-bbox="581 310 1401 451">“I have a lot more energy and I am a lot less tired. I generally just don’t have the kind of fatigue that I would get after an in-centre dialysis treatment, and I don’t feel as fatigued on the few days that I do take off.”</p> <p data-bbox="581 493 1401 709">“I am just much more physically active. Before [on IHD] I didn’t necessarily have the energy to want to work-out or do those types of things. Physically, I almost feel I need to do that now, which is different. Like, I wake up and I really want to go for a run, or I feel like I really need to burn off some energy, which is something that I haven’t felt in a long time.”</p> <p data-bbox="581 751 1344 787">“I feel like normal. I feel like there’s nothing even wrong.”</p> <p data-bbox="581 829 1377 892">“I don’t feel fatigued now. I get <i>tired</i>, which is a really nice feeling. It’s different and it’s better than being fatigued was.”</p> <p data-bbox="581 934 1377 1039">“They were able to take me off pretty much all of my blood pressure medications. So I’m only on one pill now, and it’s a lower dose than what I was originally on.”</p> <p data-bbox="581 1081 1401 1144">“Anything physical, including sex or anything like that, it’s just not there.”</p>
Mental Health, Well-Being, and Self-Perception	<p data-bbox="581 1188 1401 1404">“I feel I have a lot more of a normal life. I wake up in the morning, I go to work, I come home, I eat dinner, I hang out with my family....when I was on in-centre dialysis, the days I was dialyzing I would rush home and not have dinner, go to the hospital, be there for 5 hours, and then come home. It really breaks up your day and makes you feel like you are home less.”</p> <p data-bbox="581 1446 1409 1551">“I’m less stressed because I’m less concerned about things like my diet and my fluid intake. And I was always concerned about my fluid intake because of my heart and my blood pressure.”</p> <p data-bbox="581 1593 1401 1698">“Now that I understand dialysis in full, and know that I have the support that I have, my anxiety has been reduced down to about 10% of what it was before.”</p> <p data-bbox="581 1740 1409 1845">“I think overall I am just more independent, more in-tune to how I am feeling. I am more aware of my health, and I am just better educated about dialysis and how it is helping me.”</p>

	<p>“I am just so impressed that I’m being treated as a person and not just another case number...empowering me to make my own decisions...I feel better than I ever did before.”</p> <p>“I feel like I am a little bit alive again, rather than just someone waiting for death to occur.”</p> <p>“I feel like I have a lot more hope. I feel hopeful that I can have some sort of quality of life.”</p>
<p>Interactions with Family and Friends</p>	<p>“Everyone is used to it now. It is just another thing that we do at home.”</p> <p>“I’m spending more time with them [family]. And...I think they’re more in-tune with what I am doing as well, because it’s more front and centre and visible to them. It’s not like I’m just heading off to the hospital three times a week...It’s probably, in a sense, brought us closer together as far as my disease is concerned, because it’s not something that I’m doing in isolation on my own.”</p> <p>“[My husband] has commented since we started home dialysis that he feels that there is just way more that he can do to help. He has taken the responsibility for stringing the machine at night and doing all of the machine maintenance...he enjoys doing that and he feels able to participate more and that he’s helping to give me a better quality of life and keep me happier and feeling better.”</p> <p>“There is some impact on my wife. She feels she has to be here in the house all the time in case something goes wrong...I’m trying to reassure her that she can [leave the house] and she doesn’t have to worry about me, because I’ll be fine.”</p> <p>“We’ve had more company in our home since I started home hemodialysis than we’ve had in the previous two years [on PD]. I’ve always been open to people dropping in, but the difference is that now people <i>want</i> to drop in...I have many friends that have told me ‘You sound so much better. We didn’t want to come before because it sounded like it was going to be too much work for you.’</p>
<p>Symptoms of Kidney Disease/Dialysis</p>	<p>“I had [prior to dialysis] lots of cramping in the middle of the night...[now] I have very, very little cramping. And I mean very little.”</p>

	<p>“I noticed that I’m not as itchy on home hemo [compared to PD]...I haven’t had bouts of nausea like I used to before.”</p> <p>“I don’t get the cramps. I don’t get the itchiness. All of the nausea and throwing up and all of that stuff is gone.”</p> <p>“I do feel much better now, on home hemo, even though I have headaches that last for 5 to 6 hours after I have finished dialysis. I would choose that over the total sleeplessness, and the drain pain, and the brain fog that I had on peritoneal dialysis.”</p>
<p>Quality of Sleep</p>	<p>“Overall, I’d say it hasn’t impacted my sleep...some nights, for whatever reason, my machine alarms a couple of times, so obviously those nights I get a little less sleep. But that’s not really that often, and overall my sleeps haven’t been impacted at night.”</p> <p>“I think it’s had an impact on our sleeping patterns, both my husband and I, because we’ve slept in the same bed for 49 years now...I would say that in his sleep quality, it has impacted us negatively. But in terms of my quality of sleep, I do sleep better on home hemo that I did on peritoneal because I don’t have the pain during the night...I am sleeping more and I am sleeping better.”</p>
<p>Ability to Maintain Employment</p>	<p>“Because I just feel better at work, I think that my productivity while at work has improved.”</p> <p>“I wasn’t working while I was on PD. I just went back to work after the home hemo started...For the most part, I work half days.”</p> <p>“There are times now when I think ‘Yeah, it wouldn’t be bad to be doing a part-time position’. But I don’t think that I could work a full-time position just based on my energy levels. They’re much better than they were on PD, but still not good enough to work full time, at least right now.”</p>
<p>Participation in Hobbies, Activities & Travel</p>	<p>“Say if we wanted to go somewhere and stay somewhere else overnight, we have that possibility now. Whereas before [on PD] we had that possibility but only if we packed all of our stuff with us, which wasn’t always ideal.”</p> <p>“We have talked about going down to the States to see our son...I am to the point where I can consider that trip. Whereas,</p>

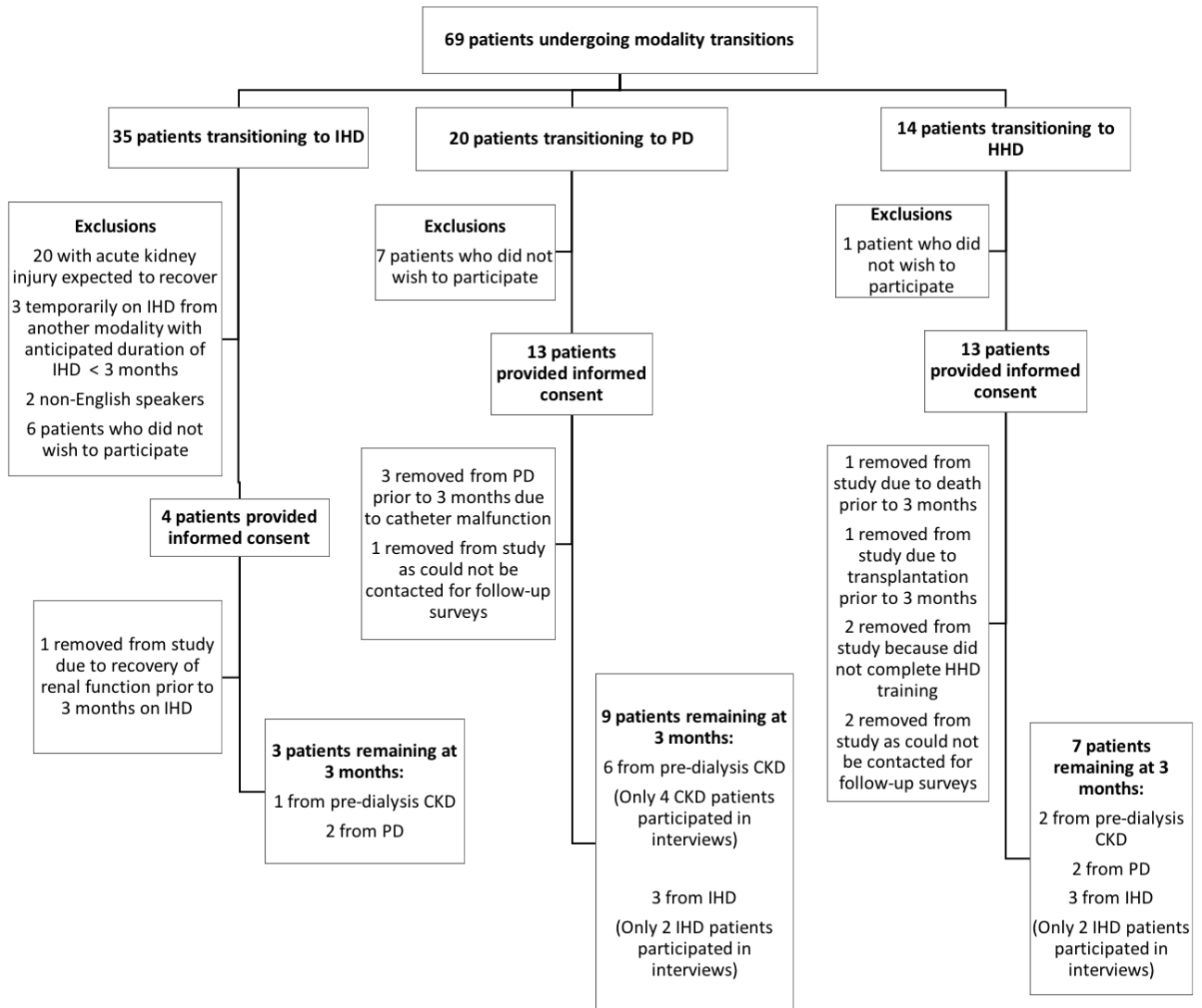
	<p>the last few years I could do it with my [PD] machine, but I didn't really enjoy it.”</p> <p>“I never did give up my license [on PD], but I just felt it wasn't safe to drive before because I was tired and my concentration skills weren't there. Now I feel safe enough to get in the car and deliver my blood samples to the hospital. I can do that now on my own, whereas before there was no way.”</p> <p>“I mean, basically these machines place you on house arrest. I can go away for a couple of days, but I have to make sure I get back in time to get onto the machine on time, otherwise I'm going to be in big trouble.”</p>
<p>Overall Changes to HRQoL</p>	<p>“I think there's flexibility and it's one of the best things about home hemo. You can pretty much be a master of your own time, you know, and do it however you like.”</p> <p>“A big positive difference is that when I am dialyzing at home, I am much less concerned about my diet...when I know I'm dialyzing or at least I have the option to, if I really wanted to have an extra couple of drinks today, or eat something that was a bit higher in potassium, I have the option to go home and dialyze. It just reduces my stress level...I think that is another really big positive on the quality of life side.”</p> <p>“On a positive note, I'm eating more...I do have to watch my potassium intake, but the potassium is being 100% controlled with dialysis.”</p> <p>“From the down-side perspective, I do think there's definitely some extra time that I need to spend with dialysis as far as setup and take-down....there's time that goes into preparing the dialysis materials and I've got to make sure that I am ordering the supplies on time. Then when they are getting delivered I have to take time to stock the shelves and put them away...from a quality of life perspective, does it make my life worse? No. Is it a hassle still? Yes. But definitely less so than in-centre dialysis.”</p> <p>“It's considerably more work to be on home hemodialysis, but I think the results, in terms of my health and how I feel, are worth the extra work.”</p>

	<p>“[One month] my water bill went from \$110 per month to \$290... we don’t have the extra money to pay that water bill when it does that, so we have to go without something else that month.”</p> <p>“Why are we making people pay for being sick? And that’s basically what is happening. I’m sick, I’ve got kidney failure, and now I’ve gotta pay an extra \$200 per month, or whatever it may be, because I’m sick.”</p>
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	Consented for Study	Did Not Consent
n	30	14
Age in Years, mean (SD)	52.1 (17.7)	54.7 (16.4)
Male, n (%)	75.8%	78.6%
Dialysis Vintage in Months, mean (range)	13.0 (0-86)	2.8 (0-13)
Predominant Cause of ESRD	Glomerulonephritis (36.4%)	Glomerulonephritis (21.4%) Diabetic Nephropathy (21.4%) Hypertensive Nephropathy (21.4%)
Comorbidities (%):		
<i>Hypertension</i>	100	100
<i>Diabetes</i>	30.0	42.9
<i>Coronary Artery Disease</i>	13.3	21.4
<i>Congestive Heart Failure</i>	10.0	7.1
<i>Peripheral Vascular Disease</i>	0	7.1
<i>Cerebrovascular Disease</i>	0	0
<i>COPD</i>	3.3	7.1
<i>Malignancy</i>	10.0	14.3

Table 5: Demographic information for the 30 patients who consented to study participation and the 14 patients who did not consent for study participation.

