DETERMINANTS OF HOME DIALYSIS USE: A MIXED-METHODS STUDY

UNDERSTANDING DETERMINANTS OF HOME DIALYSIS USE IN CANADA: A MIXED-METHODS STUDY

By GIHAD E. NESRALLAH, BSc, MD, FACP, FRCPC

A Thesis

Submitted to the School of Graduate Studies

in Partial Fulfillment of the Requirements

for the Degree of

Master of Science

McMaster University

MASTER OF SCIENCE (2013) McMaster University

Health Research Methodology Hamilton, Ontario

TITLE: Understanding Determinants of Home Dialysis Use in Canada: A Mixed-Methods Study

AUTHOR: Gihad E. Nesrallah, BSc (Ottawa University), MD (The University of Western Ontario)

SUPERVISOR: Professor G Guyatt

NUMBER OF PAGES: ix, 93

ABSTRACT

This thesis consists of three related studies presented as three separate manuscripts. The first two comprise part of a larger sequential mixed-methods study with a qualitative and subsequent quantitative (survey) component. The overarching goal of this study was to understand the factors that influence the use of home dialysis, from the perspectives of Canadian nephrologists. The third study was a methodological study (a clinical trial) embedded in the survey, evaluating a novel strategy to incentivize survey responses.

In the first paper, we aimed to develop a theoretical framework describing determinants of dialysis modality choice. We selected informants using a maximum-variation sampling strategy, and used in-depth interviews to explore their perspectives. We used a grounded theory-informed analytical approach to construct a taxonomy of barriers and related facilitators to home dialysis use. We triangulated our findings against related published studies and qualitative results from our survey study. This study informed the development of the questionnaire that is the focus of the second study.

The second paper describes the development, administration, and results of a 47-item survey measuring Canadian nephrologist perspectives on the relevance of barriers to home dialysis use, and the utility of candidate interventions to overcome them. We used factor analysis to aggregate items into domains, and examined the relationships between respondent and practice characteristics with domain-level scores. Respondents expressed enthusiasm and reluctance towards a number of strategies to optimize home dialysis use. Our findings will guide policy development and further research directed at managing barriers to home dialysis use.

The third and final study tests the effectiveness of a promised donation as an incentive for survey completion. We randomized survey recipients to receive standard notifications versus notifications that offered a charitable donation of $40 CAD to the Kidney Foundation of Canada in exchange for returning a completed survey. Contrary to our hypothesis, the intervention was not effective, thus adding to the cumulative evidence that such incentives do not impact on physician response rates.

ACKNOWLEDGEMENTS

I would like to express my sincerest gratitude to the many people who made this work possible. To my thesis supervisor, Dr. Gordon Guyatt, thank you for the learning opportunities, for sharing your wisdom, and for accommodating my sprint to the finish during the summer months. Thank you also for entertaining my *ad hoc* requests for advice on the many unrelated projects. To my thesis committee members, Dr. David Mendelssohn, Dr. Catherine Clase, and Dr. Stephen Walter, thank you for the constructive comments, ideas, and inspiration both within and outside of my thesis work. Collectively, your efforts and guidance have helped me to grow as a thinker, a writer, and as an independent researcher.

To my collaborators, Dr. Katherine Osterlund and Dr. Lianne Barnieh, thank you for your conscientious and expert contributions to the study conduct, and for making the work both interesting and fun. Thank you for the unexpected outcome that is my new understanding of qualitative research. To my colleagues at the Department of Nephrology at Humber River Hospital, thank you for making this work more manageable, by providing clinical coverage when I need to be at the University. Thank you also for the many words of encouragement over the years.

To my dear Caroline, thank you for supporting me through my graduate studies and research career. Thank you for bearing with me during the late nights and days away from home. You are my barometer for sensibility in both my personal and academic lives. To my dear little boys, Eli and Simon, who so greatly relish the fact that Dad is still in school, you are the inspiration behind all that I do. As you pursue your dreams, my hope is that you will find the same love and support that I have been so fortunate to have. You will certainly always find it at home.