Figure 1: Patient Recruitment and Retention



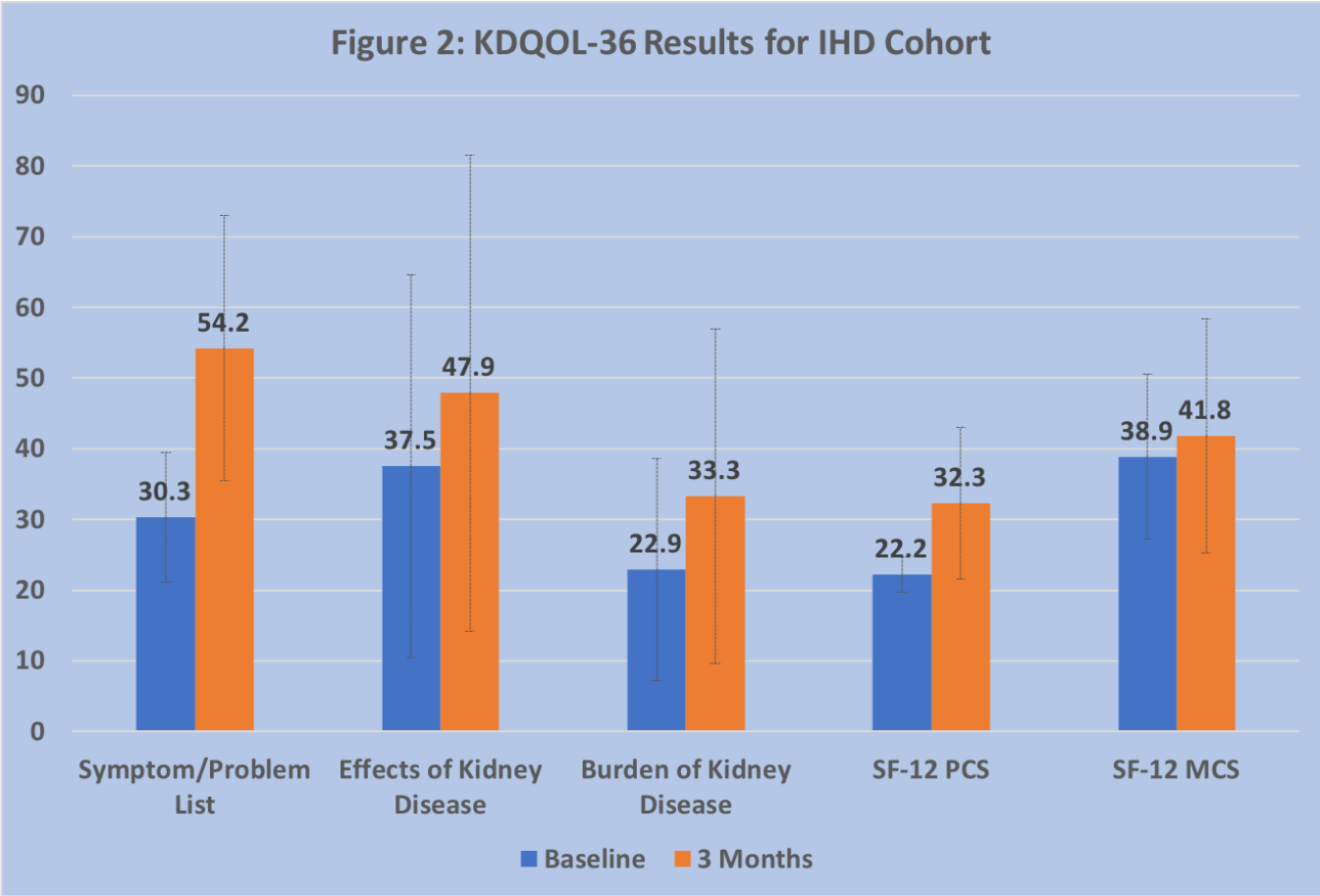


Figure 2: Results (n=3) for the 5 domains of the KDQOL-36. Bars represent mean scores at baseline and 3 months. Errors bars indicate one standard deviation above and below the mean.

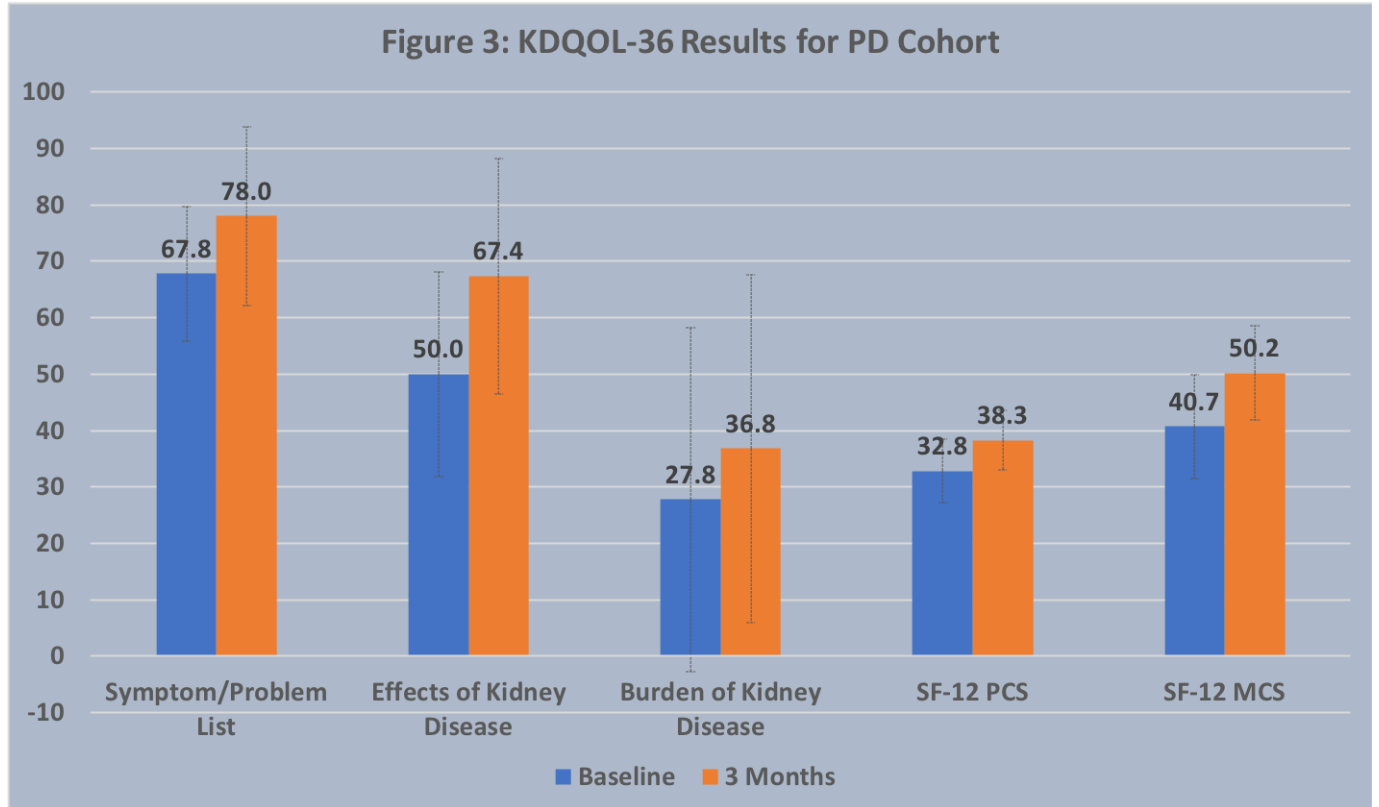


Figure 3: Results (n=9) for the 5 domains of the KDQOL-36. Bars represent mean scores at baseline and 3 months. Errors bars indicate one standard deviation above and below the mean.

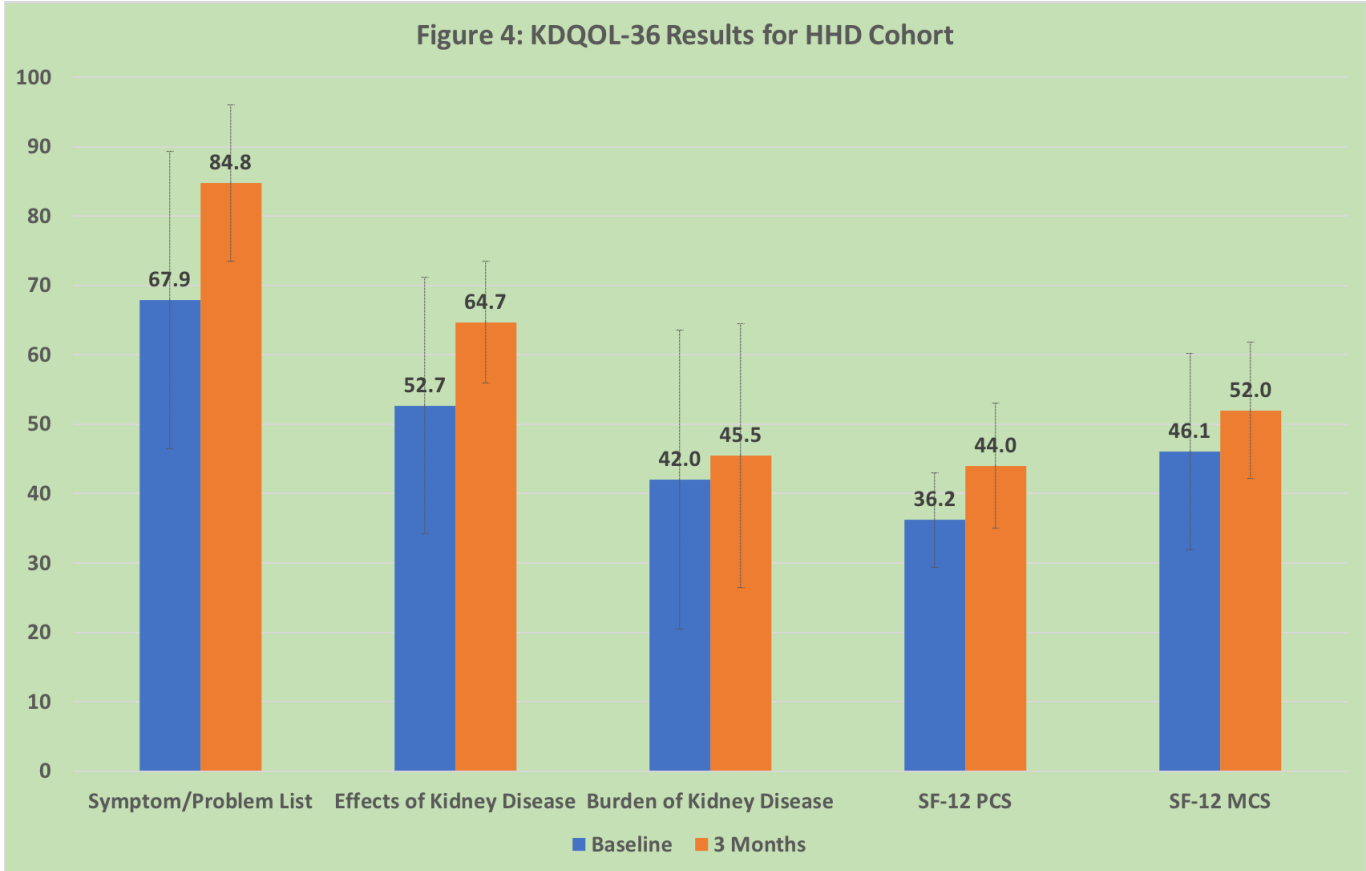


Figure 4: Results (n=7) for the 5 domains of the KDQOL-36. Bars represent mean scores at baseline and 3 months. Errors bars indicate one standard deviation above and below the mean.

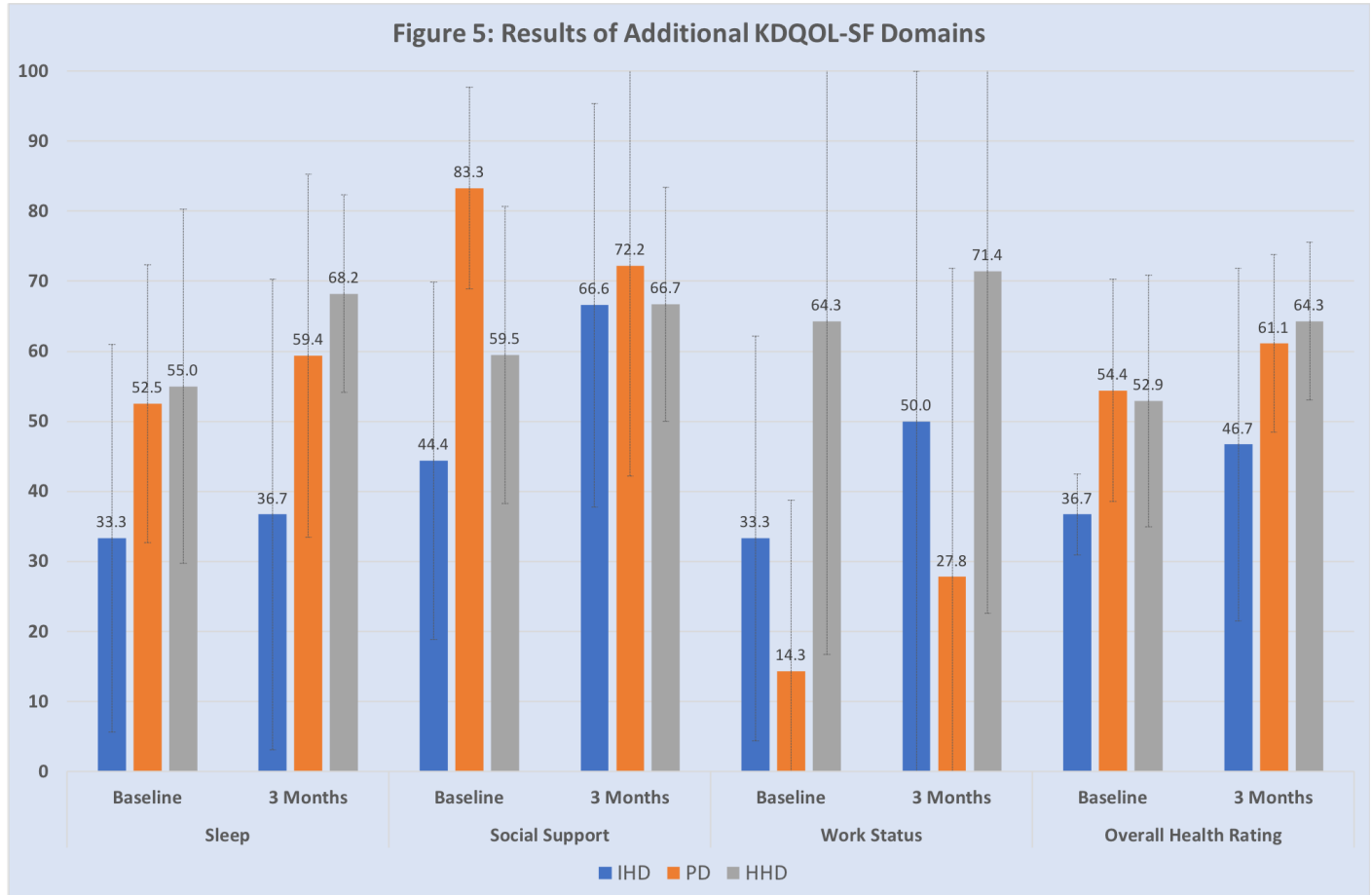


Figure 5: Results for the 4 additional domains of the KDQOL-SF. Bars represent mean scores at baseline and 3 months. Errors bars indicate one standard deviation above and below the mean.

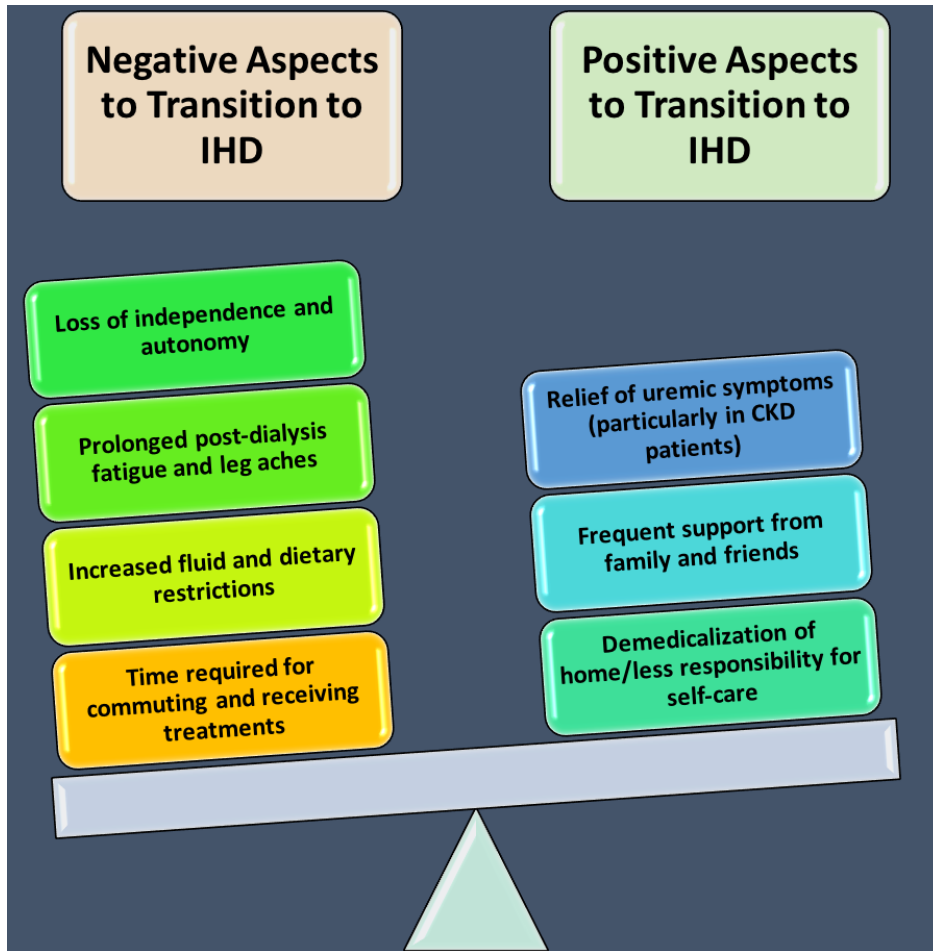


Figure 6: Positive and negative factors influencing changes in HRQoL in patients transitioning to in-centre hemodialysis (IHD).

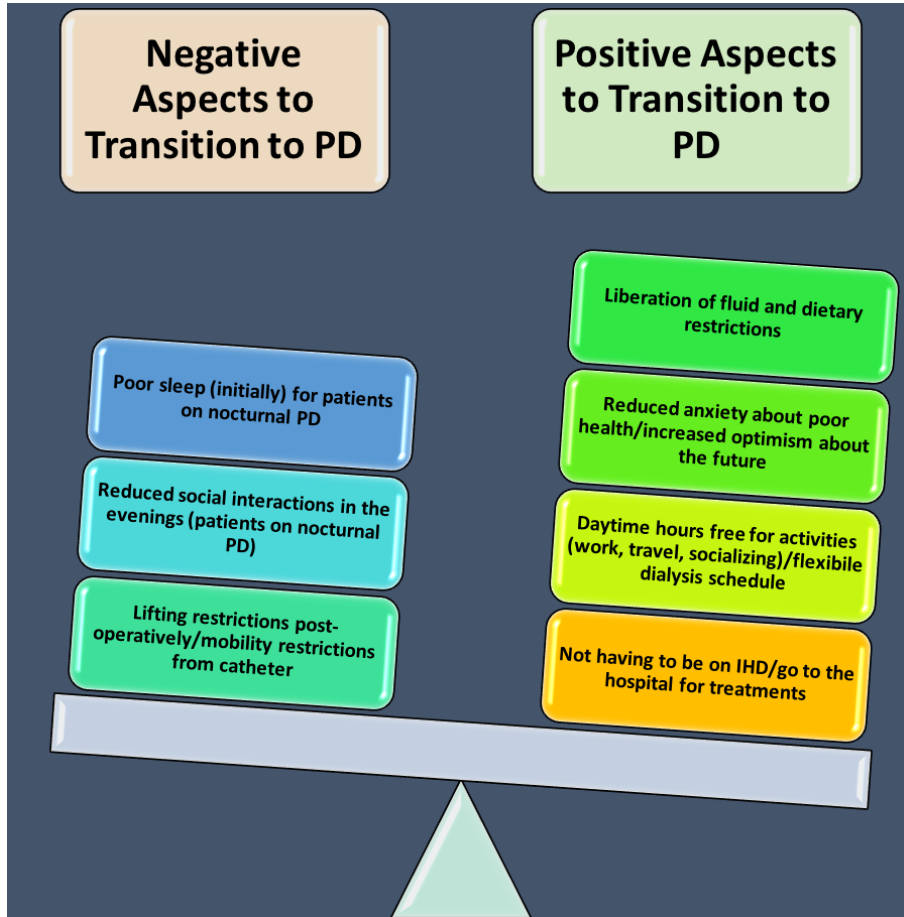


Figure 7: Positive and negative factors influencing changes in HRQoL in patients transitioning to peritoneal dialysis (PD).

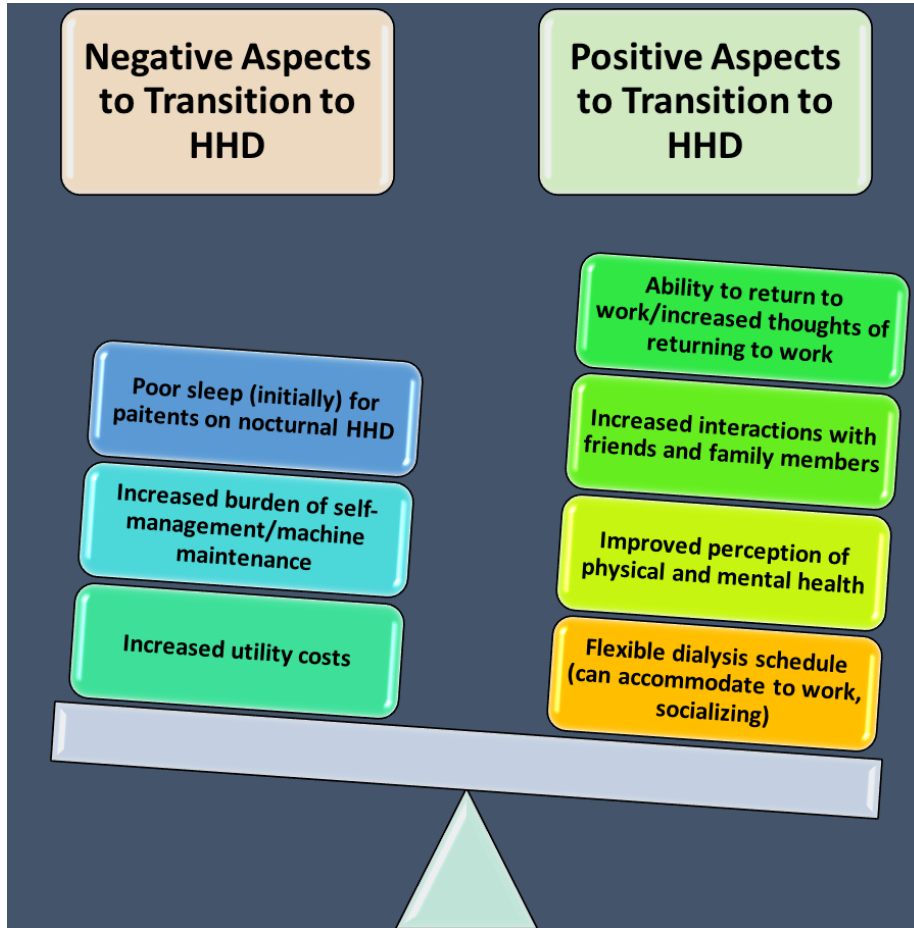


Figure 8: Positive and negative factors influencing changes in HRQoL in patients transitioning to home hemodialysis (HHD).

Chapter IV: Lessons from Patient Stories

Introduction

Chronic kidney disease (CKD) is one of the most highly prevalent disease states in the world, with an estimated global prevalence of 10.6%.¹ A significant number of patients with CKD will eventually progress to end-stage renal disease (ESRD) and require life-sustaining renal replacement therapy (most commonly, dialysis). Although dialysis sustains life, patients often suffer impaired health-related quality of life (HRQoL) as a result of both their disease and their treatment. A number of studies have shown that patients treated with in-centre hemodialysis (IHD), the most common dialysis modality, have significantly impaired HRQoL compared to healthy members of the general population.²⁻⁴ Although inconsistent, some studies show that patients on home modalities [peritoneal dialysis (PD) and home hemodialysis (HHD)] have better HRQoL scores in some domains as compared to IHD.⁵⁻⁸

While the majority of patients initiate dialysis as IHD patients, it is common for patients to change dialysis modalities a number of times during their life.⁹ As patients transition from one modality to another, a number of changes may occur in both physical and mental health. Previous literature shows that transition periods, particularly the transition from pre-dialysis CKD to an initial dialysis modality, are times when patients are at high risk of mental health disease, hospitalization, and mortality.¹⁰⁻¹⁴ However, for some patients, the transition to a new modality may also be a time of improving health, particularly for uremic patients initiating dialysis for the first time or for patients transitioning from IHD to a home modality.

We recently conducted a multi-methods study within the Southern Alberta Renal Program in Calgary, Canada, where patient experiences and changes in HRQoL during modality transitions were studied using the Kidney Disease Quality of Life-36 Survey (KDQOL-36), additional domains from the KDQOL-Short Form (KDQOL-SF), and semi-structured interviews completed 3 months after initiating a new dialysis modality. The methodology and results of this study are reported for the cohort as a whole in Chapter III and IV. Here we highlight the stories of five individual patients (Table 1). By comparing their interviews to their KDQOL scores, we highlight some of challenges patients are faced with during transition periods and discuss some

of the pearls and pitfalls clinicians should be wary of when utilizing HRQoL instruments in clinical practice.

Patient 1: Mr. M (Pre-dialysis chronic kidney disease to in-centre hemodialysis)

Mr. M described his transition as a positive experience overall, noting improvements in his energy, appetite, and a reduction in pruritus. He also noted improved sleep quality, stating that after initiating IHD, he had less nocturia, allowing him to sleep without awakening. Mr. M did not experience any side effects related to IHD and did not feel the transition to IHD had any impact on his mental health or well-being.

Because Mr. M continued to work a full-time job during his transition, his IHD treatments were scheduled in the evening. Mr. M had long dialysis days, working full-time the day of dialysis, attending his four-hour treatments in the evening, and returning home close to midnight. Despite this, he felt that dialysis had minimal impact on his ability to work, and in fact, although he was sleeping less on dialysis nights, his quality of sleep improved, allowing him to be rested and more productive at work. Mr. M did note occasionally missing socializing with friends due to his dialysis schedule, but did not feel this had a profound impact on his overall quality of life.

Commentary: Assessing the Physical Component Summary Score & Burden of Kidney Disease

Mr. M's transition from pre-dialysis care to IHD seems to have been positive, with overall improvements in HRQoL based on both his interview and his KDQOL scores (which improved in 8 of the 9 domains measured over the course of his transition, including his self-assessed overall health, which improved by 30 points).