TABLE OF CONTENTS

LIST OF FIGURES AND TABLES

Chapter 2 / Paper 1

Chapter 3 / Paper 2

Chapter 4 / Paper 3

LIST OF ABBREVIATIONS AND SYMBOLS

CANN-NET	Canadian Kidney Knowledge Generation and Translation Network
CVCs	Central venous catheters
CMS	Centres for Medicare & Medicaid Services
CHE	Continuing health education
ESRD	End-stage renal disease
HD	Hemodialysis
HHD	Home hemodialysis
KMO	Kaiser-Meyer-Olkin
KFOC	Kidney Foundation of Canada
KS	Kolmogorov-Smirnov test
KT	Knowledge translation
MATCH-D	Method to Assess Treatment Choices for Home Dialysis
ORN	Ontario Renal Network
PD	Peritoneal dialysis
PPS	Prospective payment system
QIP	Quality incentive program
QoL	Quality of life

DECLARATION OF ACADEMIC ACHEIVEMENT

This thesis is submitted in partial fulfillment of the requirements for the Master of Science program in Health Research Methodology, Clinical Epidemiology stream. The work takes the form of a sandwich thesis, consisting of three separate, but related manuscripts.

Gihad Nesrallah is the first author for all three papers. The thesis supervisor (Gordon Guyatt) and committee members (David Mendelssohn, Catherine Clase, Stephen Walter) are co-authors. Katherine Osterlund conducted in-depth interviews and developed an initial open coding system for qualitative strand. Gihad Nesrallah performed qualitative content analysis in duplicate, verified the open coding system, and developed the theoretical framework. Braden Manns, the principal investigator of the Canadian Kidney Knowledge Generation and Translation Network(CANN-NET), provided financial support for survey administration, and reviewed draft manuscripts. Lianne Barnieh assisted with survey administration, and data de-identification. Gihad Nesrallah conceived the initial idea for the first two papers; Gordon Guyatt proposed the third methodological study. Gihad Nesrallah developed the protocols for all three studies, and thesis committee members contributed ideas to further refine the methodology. Gihad Nesrallah conducted and led all of the studies, performed all statistical analyses, and created first drafts of all manuscripts. Thesis committee members and collaborators provided feedback on all manuscripts before submission.

INTRODUCTION

A Brief History of Home Dialysis

End stage renal disease (ESRD) is a chronic debilitating condition, with severely reduced survival and quality of life.(U.S. Renal Data System, 2008; Valderrabano, Jofre, & Lopez-Gomez, 2001; Walters, Hays, Spritzer, Fridman, & Carter, 2002)While transplantation offers the best possible outcomes, donor organs remain scarce, and most patients with ESRD require some form of dialysis.

Hemodialysis (with blood access; HD) has been in use as a chronic therapy since the 1960's, and remains the most prevalent form of renal replacement therapy in high-income countries.(Canadian Institute for Health Information, 2013; U.S. Renal Data System) In its earliest days, HD was a complex medical procedure, requiring specialized (and large) equipment, specially trained staff, and hence, a hospital environment. During its first decade of evolution, however, rapid advances in dialysis technology resulted in simpler, more compact HD machines, and the therapy was promptly transitioned to the home environment.(Blagg, 2007) Patients and their family members learned to perform the procedure independently, and HD was established as a home-based procedure.

During this brief era, dialysis was only available to the privileged few who could manage the cost of equipment and required materials. It was therefore not widely available until the early 1970's, when new legislation in the United States made HD universally accessible and covered under Medicare.(Cole, Blagg, Hegstrom, & Scribner, 1986) With the introduction of this new legislation came a need to rapidly expand dialysis infrastructure. This led to the commercialization of dialysis, and the proliferation of for-profit dialysis providers in the United States. The following years saw the demise of home HD, in favour of an easier "turn-key" solution that was facility-based dialysis, and a similar model of dialysis delivery was adopted world-wide.

The first use of peritoneal (abdominal cavity) dialysis (PD) in 1976 required a hospital environment and less portable glass storage containers for dialysate. By 1980, PD was a well-established therapy, and was more suitable for the home environment with the advent of disposable plastic dialysate bags. The improved portability of the therapy was followed by a "honeymoon" period with rapid uptake and prevalent rates of up to 60-70% in Canada and other countries.(Oreopoulos, 1980) Facilitated by the promotional efforts of the dialysis industry PD saw a period of rapid proliferation during its early days; but, this phenomenon was short-lived, and by the 1990's the renal community was struggling to understand the reasons for its demise.(Nissenson et al., 1997) To date, despite its lower cost, ease of use, and favourable outcomes,(Mehrotra et al., 2007)PD makes up only 10-20% of the dialysis modality mix in most developed

countries.(Canadian Institute for Health Information, 2013; U.S. Renal Data System)