Mr. M's lowest score at baseline was the Short Form 12 (SF-12) Physical Component Summary (PCS) score. The PCS is calculated from a number of questions related to self-assessed physical health and well-being. In the general American population, the mean score for both the PCS and the SF-12 Mental Component Summary (MCS) is 50.0 (standard deviation 10.0); in Canada, mean scores for the general population are slightly higher (50.5 and 51.7 for PCS and MCS, respectively).¹⁵⁻¹⁶ Dialysis patients typically have much lower PCS values than the general population.⁴ During the first 3 months of IHD, Mr. M's PCS improved from 24.0 to 44.7 (20.7

points). While the magnitude of change which is clinically important in ESRD patients is unknown, one study of patients with CKD suggested that the MCID (minimal clinically important difference) for the PCS is 5.7.¹⁷ Using this value, we observe that there may have been a clinically important improvement.

A number of studies have shown the PCS to be an independent predictor of morbidity and mortality in dialysis populations. A 2004 study showed IHD patients with PCS scores less than 25 have a 1.56 times greater risk of hospitalization and a 1.93 times greater risk of death than patients with scores greater than 46.⁴ Subsequently, a publication by Lowrie et al demonstrated that a 1-point increase in PCS is associated with a 2% reduction in both hospitalization and mortality, while another study demonstrated a 10% improvement in survival and 6% reduction in hospitalization risk with a 5-point increase in PCS.¹⁸⁻¹⁹ Mr. M's low PCS score at baseline seems to have portended a particularly poor prognosis for him, and it is reassuring that his transition to IHD resulted in a substantial improvement in his score and possibly his overall prognosis.

Mr. M's "Burden of Kidney Disease" score improved during the transition period. Questions comprising the "Burden" domain ask whether kidney disease interferes with other aspects of patients' lives, consumes too much time, causes frustration, or causes patients to feel as though they are burdening their family. It is promising to see that the transition improved his baseline score of 37.5 (his second lowest score at baseline); however, at 3 months, this score remained quite low (50.0). IHD patients may feel burdened by a number of factors related to dialysis (for example, time required to commute to and receive dialysis treatments, significant post-dialysis recovery time, need to adhere to strict dietary and fluid restrictions, and substantial medication burden); it is interesting that none of these were voiced during Mr. M's interview. Upon seeing the high degree of burden indicated by his KDQOL scores, his IHD healthcare team may consider exploring these issues to see how the burden may be lessened.

Patient 2: Mrs. L (Peritoneal dialysis to in-centre hemodialysis)

Mrs. L's transition to IHD was quite difficult for both her and her family. While on PD, she and her husband were living independently in their home of 56 years. Because of the distance from

her new hemodialysis unit, she and her family made the decision to sell the family home and relocate. At the time of her transition to IHD, Mrs. L was very frail and had fallen at home, and her husband (84 years old at the time) injured his back trying to assist her. They could no longer live independently and moved into an assisted living facility. Their daughter, who previously lived with them, opted to adopt a new work schedule which would allow her to take time off work three times per week to accompany her mother to and from her IHD treatments.

By the time 3 months had passed on IHD, Mrs. L was mobilizing better and beginning to complete some activities of daily living independently. However, she still lacked the energy for activities she truly enjoyed (primarily baking and cooking). She attributed this partially to worsened sleep on IHD and partially to prolonged post-dialysis recovery times, stating that it often took an entire 24 hours to feel “back to normal”. She stated that on hemodialysis, she was “always tired” and needed a lot of additional help. She expressed gratitude for her family members, particularly to her daughter and granddaughter who came to her home each week to clean and assist in meal preparation. However, she also stated that having increased family support often came at the expense of her own autonomy, as family members were hesitant to allow her to do things independently, something which she found frustrating at times. Despite the upheaval transitioning to IHD had brought to her life, Mrs. L stated that the transition had no impact on her mental health and that she had learned to “accept things as they are”.

Commentary: Assessing Mental Component Summary Scores & Social Supports

Mrs. L’s transition was particularly difficult; at the time, she was hospitalized with calciphylaxis and a new diagnosis of valvular heart disease, both of which likely contributed to her low KDQOL scores at baseline. It is interesting to see that while she felt her transition to IHD had negatively impacted her quality of life in a number of ways, her KDQOL scores in 7 of the 9 domains actually improved. This may be a reflection of her being quite ill at the time the baseline scores were ascertained. Unfortunately, annual assessment of HRQoL is not part of routine dialysis care in Canada, and we are therefore unable to compare her scores on IHD to scores obtained when she was thriving as a PD patient. Given her testimony, we presume that she would have had higher scores as a “healthy” PD patient than she did as an IHD patient.

However, patients doing well on PD are rarely converted to IHD, and Mrs. L's scores may therefore be more reflective of patients changing modalities out of sudden medical necessity.

There is an interesting discrepancy between Mrs. L's interview and her MCS scores. When asked, she felt that IHD had not impacted her mental health, but her KDQOL-36 indicates a large improvement in the MCS. This was also discrepant from the impression of the interviewer, who felt she indicated a decompensation in mental well-being and increased depressive symptoms throughout her testimony. Again, this discrepancy may be due to the fact that Mrs. L was unwell and hospitalized at the time of the baseline assessment (her baseline MCS score may be lower than it would have been had it been documented when she was doing well on PD). The discrepancy between her interview and her MCS scores may also be reflective of recall bias during her interview (perhaps she falsely recalled the state of her mental health at the time of her transition 3 months prior). Finally, it may reflect the fact that HRQoL surveys are limited in their ability to accurately ascertain a patient's clinical status.

Regardless of why the discrepancy was seen, the fact that the KDQOL score did not correlate with her testimony is important. An MCS score of less than 42 has a 74% sensitivity and 81% specificity at detecting depression; Mrs. L's scores were 35.2 at baseline and 52.9 after 3 months (similar to the mean score of 51.7 for the Canadian population).^{16,20} If solely the KDQOL-36 were used to screen for signs of low mood, one may not question her further about depressive symptoms given her exemplary 3-month scores. However, Mrs. L appeared to have low mood, was teary, and may have benefited from increased attention from mental health professionals who could help her cope with her transition to IHD. This should be taken as a lesson that while HRQoL tools are helpful to screen for mental health problems, they cannot be used to replace one-on-one interactions between patients and healthcare providers.

In keeping with her interview is an improvement in the "Social Supports" domain (50.0 to 83.3). Mrs. L spoke at length about increased support from her family, and one hopes that all patients making this difficult transition have access to such strong social support networks. Loss of independent living, requirement for relocation, reduced social interactions, and feelings of isolation are all commonplace amongst older adults who find themselves requiring dialysis.

These effects may feel particularly pronounced amongst those transitioning from a home modality to IHD. While patients initiating IHD for the first time may have the opportunity to transition to a home modality in the future, patients who are forced to cease home dialysis out of medical necessity may be facing the reality that IHD is their only remaining option. Dialysis clinicians should be cognizant of this fact and give increased attention to the emotional and mental health challenges that such patients are coping with during their transition.

Patient 3: Mr. E (Pre-dialysis chronic kidney disease to peritoneal dialysis)

Mr. E is a welder in the oilfield, and one of the most important factors in his choice of PD was the ability to continue working and providing for his family. Unfortunately, he required an extended period of time off work due to both expected delays (time for PD catheter surgery, post-operative recovery, PD training) and unexpected delays (catheter dysfunction requiring a second catheter placement and further recovery time). Because of his loss of income during the transition to PD, he and his family continued to have ongoing financial difficulties at the time of the interview 3 months later. While he was able to return to work, he felt “sluggish” as a result of having fluid within his abdomen and felt that his mobility was restricted by the PD catheter. As such, he required assistance at work with more physically laborious tasks.

Due to his work schedule, Mr. E had to be awake by 5:30 am. As his CCPD prescription was for 8 hours, he went to bed at 8:30 pm each night, a significant change for him. He stated that it felt as though PD had “made his life shorter” because he had lost time in the evening in which he could see his family and friends. While he was getting more hours of sleep as a result of this change, his sleep was often discontinuous, which he attributed to a PD-induced worsening of nocturnal gastroesophageal reflux disease (GERD) symptoms.

With the exception of mobility restrictions imposed by the PD catheter/fluid, Mr. E did not feel transitioning to PD had any significant impact on his physical health or well-being; similarly, he did not feel like his mental health had been impacted by the transition. He did not feel that PD had improved any symptoms of kidney disease (primarily because he did not recall ever having any uremic symptoms), and the only side effect of PD he noted was the aforementioned increased in GERD symptoms. Overall, Mr. E felt quite grateful that he had chosen PD as a

modality. In his opinion, the fact that he could do PD at home and could continue to work, even at a reduced capacity, outweighed any negative aspects to the modality.

Commentary: Returning to Work, Assessing Symptoms, and Trade-Offs in Modality Choices

PD is the most commonly used home modality in Canada and is often promoted as a more “lifestyle friendly” option than IHD.²¹ Indeed, PD seemed to suit Mr. E’s lifestyle much better than IHD, and because of PD, he was able to achieve his primary goal of returning to work. We see this reflected in the “Work Status” score of the KDQOL-SF; however, the fact that he was unable to return to work at full capacity is an important finding that is not captured by the KDQOL, which simply assesses whether or not dialysis prevents patients from working at a paying job. In our study, a common theme amongst patients transitioning to PD was disappointment that they remained limited in their ability to perform physical labour and feelings that they were not aware there may still be limitations after transitioning to PD. It is important, therefore, that clinicians encourage patients to set realistic employment goals prior to the modality transition.

Mild improvements were seen in the “Symptom/Problem List” domain of the KDQOL-36 but such changes were not reflected in Mr. E’s 3-month interview. His scores were relatively high at baseline, indicating that, in keeping with his interview, his symptom burden was low. This is not the case for many CKD/ESRD patients, who frequently suffer from a number of symptoms.²² Many tools exist to aid clinicians in symptom detection and management, but it is important to remember that such tools are not exhaustive. For example, the most bothersome symptom Mr. E experienced during the transition period was severe heartburn, a symptom that is not interrogated by the KDQOL-36 and which would be missed if this tool was used exclusively to assess symptom burden. Again, this is a lesson that while HRQoL tools are useful adjuncts to routine clinical care, they do not replace communication between physician and patient.

Mr. E’s story highlights that all modalities come with inherent pros and cons. For Mr. E, the fact that PD resulted in reduced free time and social interactions in the evenings, resulted in more disturbed sleep, and limited his ability to perform some physical tasks was balanced by the fact that he could dialyze independently at home and maintain employment, factors which, to him,

were more important. This highlights the importance of well-informed, collaborative decision-making when choosing a modality. In Mr. E's case, he seems to have been matched to the modality best-suited to his lifestyle and goals, and we should strive to provide the same level of individualized care to all patients.

Patient 4: Mr. A (In-centre hemodialysis to peritoneal dialysis)

During his interview, Mr. A stated that overall, the transition to PD had been positive. He was appreciative of the fact that PD allowed him to dialyze at home, because as an IHD patient, he had been commuting over an hour to and from IHD thrice weekly and had been missing out on valuable time with his family. Not having to commute to IHD also resulted in cost-savings (fuel and parking), an important factor for Mr. A, who could not maintain employment as an IHD patient. During his transition to PD, he noted an improvement in pruritus and appetite and fortunately had not noticed any side effects of his new modality.

There were some negative aspects to the transition period. Mr. A felt his energy levels had declined on PD. He found that with the PD fluid in his abdomen, he often found it difficult to eat or even breathe, attributing this to limited space in his abdomen due to his substantially enlarged kidneys. Three months after starting PD, he continued to avoid lifting anything weighing over 10 pounds, as he feared exacerbating a recurrent hernia and needing to transition back to IHD. Because of this, he felt guilty that he was not able to help his wife and children with physical tasks as much as he would have liked. He also expressed feelings of frustration that, at times, his family would prevent him from helping with household chores, as they feared he may develop an injury or infection.

Mr. A stated that ESRD and dialysis in general had negatively impacted his mental health but that he had not noticed a substantial change since transitioning to PD. He expressed a desire to return to work and felt that would help improve his mental well-being; however, he stated that due to the lifting restrictions, as well as difficulties with anemia and dizziness, he was unable to work at his previous job and did not have the energy (or desire) to retrain for a new career.

Overall, Mr. A felt that he had made the right decision in changing to PD, stating that the fact that he could perform his treatments at home and have his daytime hours free for other activities outweighed any negative aspects of the transition.

Commentary: The Value of HRQoL Instruments as Conversation-Starters

Comparing Mr. A's interview responses to his KDQOL scores reveals some interesting, and concerning, discrepancies. In his interview, Mr. A described some negative changes that had occurred in his HRQoL, but stated that overall, the transition to PD had a positive impact and that he was happy he had transitioned from IHD to PD. This is not reflected in his KDQOL scores, which decreased in 7 of the 9 domains. His low scores indicate that after 3 months on PD, Mr. A was suffering from a high number of symptoms, felt substantially burdened by his disease, and felt his overall health had declined. Additionally, his low MCS suggests he may be suffering from depression, while his low PCS indicate he is at increased risk for hospitalization and mortality.

In their 2005 review, Unruh et al state that one of the potential values of routine standardized measurements of HRQoL is that patients may be able to relay concerns that they may otherwise be uncomfortable disclosing, either due to discomfort or, perhaps, to a sense of stoicism.²³ It is possible that Mr. A did not want to disclose his struggles with PD to an interviewer with whom he was relatively unfamiliar and that he may have answered questions differently were he speaking to a familiar healthcare provider. However, his case highlights the fact that HRQoL instruments may be used to generate discussions about mental health and other sensitive items that patients may not bring up of their own volition, but that may be severely impacting their quality of life.

One hopes that Mr. A's case is not typical of the transition from IHD to PD, and indeed, we know from previous studies that this transition is often accompanied by improvements in HRQoL across several domains.⁵⁻⁶ This case, however, should remind clinicians that the impact of modality transitions varies greatly between individuals, and frequent assessments of physical and mental health during transitions are critical to ensure that issues are promptly detected and managed.

Patient 5: Mrs. W (Peritoneal Dialysis to Home Hemodialysis)

As a PD patient, Mrs. W had struggled with weight gain, frequent gastrointestinal upset, poor blood sugar control, and significant “drain pain”, which resulted in poor sleep and chronic fatigue. As she transitioned to HHD, she enjoyed improved blood sugar control, sleep, energy, and mental clarity. Mrs. W did state that the transition to HHD had been accompanied by the onset of headaches which occurred midway through her dialysis treatments and lasted for up to 6 hours. However, while this was bothersome, she stated that she would “choose the headaches over the total sleeplessness, and the drain pain, and the brain fog that [she] had on peritoneal dialysis”.

While Mrs. W felt that HHD was significantly more work than PD, she also felt the extra work was worth the improved overall health that she was enjoying. While her sleep had improved on HHD, the machine was disruptive to her husband’s sleep, and she worried this was causing him to feel fatigued during the day. However, she and her husband both enjoyed the fact that unlike CCPD, which required her to dialyze every night, they were able to sleep “machine-free” every other night. This provided them with nights of completely undisturbed sleep and also allowed them to take overnight trips, something which they had rarely done while on PD, as they found it onerous to travel with all of the supplies.

With regards to her mental health, Mrs. W felt that the transition to HHD had brought about a significant improvement. One of the driving factors for this was a restoration of social interactions. She stated that her improved physical health had resulted in her and her husband significantly increasing their time with family and friends. She had also started driving, an activity she had given up on PD as she did not feel she had the mental capacity to drive safely. Finally, she and her husband were contemplating overseas travel to visit their daughter in Europe, a possibility that, due to her poor health, they had never considered while she was on PD.

Mrs. W felt that in addition to improving her quality of life, the transition to HHD had a profound impact on her husband, who often felt “helpless” while she was on PD. During the transition, he was able to take on a more active role, helping to set up and maintain the HHD

machine each night. Mrs. W stated this brought him enjoyment, as well as a sense of pride that he was able to help give his wife improved quality of life.

Commentary: Ensuring Patients (and Family Members) Are Thriving

Perhaps the most important lesson to be learned from Mrs. W's case is that as clinicians, we must be watchful for signs that patients are failing to thrive on their modality. In speaking with Mrs. W, it was clear that for some time she had felt profoundly unwell on PD, and her KDQOL scores attest to the fact that she had very poor HRQoL at the time of her transition. Whether or not Mrs. W had brought up her concerns with her PD team is unclear, and perhaps there were a number of reasons that she was maintained on PD as long as she was. However, this highlights one of the potential benefits of routine assessments of HRQoL using standardized measurement tools, which is that it may allow clinicians to detect impairments that otherwise may not come to light (as in the previous case with Mr. A).

One of the other lessons to be learned from Mrs. W's case is that modality changes impact not only the patient, but family members as well. For example, while HHD significantly improved Mrs. W's sleep, she felt that her husband's sleep quality had diminished as a result; the trade-off for this was that she felt his overall quality of life had improved because he was able to enjoy taking a more active role in her care and because they were able to engage in more activities as a couple (socializing, traveling) as a result of her improved health. It is vital that during transition periods, health care providers assess the impact that a new modality has not just on the patient, but on the entire family.

Conclusion

Through the use of patient stories, we hope to have portrayed both the triumphs and tribulations that can accompany dialysis modality transitions. As clinicians, we may often forget the extent to which our patients' lives are impacted by a modality change, and we may assume that modality changes uniformly improve (or worsen) health-related quality of life. However, the lesson to be learned from this *collection* of stories is that each patient has their *own* story, and in order to provide them with optimal care, we must listen and respond to these stories. Validated HRQoL assessment tools, such as the KDQOL surveys, may aid us in the detection of clinical

problems that require increased attention; however, as evidenced by a number of our patients, scores from these surveys do not always correlate with patient testimony. It is important, therefore, that clinicians continue to engage in meaningful conversations with their patients about the impact dialysis may have on HRQoL, not just transition periods, but in an ongoing manner throughout the patient's life on dialysis.

Table 1: Patient Demographics

Patient	Age	Etiology of ESRD	Comorbidities	Transition From	Transition To	Reason for Transition
1: Mr. M	42	PCKD	HTN	CKD	IHD	Uremia
2: Mrs. L	81	PCKD	HTN, T2DM, CAD, Valvular heart disease	PD	IHD	Calciphylaxis
3: Mr. E	45	Goodpasture syndrome	HTN	CKD	PD	eGFR < 7 ml/min/1.73 m ²
4: Mr. A	48	PCKD	HTN	IHD	PD	Desire for home modality
5: Mrs. W	68	DN	HTN, T2DM	PD	HHD	Failure to thrive on PD

Table 1: Patient Demographics. PCKD = polycystic kidney disease; CKD = chronic kidney disease; IHD = in-centre hemodialysis; HTN = hypertension; T2DM = type 2 diabetes mellitus; PD = peritoneal dialysis; DN = diabetic nephropathy; HHD = home hemodialysis; eGFR = estimated glomerular filtration rate