Over the last decade, the menu of home dialysis options has grown further.(G. Nesrallah & Mendelssohn, 2006)In addition, with ongoing advances in technology, home HD has become simpler, and therefore potentially accessible to more patients.(Moran, 2009; G. E. Nesrallah et al., 2009; Schlaeper & Diaz-Buxo, 2005) Moreover, both home HD and PD allow greater flexibility in the dialysis schedule, and the opportunity to provide more frequent or longer dialysis sessions at any time of day that is convenient for a given patient. In many instances, this results in dialysis being delivered overnight during sleep (nocturnal HD and nightly cycler PD).

Home Dialysis Outcomes: Promise and Uncertainty

The potential impact of home dialysis is several fold: 1) greater schedule flexibility may allow patients to return to gainful employment; 2) the opportunity to perform longer or more frequent dialysis may improve several physiological outcomes,(R. S. Suri et al., 2006; Walsh, Culleton, Tonelli, & Manns, 2005) including ventricular hypertrophy,(Culleton et al., 2007) uremic solute clearance,(R. Suri, Depner, Blake, Heidenheim, & Lindsay, 2003) phosphate removal,(Mucsi et al., 1998) and others; and 3) these changes may translate into improved survival, well-being, and quality of life.(Kliger, 2007, 2009a, 2009b)

Studies have suggested better patient survival and quality of life with all forms of home dialysis, including conventional home HD,(Woods, Port, Stannard, Blagg, & Held, 1996) more frequent or longer home HD,(G. C. Nesrallah, M.; Suri, R.; Moist, L.; Garg, A.; Pisoni, R.; Bragg-Gresham, J.; Robinson, B.; Port, F.; McDonald, S.; Hawley, C.; Lindasy, R., 2010; Pauly et al., 2010) and PD.(Weinhandl et al., 2010) To date, survival comparisons with various dialysis modalities have been limited to observational study designs. Therefore, significant residual confounding related to patient selection (including self-selection) to home therapies limit the validity of inferences drawn from these studies. More specifically, patients who are able to perform their own dialysis at home, or who have adequate support systems in place (assistance from friends and families) may have better survival and quality of life for reasons that are not related to the dialysis prescription itself. Unfortunately, the more rigorous study designs (randomized clinical trials) that are needed to disentangle these factors are currently thought to be infeasible, and it therefore seems unlikely that higher quality studies will be available in the near future.(Korevaar et al., 2003; Pipkin et al., 2010)

Despite limitations in the current literature, the renal community has embraced, and seeks to promote home dialysis.(Pierratos, 1999; Young et al., 2012)On

balance renal health care professionals and policy-makers seem to perceive that the current observational data and patient values and preferences provide sufficient justification for adopting home dialysis, and that proof of causation is not necessary – especially when one considers the numerous potential ancillary benefits of home-based therapy.(Agraharkar, Patlovany, Henry, & Bonds, 2003; Blagg, 2008; Burkart, 2008, 2009; Golper, Mehrotra, & Schreiber, 2013; Kerr, Polkinghorne, & McDonald, 2008; Schatell, 2006; Su, Lu, Chen, & Wang, 2009; Thodis & Oreopoulos, 2011) Home dialysis therapies are cost saving relative to centre HD, especially when larger programs can realize economies of scale.(Komenda, Gavaghan, Garfield, Poret, & Sood, 2012)This is in part due to significantly lower direct costs of nursing care, and possibly also due to lower medication and hospitalization costs.(P. McFarlane & Komenda, 2011)Therefore, although the rationale for promoting home dialysis has not been formally articulated as such, it may be reasonable to consider that the net balance of benefits and harms, cost savings, and patient values and preferences serve as a sufficient basis for the promotion of home dialysis to all capable and willing patients.