Figure 1: Mr. M's KDQOL Scores

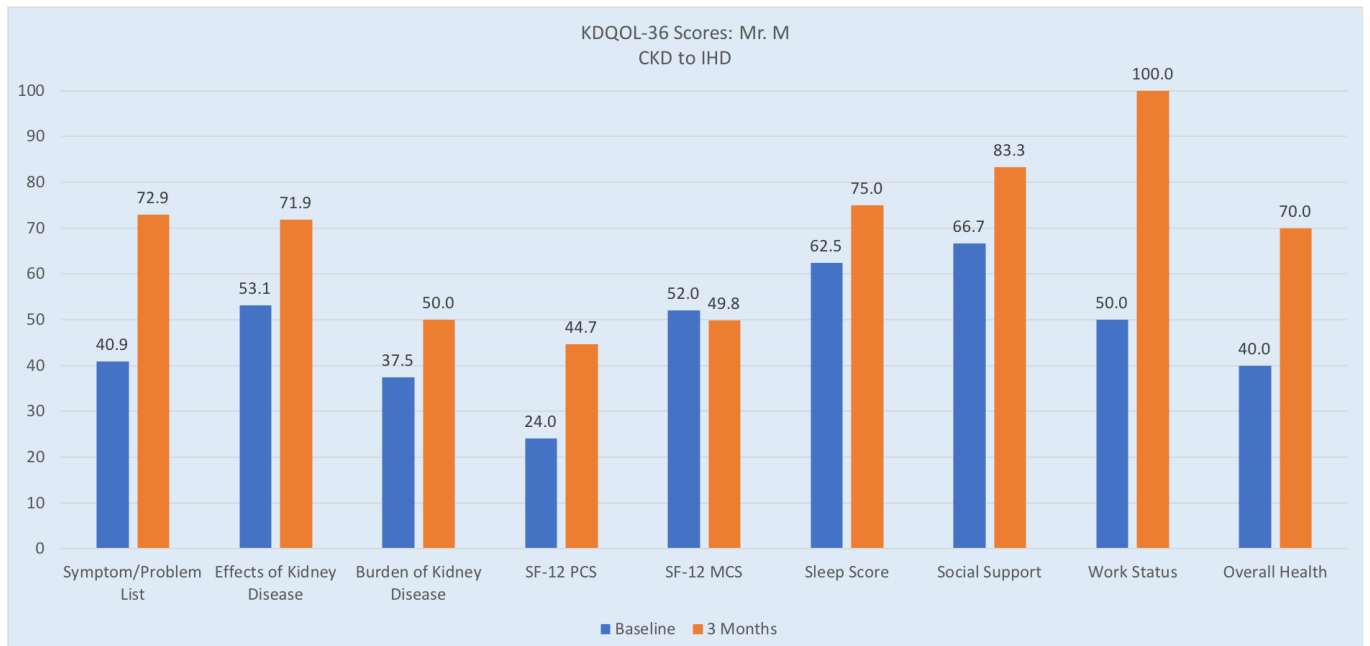


Figure 2: Mrs. L's KDQOL Scores

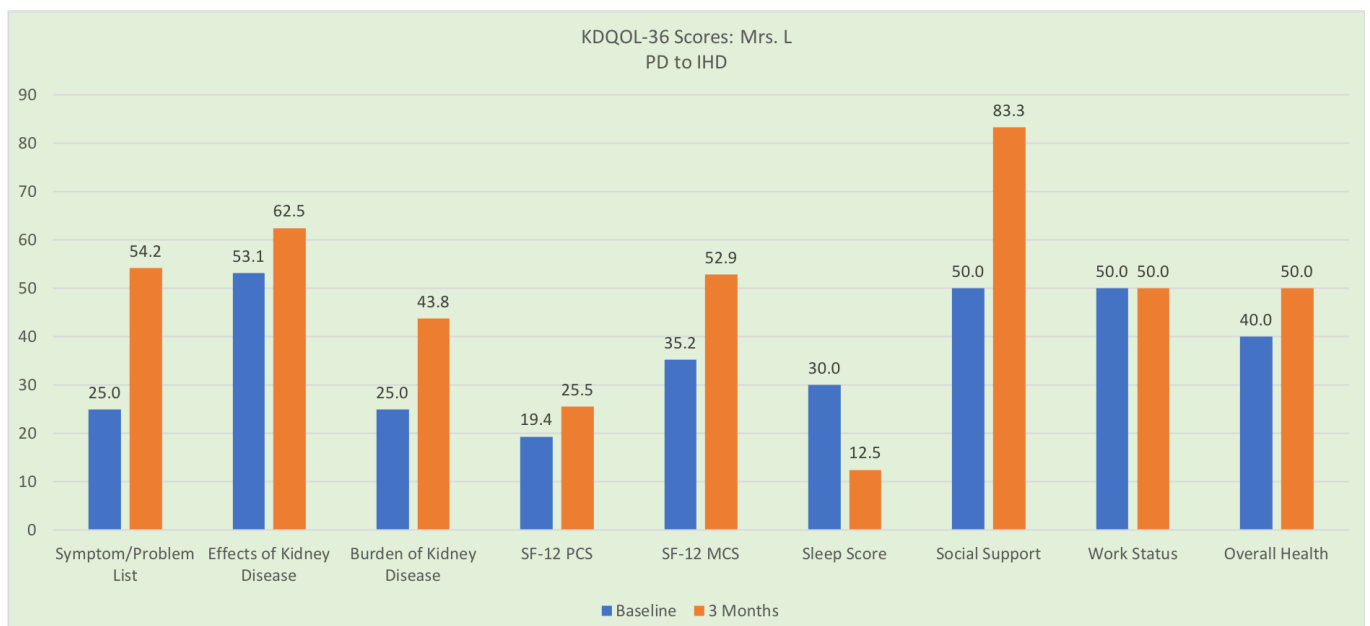


Figure 3: Mr. E's KDQOL Scores

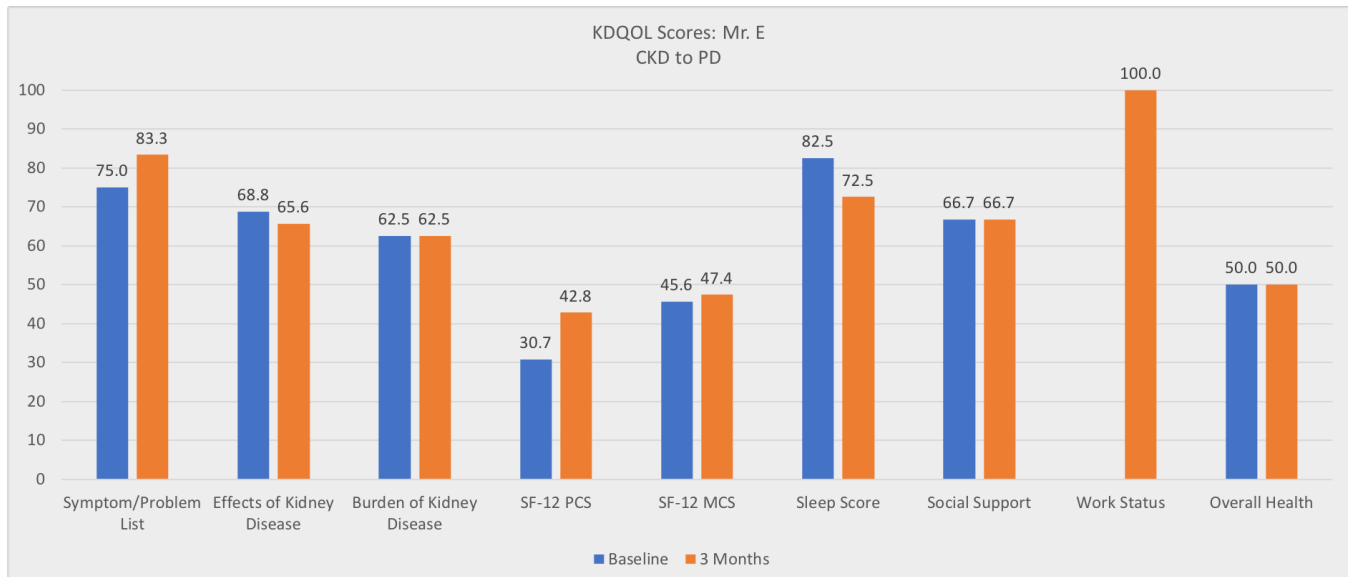


Figure 4: Mr. A's KDQOL Scores

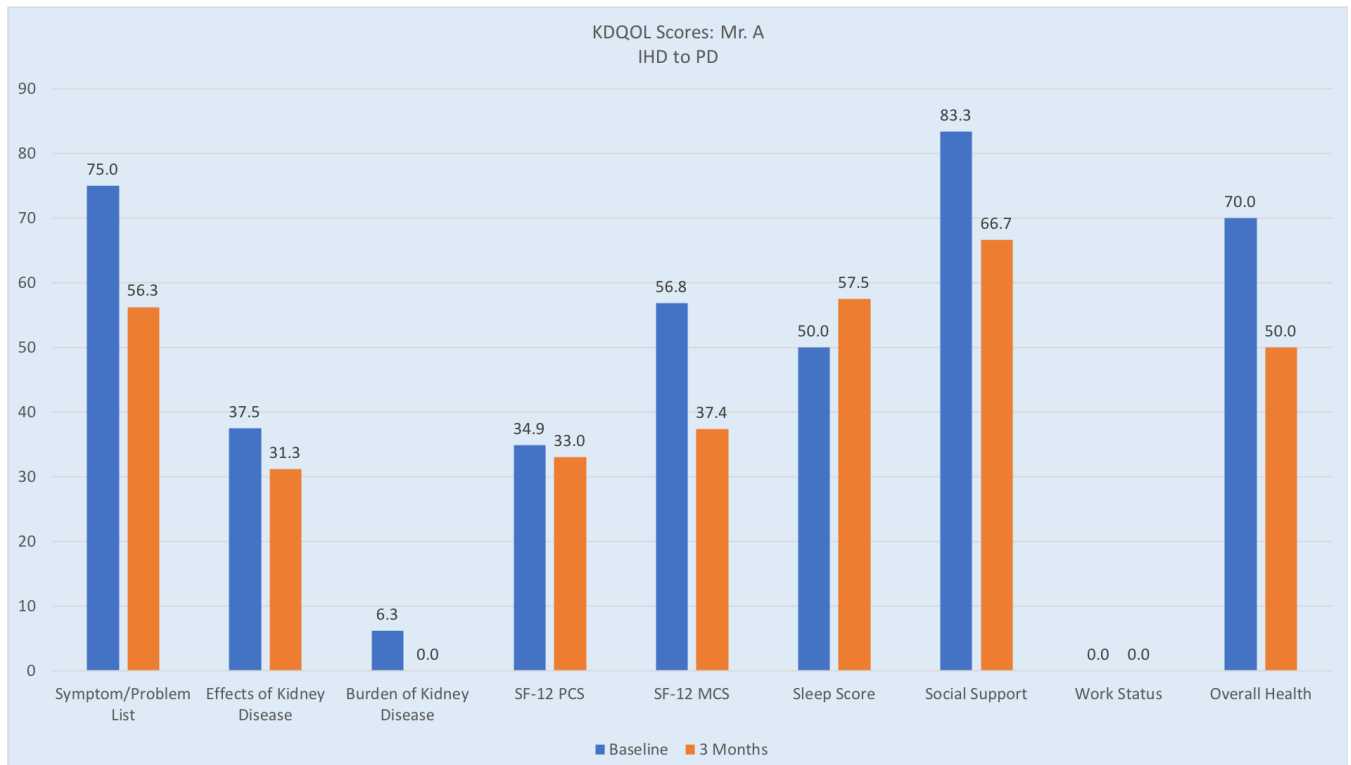
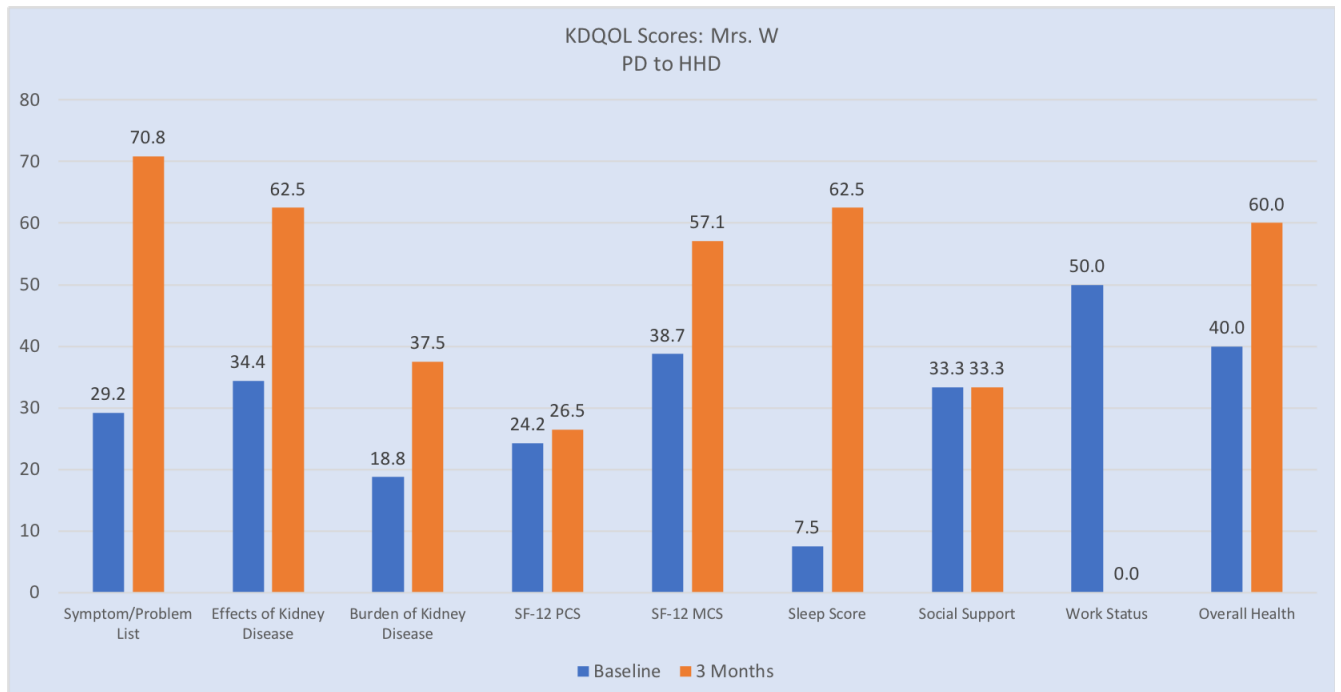


Figure 5: Mrs. W's KDQOL Scores



CHAPTER IV REFERENCES:

1. Hill NR, Fatoba ST, Oke JL, et al. Global Prevalence of Chronic Kidney Disease – A Systematic Review and Meta-Analysis. *PLoS One* 2016;11(7):e0158765.
2. Evans R, Manninen D, Garrison L Jr, et al. The quality of life of patients with end-stage renal disease. *N Engl J Med* 1985;312:553-9.
3. Gorodetskaya I, Zenios S, McCulloch CE, et al. Health-related quality of life and estimates of utility in chronic kidney disease. *Kidney Int* 2005;68:2801-8.
4. Mapes D, Lopes AA, Satayathum S, et al. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 2003;64:339-49.
5. Wu AW, Fink NE, Marsh-Manzi JVR, et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *JASN* 2004;15(3):743-53.
6. Kutner NG, Zhang R, Barnhart H, et al. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 2005;20:2159-67.
7. Tennankore KK, Chan CT, Curran SP. Intensive home hemodialysis: benefits and barriers. *Nat. Rev. Nephrol* 2012;8:515-22.
8. Finkelstein F, Schiller B, Daoui R, et al. At-home short daily hemodialysis improves the long-term health-related quality of life (FREEDOM Study). *Kidney Int* 2012;82:561-69.
9. CIHI Snapshot: Treatment of End-Stage Organ Failure in Canada, CORR 2005-2014. *Canadian Institute of Health Information*.
https://www.cihi.ca/sites/default/files/document/2016_corr_snapshot_enweb.pdf. Accessed April 16th, 2018.
10. Hutchinson TA. Transitions in the lives of patients with end stage renal disease: a cause of suffering and an opportunity for healing. *Palliat Med* 2005;19:270-7.
11. Gregroy DM, Way CY, Hutchinson TA, et al. Patients' perceptions of their experience with ESRD and haemodialysis treatment. *Qual Health Res* 1998;8:764-83.
12. Watnick S, Kirwin P, Mahnensmith R, et al. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003;41:105-10.
13. Pulliam J, Li N-C, Maddux F, et al. First-year outcomes of incident peritoneal dialysis patients in the United States. *Am J Kidney Dis* 2014;64(5):761-9.

14. Lukowsky LR, Kheifets L, Arah OA, et al. Patterns and predictors of early mortality in incident hemodialysis patients: new insights. *Am J Nephrol* 2012;35(6):548-58.
15. Farivar SS, Cunningham WE, Hays RD. Correlated physical and mental health summary scores for the SF-36 and SF-12 Health Survey, V.1. *Health and Quality of Life Outcomes* 2007;5:54.
16. Hopman WM, Towheed T, Anastassiades T, et al. Canadian normative data for the SF-36 health survey. *CMAJ* 2000;163(3):265-71.
17. Samsa G, Edelman D, Rothman ML, et al. Determining clinically important differences in health status measures: a general approach with illustration to the Health Utilities Index Mark II. *Pharmacoeconomics* 1999;15:141-55.
18. Lowrie EG, Curtin RB, LePain N, et al. Medical outcomes study Short Form-36: a consistent and powerful predictor of morbidity and mortality in dialysis patients. *Am J Kidney Dis* 2003;41(6):1286-92.
19. DeOreo PB. Hemodialysis patient-assessed functional health status predicts continued survival, hospitalization, and dialysis-attendance compliance. *Am J Kidney Dis* 1997;30(2):204-12
20. Ware JE Jr, Kosinski M, Keller SK. SF-36 physical and mental health summary scales: a user's manual. Boston: The Health Institute, New England Medical Center; 1994.
21. CIHI Snapshot: Treatment of End-Stage Organ Failure in Canada, CORR 2005-2014. *Canadian Institute of Health Information*.
https://www.cihi.ca/sites/default/files/document/2016_corr_snapshot_enweb.pdf. Accessed April 16th, 2018.
22. Weisbord SD, Fried LF, Arnold RM, et al. Prevalence, severity, and importance of physical and emotional symptoms in chronic hemodialysis patients. *J Am Soc Nephrol* 2005;16:2487-94.
23. Unruh ML, Weisbord SD, Kimmel PL. Health-Related Quality of Life in Nephrology Research and Clinical Practice. *Semin Dial* 2005; 8(2):82-90.

Chapter V: Concluding Statements

Was Combining KDQOL Surveys with Semi-Structured Patient an Effective Method of Learning About Transition Periods?

Optimizing quality of life is one of the top priorities for patients and families living with kidney disease and, as such, should also be one of the priorities of health care providers and medical researchers. Unfortunately, a number of factors contribute to reduced health-related quality of life in patients with advanced chronic kidney disease, especially those who find themselves requiring life-sustaining (and life-altering) dialysis treatments. As patients transition to life on dialysis or transition between dialysis modalities, it is important for health care providers to remain cognizant of the significant impact that transitions may have and to employ all measures possible to negate any decline in quality of life.

In this study, we evaluated patient experiences and changes in HRQoL during transition periods using both quantitative and qualitative methods. Each of these methods was found to have pros and cons that should be considered during the design and implementation of future studies.

Assessing HRQoL in a quantitative manner, such as with the KDQOL questionnaires, is rapid (patients took, on average, 10-15 minutes to complete the surveys), easy to conduct in current models of care (can be incorporated into a routine clinic visit or IHD treatment), and generates numerical data that can be compared to other CKD/ESRD patients, to healthy patients, or to the same patient in a longitudinal manner. However, the major downside to the KDQOL is that in the absence of well-defined MCID values, it is difficult (or impossible) to know whether the changes observed are clinically important or not; indeed, all that may really be commented upon is whether the change in HRQoL seems to be positive, negative, or neutral.

Our semi-structured interviews provided much greater insight regarding modality transitions and yielded information that could be translated into tangible interventions to aid in improving/maintaining patient quality of life. However, these interviews were time-consuming and could not easily be incorporated into routine clinical care, making it unlikely that such interviews will be commonplace. While more studies utilizing qualitative methodology are needed to better understand transition periods, what is truly needed are studies which anchor

patient testimony to KDQOL questionnaire responses to determine MCID values. Only then can the KDQOL-36, which is already considered standard of care in some jurisdictions, be interpreted in a meaningful fashion.

What Did We Learn and What Direction Should Future Research Take?

This study was, first and foremost, a pilot project seeking to identify the best way to study changes in HRQoL that occur during the first three months of a patient's transition to a new dialysis modality. As commented on above, utilizing both quantitative and qualitative methods proved to be an effective way of assessing patient experiences during modality transitions. However, as a pilot project, this study was not powered to determine whether modality transitions resulted in statistically significant changes in HRQoL. That being said, it is promising that regardless of the modality patients were transitioning to (in-centre hemodialysis, peritoneal dialysis, or home hemodialysis), trends towards improved HRQoL were observed in most KDQOL domains. Future studies adequately powered to detect statistically significant changes are important to better quantify the changes in HRQoL that occur during transition periods.