Recent policies of various regulatory bodies in Canada and abroad speak to the growing enthusiasm for home therapies. The recently formed Ontario Renal Network and the British Columbia Renal Agency, have, for example, placed the promotion of home dialysis at the forefront of their mandates.(British Columbia Renal Agency, 2013; Ontario Renal Network, 2013)For both organizations, this has translated into dedicated funding for patient training and equipment for home dialysis. In addition, a recently revised reimbursement scheme in the United States has also made provisions for incremental funding for home dialysis training.(Department of Health and Human Services) However, financial factors are but one facet of the modality selection process. This is supported by observation that PD uptake in Ontario (Canada's most populous province) remains limited despite the use of a capitated reimbursement scheme that places PD at par with HD from a physician perspective, and makes PD cost-saving from a facility perspective.(Mendelssohn, Langlois, & Blake, 2004)A better understanding of non-financial factors therefore seems essential to optimizing the utilization of home-based dialysis modalities.

Addressing Unexplained Variance in Home Dialysis Use

In light of the above, it is not surprising that home dialysis utilization varies widely across Canada, and even within individual provinces.(Canadian Institute for Health Information, 2013) Moreover, although the last decade has seen significant proliferation of home HD in the developed world, overall prevalence rates for home dialysis (HD and PD combined) remain significantly lower than is considered ideal (<20%) in Canada, the United States, and Europe. This was also the case in the 1990's, when surveyed nephrologists in Canada, the United

Kingdom, and the United States suggested that 30% of ESRD patients should be able to undergo PD at home.(Charest & Mendelssohn, 2001; Jassal, Krishna, Mallick, & Mendelssohn, 2002; Jung, Blake, Mehta, & Mendelssohn, 1999; Mendelssohn, Mullaney, Jung, Blake, & Mehta, 2001)

Prevalent rates for home dialysis utilization vary widely by country as well. The current home HD prevalent rate of less than 5% in Canada, for example, is considerably lower than the current rate of approximately 11% in Australia and New Zealand.(Kerr et al., 2008) This is particularly striking considering the similarities in health systems, societal values, and patient populations. Although reasons for this disparity are unclear, the success achieved in Australia demonstrates that higher targets are realistic, and likely to be feasible in Canada. The essential next step in expanding home dialysis therapies in Canada is to identify barriers to their wider adoption, and subsequently to identify facilitating factors that can be implemented by way of policy and program changes.

The Central Role of the Physician's in the Modality Selection Process

Dialysis modality decisions are complex. Determinants of modality choice can be broadly categorized as: patient, physician (or health care provider), and health care system-related factors.(Mattern et al., 1989; Nissenson et al., 1997) The physician sits at the interface between the patient and health care system, and is therefore uniquely poised to offer important insights at all levels of the modality selection process. Furthermore, physician biases for or against a given modality and their preconceptions regarding a patient's suitability for a given therapy may be potent determinants of a patient's final modality choice.(Hingwala et al., 2012)An in-depth understanding of physician attitudes towards dialytic therapies and modality selection factors is therefore critical to expanding home dialysis utilization.

A survey of Canadian nephrologists' attitudes towards current dialysis modality options will serve as an essential next step in understanding factors that determine modality choice, including both barriers, and strategies to overcome them. However, low response rates are a well-recognized challenge in surveys targeting physicians.(AAPOR, 2008; Grava-Gubins & Scott, 2008; VanGeest, Johnson, & Welch, 2007)Although physician surveys are less prone to non-response bias than surveys of the general population,(E. McFarlane, Olmsted, Murphy, & Hill, 2007)higher response rates are desirable, and strategies to increase response rates are needed. Direct monetary incentives, short surveys, multiple contacts (e.g. the Tailored Design Method), and personalized letter formats are effective strategies that are in routine use.(Edwards et al., 2009) The effectiveness of non-monetary incentives such as charitable donations to organizations of interest to the target population is less well studied.(Deehan, Templeton, Taylor, Drummond, & Strang, 1997; Gattellari & Ward, 2001)

METHODOLOGICAL CONSIDERATIONS

The first two studies included in this thesis each presented unique methodological challenges, which were considered during the study design, analysis, and interpretation stages. The purpose of this section is to highlight some of the methodological issues addressed in developing this sequential mixed-methods study that the author did not elaborate upon in the manuscripts due to space constraints imposed by target journals. The third related study evaluating the effectiveness of a charitable donation incentive was methodologically straightforward, and does not require any elaboration beyond what the main manuscript presents (Chapter 4 of this thesis).

Paper 1: Identification of Facilitators and Barriers to Home Dialysis Selection by Canadian Adults with ESRD

This was a qualitative study, the primary objective of which was to develop a taxonomy of determinants of dialysis modality choice, and in particular, to understand barriers and facilitators that might impact on choice of home versus hospital-based dialysis. The study began with in-depth interviews with key informants who had varying levels of exposure to, expertise with, and interest in home dialysis. Grounded-theory informed the approach to analysis, in that open codes were grouped into categories in an iterative and recursive fashion.(Corbin & Strauss, 2008)

The rationale for choosing a grounded-theory approach requires some expansion. It is first worth pointing out that none of the technical aspects of available qualitative analysis methods are mutually exclusive, and that hybrid approaches are often appropriate or optimal. Nevertheless, the approach to qualitative data analysis can impact significantly on the richness and quality of the final summary data. 'Content analysis' and 'thematic analysis' represent two major approaches to qualitative analysis, with important differences in their technical performance, that impact differentially on reliability and validity.

A standard content analysis approach involves coding raw textual messages, and organizing them within a classification scheme. Software-driven computerized algorithms can extract specified phrases and provide counts or frequencies as well. The primary disadvantage of this approach is the inability to consider context, or implicit meaning.(Kondracki, Wellman, & Amundson, 2002) This ultimately translates in to an analysis that includes 'manifest' (explicitly stated), but not 'latent' (implicitly stated) knowledge.(Berg, 1998) Given the anticipated complexity and degree of nuance in this study, inclusion of manifest content was paramount. Grounded theory is one of many thematic analysis techniques that allows for the incorporation of manifest concepts. The defining feature of

grounded theory – that it is 'data-driven' – is both an advantage, and limitation.(Glaser & Strauss, 1967) To the extent that the qualitative data directly produce the coding system, grounded-theory maintains high fidelity to the original data, and is thus more valid than a content analysis-based method, which cannot consider context. In contrast, analysts applying a grounded-theory approach may interpret context and latent constructs differently, which may lead to problems with reliability. For this reason, duplicate coding using an iterative and consultative process between coders is essential to ensure optimal reliability. This aspect of the study's design was a key determinant of the trustworthiness of the final theoretical framework.

Paper 2: Determinants of Home Dialysis Use: A Canadian National Survey of Nephrologists' Attitudes

This was a cross-sectional survey of Canadian nephrologists providing dialysis services and predialysis care to adult patients with ESRD. The survey explored respondent perceptions regarding potential barriers to home dialysis, and enthusiasm for various program and policy interventions to increase the appropriate use of home dialysis therapies.

The analysis of this 47-item survey included descriptive reporting of frequencies of response category at the item level, as well as an exploration of respondent and practice characteristics that were associated with responses. Statistical analyses examining relationships between item-level scores and predictor variables would have been problematic due to a high risk of Type I error. It was therefore necessary to perform dimension reduction procedures that to collapse items into clusters or domains, and to proceed with regression analyses using domain-level scores as the dependent variable. Using this approach reduced the number of statistical comparisons, rendering the analysis less prone to the effects of multiplicity.

Factor analysis is a commonly used statistical procedure for data reduction in attitudinal survey development. Among the various factor analysis subtypes, exploratory factor analysis is considered most appropriate when there are no strong preconceptions regarding the underlying structure of inter-related variables represented by questionnaire items.(Child, 1990) Factor analysis identifies latent constructs, or factors that are common to groups of items, thus allowing the information represented by these items to be summarized in a single, more reliable score. Commonly used factor extraction techniques include principal axis factoring and principal components analysis, which differ in their derivation of communalities (the variance that each variable shares with other variables). Monte Carlo simulations have suggested that principal axis factoring produces more stable, and less biased factor loadings across a range of assumptions, and this technique is therefore recommended over principal components analysis for

most applications.(Widaman, 1993) Once factor loadings are established, composite scores can be derived using a variety of weighting procedures. However, empiric studies have suggested that these techniques may inflate random error, and simple arithmetic sums or means have been recently recommended as the preferred approach.(Russell, 2002) These factors were all incorporated into the statistical analytical plan for this study.

OBJECTIVES OF THE THESIS

Paper 1 Objective

We performed a qualitative study to construct a modern taxonomy of determinants of dialysis modality choice (barriers and facilitators) operational at various levels of the dialysis modality selection process.