A common criticism of research utilizing patient-reported outcomes is a lack of clarity regarding how to interpret and apply findings in the clinical world. As previously discussed, the lack of well-defined MCID values for the KDQOL instruments is a barrier to fully interpreting the results of our study (and all such studies examining HRQoL in patients with kidney disease). It is surprising that the KDQOL-36 does not have defined MCID values, as it has been the recommended tool for annual assessments of HRQoL in hemodialysis patients for almost a decade. Studies such as ours, which utilize multiple methods to anchor KDQOL-36 responses to patient testimony, will be critical in the determination of MCID values for this questionnaire. While this was not the goal of this study, it is feasible that a similar study design (with a more specific interview focused on each of the items of the KDQOL-36) could be utilized to create anchor-based MCID values.

While our study was not adequately powered to detect statistically significant changes in the KDQOL-36, we did have adequate patient numbers to complete a thematic analysis of the shared

experiences of patients undergoing modality transitions. A key finding from our patient interviews was that the perceived change in HRQoL during a modality transition is heavily influenced by a patient's baseline status; for example, the experience of the patient transitioning to IHD from CKD care was quite different than that of the two patients transitioning to IHD from PD (whose experiences aligned much more closely with one another). Due to the small number of patients enrolled in this pilot project, we lacked the ability to perform subgroup analysis on all nine possible transitions that may occur (CKD to IHD, CKD to PD, CKD to HHD, IHD to PD, IHD to HHD, PD to IHD, PD to HHD, HHD to PD, and HHD to IHD). This would be an important consideration for future studies examining changes in HRQoL during transition periods. Future studies should also subdivide the home modalities (PD and HHD) into patients who complete their treatments during the day and patients who complete their treatments nocturnally, as there seemed to be unique concerns from patients on nocturnal PD or HHD that were not echoed by their counterparts on daytime dialysis (and vice versa).

The fifteen patients who participated in our interview process provided rich testimony of their experience during their modality transitions. With over six hours of recorded interviews, it is impossible to fully portray their experiences on paper. However, these interviews helped to shed light on a number of important and under-recognized issues that dialysis patients face during transition periods. In general, patients transitioning to in-centre hemodialysis described a negative experience, particularly if they were transitioning from a home modality; the transition period was described as a time when independence was lost, when patients became more reliant upon family members to care for them, when social interactions declined, and when overall quality of life was reduced by prolonged dialysis recovery times, dialysis-related symptoms, and strict dietary/fluid restrictions. Many of these factors are difficult to counteract in IHD patients and are a sad reality of life on in-centre hemodialysis. However, dialysis facilities should be cognizant of the negative impact transitioning to IHD may have on patients and employ measures to help patients cope with these changes. This may include increased access to individualized care (such as with a transition unit, as some experts have proposed) and increased access to social workers, physiotherapists, occupational therapists, and mental health care professionals.

Home modalities are often considered superior to in-centre hemodialysis for a number of reasons (liberation from a hospital setting, fewer fluid/dietary restrictions, reduced medication burden, increased autonomy, fewer dialysis-related symptoms, and increased ability to maintain employment). Indeed, the transition period to a home modality, whether it be peritoneal dialysis or home hemodialysis, was described in much more positive terms than the transition to IHD. However, there were a number of opportunities to improve HRQoL during the transition period. For example, patients initiating nocturnal dialysis therapies at home commonly spoke of sleep disturbances during the first few months, something that negatively impacted their quality of life. Patients also frequently discussed that while they felt confident to perform their treatments independently at home, their families were often reluctant to leave them alone in the house while dialysis was occurring; many patients expressed that they wished their families would take full advantage of the increased autonomy provided by a home modality and pursue activities (such as socializing and traveling) that they had been neglecting in order to care for the patient. Many patients also expressed that while they had improved energy and increased ability to work following their transition, they were often disappointed that they were unable to return to work at full capacity and felt they had been misinformed about the reality of working while on a home modality; this was more common with peritoneal dialysis patients than with home hemodialysis patients.

Such findings are important for home modality training facilities to be aware of and may prompt changes in how patients and their families are educated during the training period. For example, patients and their sleeping partners should be warned that, at least initially, sleep disturbance may be a problem; education regarding sleep hygiene and pharmaceutical sleeping aids may be necessary. Patients should also be encouraged to engage their family members as much as possible during the education process so that families feel confident in their loved ones' ability to safety and independently do dialysis at home without constant supervision. Our results also suggest that patients need to be given realistic expectations about the ability to return to work on a home modality; while a full return to work may be possible for some patients, those in physically strenuous jobs may still find themselves unable to work at their pre-illness capacity. Access to graduated return-to-work programs or vocational training for patients unable to return to their former employment may be important resources in this scenario. Finally, patients on

nocturnal dialysis often discussed missing important social events with family and friends as a result of their treatments. It is therefore important that home modality training includes education on how to safely modify the timing and duration of dialysis treatments so that important life events are not missed as a result of patients feeling they need to adhere to a strict dialysis schedule.

Do the KDQOL Instruments Accurately Portray Patient Experiences?

Our study was not intended to assess the extent to which quantitative tools, such as the KDQOL questionnaires, accurately represent patient experiences. Indeed, a much more rigorous patient interview that interrogates each individual question in the KDQOL would be required to ascertain this. However, comparing the overall change in a few domains of the KDQOL to the themes in patient interviews does give some insight into how well patient experiences were portrayed by the KDQOL tools.

The mean ‘Symptoms/Problems’ score of the KDQOL-36 was seen to improve regardless of modality, a change that reached statistical significance in patients transitioning to HHD. At least for HHD patients, this seems to correlate with patient testimony, as the majority of patients within the HHD subgroup reported improvement in uremic or dialysis-related symptoms, with very few reporting worsening of symptoms. For PD patients, the correlation is less clear; while some patients reported improved symptoms, others reported worsening of symptoms as well as new symptoms (especially gastrointestinal upset and symptoms related to heartburn) that are not specifically questioned by the KDQOL-36. For patients transitioning to IHD, the KDQOL-36 score did not seem to correlate well with patient testimony, as two of the three patients consistently reported increased dialysis-related symptoms after transition from PD to IHD. However, as this group only had three patients, it could be the answers of the sole patient transitioning from pre-dialysis CKD to IHD (who reported an overall improvement in uremic symptoms) caused a skew in the mean. The fact that the ‘Symptoms’ domain did not seem to correlate with patient testimony is perhaps reflective of the fact that the domain includes questions about 12 different symptoms related to uremia and dialysis. Trying to assess 12 symptoms with one aggregate score may not be a useful endeavor to optimize patient management. Patients who are severely suffering from one or two symptoms, but not suffering

at all from other symptoms interrogated, may have misleadingly high scores in the domain as a whole. Therefore, it is likely more useful (both in clinical practice and in research) to study each individual symptom individually rather than as an aggregate score.

The mean 'Burden of Kidney Disease' score was also seen to improve regardless of modality. Interestingly, the largest improvement was in the IHD cohort; two of the three patients in this cohort were transitioning from PD and, while one did mention the fact that being on IHD alleviated some stress that came along with self-management, both patients spoke frequently and passionately about the burdens of IHD, particularly the time required for travel to and from dialysis and for treatments. It seems that the domain score, therefore, did not adequately portray the extent to which patients felt burdened by IHD; again, this score may have been skewed by the third patient in the IHD cohort, who was transitioning from pre-dialysis CKD and did not seem to feel burdened by IHD during their interview.

'Burden' scores also improved in PD/HHD patients, but remained quite low at 3 months (less than 50 in both groups). Patients in these groups often spoke about the increased responsibility and time demands that came along with a home modality; however, most also stated that while home modalities increased the individual workload of dialysis, the benefits seen in overall health were worth this trade-off. Patients transitioning to PD/HHD from IHD also frequently stated that having flexibility in their dialysis scheduling and not needing to strictly adhere to hospital-based treatments had alleviated a lot of the burden they experienced with kidney disease. Recognizing this, the change in 'Burden' score does seem to adequately portray patient experiences; the mild improvement in scores likely represents reduced burden compared to IHD treatments, while the low overall scores may be reflective of the fact that although the burden of disease is less on home modalities, living with dialysis remains a substantial burden, regardless of modality.

Despite patients in the IHD cohort generally talking about declining mental health and increasing feelings of depression during the transition period, the mean mental component summary score (MCS) actually changed very little, suggesting that the MCS may not be fully responsive to declining mental health and depressive symptoms. HHD patients tended to speak more positively about the impact of their modality change than PD patients; however, the overall mean

MCS score increased by a larger magnitude in PD patients than in HHD patients. Again, this suggests that the MCS may not be a reliable or sensitive method of assessing changes in mental health that occur during transition periods; indeed, it is unlikely that any standardized questionnaire to assess mental health will ever be as effective as an individualized approach with each patient.

Finally, mean scores in the ‘Sleep’ domain improved in all 3 patient subgroups, despite reduced sleep quality being a common (although not universal) theme. Patients on IHD seemed to have the worst overall sleep, which did seem to correlate with the testimony of patients in the IHD group, particularly the two who had transitioned from PD and felt their sleep quality had suffered as a result of the transition. While PD and HHD patients utilizing nocturnal modalities frequently spoke of poor sleep quality during the transition, the majority of these patients did state that the quality of sleep gradually improved over the course of the first three months. Their 3 month scores do seem to correlate well with their testimony; however, this is an excellent example of information that would have been missed had we chosen to study the transition period using solely the KDQOL instruments.

It seems that overall, the KDQOL instruments correlate reasonably well with patient testimony, a reassuring fact as the KDQOL-36 is the recommended tool for annual assessment of HRQoL in both the United States and Europe (and, as such, will likely become increasingly used in other jurisdictions as well). However, it is evident that using the mean score obtained from a group of patients does not accurately represent the experience of all patients within that group. Furthermore, even repeating KDQOL questionnaires at relatively short intervals (in this case, three months apart) fails to capture a number of transient changes in HRQoL.

While the KDQOL instruments will likely continue to be widely used in the research world, these findings are testimony to the fact that standardized questionnaires to assess and track changes in HRQoL cannot be used as a substitute for open dialogue between patients and health care providers.

Conclusion

In conclusion, we found that combining a semi-structured patient interview with the KDQOL questionnaires was an effective way of assessing changes in HRQoL that occur during the first three months following transition to a new dialysis modality. Supplementing the KDQOL with patient testimony was critical in gaining complete understanding of the changes in HRQoL that occurred as a result of modality transition and to identify factors which may be amenable to intervention from health care providers.

As a pilot study with a small sample size, we are unable to comment upon statistically significant changes during the transition period and our findings should be interpreted as hypothesis-generating rather than conclusive. Although further large-scale studies are needed to truly understand the changes in HRQoL during transition periods, our findings have already highlighted some key drivers of change that health care providers and dialysis units should be cognizant of as patients change modalities. Further study is needed to determine the most effective interventions to prevent declines in HRQoL and how best to employ such interventions in real-world practice.

Bibliography

Arora P, Vasa P, Brenner D, et al. Prevalence estimates of chronic kidney disease in Canada: results of a nationally representative survey. *CMAJ* 2013;185 (9): E417-E423.

Boissinot L, Landru I, Cardineau E, et al. Is transition between peritoneal dialysis and hemodialysis really a gradual process? *Peritoneal Dialysis International* 2013; 33: 391-397.

Bossola M, Pepe G, Marzetti E. Health-related quality of life of patients on chronic dialysis: the need for a focused effort. *Seminars in Dialysis* 2017; 30: 413-416.

Bowman B, Zheng S, Yang A, et al. Improving incident ESRD care via a transitional care unit. *Am J Kidney Dis* 2018; XX(XX):1-6. Published online ahead of print: doi: 10.1053/j.ajkd.2018.01.035

Breckenridge K, Bekker HL, Gibbons E, et al. How to routinely collect data on patient-reported outcome and experience measures in renal registries in Europe: an expert consensus meeting. *Nephrol Dial Transplant* 2015. <https://doi.org/10.1007/s11136-011-0009-2>

Chow SKY, Tam BML. Is the kidney disease quality of life-36 (KDQOL-36) a valid instrument for Chinese dialysis patients? *BMC Nephrology* 2014; 15: 199.

CIHI Snapshot: Treatment of End-Stage Organ Failure in Canada, CORR 2005-2014. *Canadian Institute of Health Information*. https://www.cihi.ca/sites/default/files/document/2016_corr_snapshot_enweb.pdf. Accessed April 16th, 2018.

Claxton RN, Blackhall L, Weisbord SD, et al. Undertreatment of symptoms in patients on maintenance hemodialysis. *J Pain Symptom Manage* 2010; 39: 211-218.

Cook CE. Clinimetrics Corner: The Minimal Clinically Important Change Score (MCID): a necessary pretense. *The Journal of Manual and Manipulative Therapy* 2008; 16(4): E82-83.

Covic A, Bammens B, Lobbedez T, et al. Educating end-stage renal disease patients on dialysis modality selection: a clinical advice from the European Renal Best Practice (ERBP) Advisory Board. *NDT Plus* 2010; 3: 225-233.

Culleton BF, Walsh M, Klarenbach SW, et al. Effect of frequent nocturnal hemodialysis vs conventional hemodialysis on left ventricular mass and quality of life: a randomized controlled trial. *JAMA* 2007; 298 (11): 1291-1299.

DeOreo PB. Hemodialysis patient-assessed functional health status predicts continued survival, hospitalization, and dialysis-attendance compliance. *Am J Kidney Dis* 1997;30(2):204-12.

Ebrahim S. Clinical and public health perspectives and applications of health-related quality of life measurement. *Social Science and Medicine* 1995; 41: 1383-1394.

Elkinton JR. Medicine and the quality of life. *Annals of Internal Medicine* 1966; 64: 711-714.

EQ-5D. 'EQ-5D Instruments'. *About EQ-5D*. Retrieved April 16, 2018, from <https://euroqol.org/eq-5d-instruments/>.

Erez G, Selman L, Murtagh FEM. Measuring health-related quality of life in patients with conservatively managed stage 5 chronic kidney disease: limitations of the Medical Outcomes Study Short Form 36: SF-36. *Qual Life Res* 2016; 25: 2799-2809.

Erickson KF, Zhao B, Ho V, et al. Employment among Patients Starting Dialysis in the United States. *Clin J Am Soc Nephrol* 2018; 13: 265-273.

Evans R, Manninen D, Garrison L Jr, et al. The quality of life of patients with end-stage renal disease. *N Engl J Med* 1985; 312: 553-9.

Farivar SS, Cunningham WE, Hays RD. Correlated physical and mental health summary scores for the SF-36 and SF-12 Health Survey, V.1. *Health and Quality of Life Outcomes* 2007;5:54.

Finkelstein FO, Finkelstein SH. Time to rethink our approach to patient-reported outcomes measures for ESRD. *Clin J Am Soc Nephrol* 2017; 12: 1885-1888.

Finkelstein F, Schiller B, Daoui R, et al. At-home short daily hemodialysis improves the long-term health-related quality of life (FREEDOM Study). *Kidney International* 2012; 82:561-569.

Ginieri-Cocossis M, Theofilou P, Synodinou C, et al. Quality of life, mental health and health beliefs in haemodialysis and peritoneal dialysis patients: investigating differences in early and later years of current treatment. *BMC Nephrology* 2008; 9: 14.

Gorodetskaya I, Zenios S, McCulloch CE, et al. Health-related quality of life and estimates of utility in chronic kidney disease. *Kidney Int* 2005; 68: 2801-2808.

Gregroy DM, Way CY, Hutchinson TA, et al. Patients' perceptions of their experience with ESRD and haemodialysis treatment. *Qual Health Res* 1998; 8: 764-783.

Grincenkov FR, Fernandes N, Pereira Bdos S, et al. Impact of baseline health-related quality of life scores on survival of incident patients on peritoneal dialysis: a cohort study. *Nephron* 2015; 129(2): 97-103.

Hall RK, Luciano A, Pieper C, et al. Association of Kidney Disease Quality of Life (KDQOL-36) with mortality and hospitalization in older adults receiving hemodialysis. *BMC Nephrology*. 2018; 19:11.

- Hill NR, Fatoba ST, Oke JL, et al. Global Prevalence of Chronic Kidney Disease – A Systematic Review and Meta-Analysis. *PLoS One* 2016;11(7):e0158765.
- Hopman WM, Towheed T, Anastassiades T, et al. Canadian normative data for the SF-36 health survey. *CMAJ* 2000;163(3):265-71.
- Hutchinson TA. Transitions in the lives of patients with End Stage Renal Disease: a cause of suffering and an opportunity for healing. *Palliative Medicine* 2005; 19: 270-277.
- Jaeschke R, Singer J, Guyatt GH. Measurement of health status. Ascertaining the minimally clinically important difference. *Control Clin Trials* 1989; 10 (4): 407-415.
- Janssen I, Gerhardus A, von Gersdorff G, et al. Preferences of patients undergoing hemodialysis: results from a questionnaire-based study with 4,518 patients. *Patient Preference Adherence* 2015; 9: 847-855.
- Jayadevappa R, Cook R, Chhatre S. Minimal important difference to infer changes in health-related quality of life – a systematic review. *Journal of Clinical Epidemiology* 2017; 89: 188-198.
- Johnston BC, Ebrahim S, Carrasco-Labra A, et al. Minimally important difference estimates and methods: a protocol. *BMJ Open* 2015; 5: e007953.
- Kaplan RM, Bush JW. Health-related quality of life measurement for evaluation research and policy analysis. *Health Psychology* 1982;1:61-80.
- Karimi M, Brazier J. Health, Health-Related Quality of Life, and Quality of Life: What is the Difference? *Pharmacoeconomics* 2016.; 34(7): 645-649.
- Kraus MA, Fluck RJ, Weinhandl ED, et al. Intensive hemodialysis and health-related quality of life. *Am J Kidney Dis* 2016; 68(5)(Suppl 1): S33-S42.
- Kutner NG, Zhang R, Barnhart H, Collins AJ. Health status and quality of life reported by incident patients after 1 year on haemodialysis or peritoneal dialysis. *Nephrol Dial Transplant* 2005; 20: 2159-2167.
- Lin XJ, Lin IM, Fan SY. Methodological issues in measuring health-related quality of life. *Tzu Chi Medical Journal* 2013; 25: 8-12.
- Loosman WL, Hoekstra T, van Dijk S, et al. Short-Form 12 or Short-Form 36 to measure quality-of-life changes in dialysis patients? *Nephrol Dial Transplant* 2015; 30: 1170-1176.
- Lopes AA, Bragg-Gresham JL, Goodkin DA, et al. Factors associated with health-related quality of life among hemodialysis patients in the DOPPS. *Qual Life Res* 2007; 16: 545-557.

- Lowrie EG, Curtin RB, LePain N, et al. Medical outcomes study Short Form-36: a consistent and powerful predictor of morbidity and mortality in dialysis patients. *Am J Kidney Dis* 2003;41(6):1286-92.
- Lukowsky LR, Kheifets L, Arah OA, et al. Patterns and predictors of early mortality in incident hemodialysis patients: new insights. *Am J Nephrol* 2012; 35(6): 548-558.
- Mapes D, Lopes AA, Satayathum S, et al. Health-related quality of life as a predictor of mortality and hospitalization: the Dialysis Outcomes and Practice Patterns Study (DOPPS). *Kidney Int* 2003; 64: 339-349.
- McGlothlin AE, Lewis RJ. Minimal Clinically Important Difference: Defining What Really Matters to Patients. *JAMA Guide to Statistics and Methods* 2014; 312: 13.
- Morfin JA, Yang A, Wang E, et al. Transitional dialysis care units: a new approach to increase home dialysis modality uptake and patient outcomes. *Seminars in Dialysis* 2018; 31: 82-87.
- Mujais SK, Story K, Brouillette J, et al. Health-related Quality of Life in CKD Patients: Correlates and Evolution Over Time. *Clin J Am Soc Nephrol* 2009; 4(8): 1293-1301.
- Murtagh FE, Addington-Hall J, Higginson IJ. The prevalence of symptoms in end-stage renal disease: a systematic review. *Adv Chronic Kidney Dis* 2007; 14: 82-99.
- Norman GR, Sloan JA, Wyrwich KW. Interpretation of changes in health-related quality of life: the remarkable universality of half a standard deviation. *Med Care* 2003; 41 (5): 582-592.
- Office of Disease Prevention and Health Promotion. 'Healthy People 2020'. *Health-related quality of life and well-being*. Retrieved April 16, 2018 from <https://www.healthypeople.gov/2020/about/foundation-health-measures/Health-Related-Quality-of-Life-and-Well-Being>.
- Poulsen CG, Kjaergaard KD, Peters CD, et al. Quality of life during initial hemodialysis therapy and association with loss of residual renal function. *Hemodialysis International* 2017; 21: 409-421.
- Pulliam J, Li N-C, Maddux F, et al. First-year outcomes of incident peritoneal dialysis patients in the United States. *Am J Kidney Dis* 2014; 64(5): 761-769.
- RAND Corporation. 'Surveys'. *36-Item Short Form Survey (SF-36)*. Retrieved April 16, 2018 from https://www.rand.org/health/surveys_tools/mos/36-item-short-form.html.
- RAND Corporation. 'Surveys'. *Kidney Disease Quality of Life (KDQOL) Instrument*. Retrieved April 16, 2018, from https://www.rand.org/health/surveys_tools/kdqol.html.

- Rayner HC, Zepel L, Fuller DS, et al. Recovery Time, Quality of Life, and Mortality in Hemodialysis Patients: The Dialysis Outcomes and Practice Patterns Study (DOPPS). *Am J Kidney Dis* 2014; 64(1): 86-94.
- Reid C, Seymour J, Jones C. A thematic synthesis of the experiences of adults living with hemodialysis. *Clin J Am Soc Nephrol* 2016; 11(7): 1206-1218.
- Ricardo AC. Validation of the Kidney-Disease Quality of Life Short Form 36 (KDQOL-36TM) US Spanish and English Versions in a Cohort of Hispanics with Chronic Kidney Disease. *Ethn Dis* 2013; 23(2): 202-209.
- Rocco MV, Lockridge RS Jr, Beck GJ, et al. The effects of frequent nocturnal home hemodialysis: the Frequent Hemodialysis Network Nocturnal Trial. *Kidney Int* 2011; 80: 1080-1091.
- Samsa G, Edelman D, Rothman ML, et al. Determining clinically important differences in health status measures: a general approach with illustration to the Health Utilities Index Mark II. *Pharmacoeconomics* 1999; 15: 141-155.
- Schatell D, Witten B. Measuring Dialysis Patients' Health-Related Quality of Life with the KDQOL-36TM. *KDQOL COMPLETE*. 2012. Retrieved April 16, 2018, from <https://kdqol-complete.org/pdfs/kdqol-36.pdf>.
- Spitzer WO. State of science 1986: quality of life and functional status as target variables for research. *J Chronic Dis* 1987;40:465-71.
- Tannor EK, Archer E, Kapembwa K, et al. Quality of life in patients on chronic dialysis in South Africa: a comparative mixed methods study. *BMC Nephrol* 2017; 18: 4.
- Tennankore KK, Chan CT, Curran SP. Intensive home hemodialysis: benefits and barriers. *Nat. Rev. Nephrol* 2012; 8: 515-522.
- Unruh ML, Weisbord SD, Kimmel PL. Health-Related Quality of Life in Nephrology Research and Clinical Practice. *Seminars in Dialysis* 2005; 18(2): 82-90.
- Urquhart-Secord R, Craig J, Hemmelgarn B, et al. Patient and caregiver priorities for outcomes in hemodialysis: an international nominal group technique study. *Am J Kidney Dis* 2016 ;68(3): 444-54.
- Walker RC, Hanson CS, Palmer SC, et al. Patient and caregiver perspectives on home hemodialysis: a systematic review. *Am J Kidney Dis* 2015; 65(3): 451-463.
- Ware JE Jr, Kosinski M, Keller SK. SF-36 physical and mental health summary scales: a user's manual. Boston: The Health Institute, New England Medical Center; 1994.

Watnick S, Kirwin P, Mahnensmith R, et al. The prevalence and treatment of depression among patients starting dialysis. *Am J Kid Dis* 2003; 41:105-110.

Weisbord SD, Fried LF, Mor MK, et al. Renal provider recognition of symptoms in patients on maintenance hemodialysis. *Clin J Am Soc Nephrol* 2007; 2: 960-967.

World Health Organization. 'Introducing the WHOQOL instruments'. *WHOQOL: Measuring Quality of Life*. Retrieved April 16, 2018 from <http://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>.

Wu AW, Fink NE, Marsh-Manzi JVR, et al. Changes in quality of life during hemodialysis and peritoneal dialysis treatment: generic and disease specific measures. *JASN* 2004; 15(3): 743-753.

Yang F, Wang VW, Joshi VD, et al. Validation of the English Version of the Kidney Disease Quality of Life Questionnaire (KDQOL-36) in Haemodialysis Patients in Singapore. *Patient* 2013; 6: 135-141.

Zazzeroni L, Pasquinelli G, Nanni E, et al. Comparison of quality of life in patients undergoing hemodialysis and peritoneal dialysis: a systematic review and meta-analysis. *Kidney Blood Press Res* 2017; 42: 717-727.

APPENDIX A: Interview Script

Structured Telephone Interview Script

When Calling Patients for Quality of Life Assessment

Hello, my name is _____, and I am one of the researchers from the Southern Alberta Renal Program. I am leading the dialysis transitions study that you are participating in. This is one of the scheduled phone calls that was discussed when you signed up to participate in this study. I would like to ask you a few questions about your experience with dialysis so far. Do you have time to answer a few questions right now?

Before we begin, I just want to remind you that these questions are only being used for the study. Your responses are confidential and will be made anonymous as soon as this phone call is completed. This phone call will be recorded so that we can review your answers if we need to as the study moves forward.

I'm interested in learning about your experience receiving a new modality of dialysis. I would also like to know about any changes that have occurred in your daily living since starting your new dialysis therapy.

First Question:

To begin, can you describe any changes in your quality of life that immediately come to mind? These can be either positive changes or negative changes.

- Depending on the response, use open-ended questions to prompt for more information:
 - Can you tell me more about that?
 - What impact do you think that has had?

Second Question:

Now there are some specific areas of quality of life we'd like to explore, and I'm interested in your thoughts on each of these areas. How do you think your new dialysis therapy has impacted your life in terms of:

- a) Physical health and well-being (for example, energy levels, ability to perform physical tasks, ability to get things done)*
- b) Mental health and well-being*
- c) Interactions with family and friends*
- d) Symptoms of kidney disease or side effects of dialysis – have you noticed anything that's gotten particularly better or worse on your new therapy?*
- e) Sleep*

f) Ability to work

Third Question:

Could you tell me about any concerns related to the impact of your dialysis therapy on your family members or other caregivers?

- If changed dialysis modalities, ask about a comparison to previous modality.

Final Question

Are there any other comments or concerns you have for us before we end our conversation today?

That's all the questions I have today. Thank you very much for participating in this phone survey.