Paper 2 Objective

We conducted a national survey to characterize Canadian nephrologists' attitudes towards home dialysis (home HD and PD), barriers and facilitators affecting its adoption, and to measure their willingness to endorse and participate in a range of policies and interventions to increase the appropriate use of home dialysis.

Paper3 Objective

We conducted a randomized trial to determine whether a promised charitable donation incentive increases survey response rates among Canadian nephrologists, as compared with no promised donation incentive.

REFERENCES

AAPOR. (2008). Conducting Survey Research among Physicians and other Medical Professionals – A Review of Current Literature.

Agraharkar, M., Patlovany, M., Henry, S., & Bonds, B. (2003). Promoting use of home dialysis. *Adv Perit Dial, 19*, 163-167.

Berg, B. (1998). Content analysis *Qualitative Research Methods for the Social Sciences* (pp. 232-252). Boston, Massachusetts: Allyn & Bacon.

Blagg, C. R. (2007). The early history of dialysis for chronic renal failure in the United States: a view from Seattle. *Am J Kidney Dis, 49*(3), 482-496. doi: 10.1053/j.ajkd.2007.01.017

Blagg, C. R. (2008). The renaissance of home hemodialysis: where we are, why we got here, what is happening in the United States and elsewhere. *Hemodial Int, 12 Suppl 1*, S2-5. doi: 10.1111/j.1542-4758.2008.00287.x

British Columbia Renal Agency. (2013). Home/Independent Dialysis. Retrieved September 1, 2013, 2013, from http://www.bcrenalagency.ca/patients/home-independent-dialysis

Burkart, J. (2008). Role of peritoneal dialysis in the era of the resurgence of home hemodialysis. *Hemodial Int, 12 Suppl 1*, S51-54. doi: 10.1111/j.1542-4758.2008.00297.x

Burkart, J. (2009). The future of peritoneal dialysis in the United States: optimizing its use. *Clin J Am Soc Nephrol, 4 Suppl 1*, S125-131. doi: 10.2215/cjn.04760709

Canadian Institute for Health Information. (2013). Treatment of End-Stage Organ Failure in Canada, 2002 to 2011—CORR 2013 Annual Report. from https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1696

Charest, A. F., & Mendelssohn, D. C. (2001). Are North American nephrologists biased against peritoneal dialysis? *Perit Dial Int, 21*(4), 335-337.

Child, D. (1990). *The Essentials of Factor Analysis* (2nd ed.). London, United Kingdom: Cassel Educational Limited.

Cole, J. J., Blagg, C. R., Hegstrom, R. M., & Scribner, B. H. (1986). Early history of the Seattle dialysis programs as told in the Transactions--American Society for Artificial Internal Organs. *Artif Organs, 10*(4), 266-271.

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (3 ed.). London, UK: Sage Publications Inc.

Culleton, B. F., Walsh, M., Klarenbach, S. W., Mortis, G., Scott-Douglas, N., Quinn, R. R., et al. (2007). Effect of frequent nocturnal hemodialysis vs conventional hemodialysis on left ventricular mass and quality of life: a

randomized controlled trial. *JAMA, 298*(11), 1291-1299. doi: 298/11/1291 [pii]
10.1001/jama.298.11.1291

Deehan, A., Templeton, L., Taylor, C., Drummond, C., & Strang, J. (1997). The effect of cash and other financial inducements on the response rate of general practitioners in a national postal study. *Br J Gen Pract, 47*(415), 87-90.

Department of Health and Human Services. Medicare Program; End-Stage Renal Disease Prospective Payment System, Quality Incentive Program, and Bad Debt Reductions for All Medicare Providers; Final Rule. *Federal Register, 77*(218), 67449-67531.

Edwards, P. J., Roberts, I., Clarke, M. J., Diguiseppi, C., Wentz, R., Kwan, I., et al. (2009). Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev*(3), Mr000008. doi: 10.1002/14651858.MR000008.pub4

Gattellari, M., & Ward, J. E. (2001). Will donations to their learned college increase surgeons' participation in surveys? A randomized trial. *J Clin Epidemiol, 54*(6), 645-649.

Glaser, B., & Strauss, A. (1967). *The Discovery of Grounded Theory: Strategies for Qualitative Research*. New York: Aldine.

Golper, T. A., Mehrotra, R., & Schreiber, M. S. (2013). Is Dorothy correct? The role of patient education in promoting home dialysis. *Semin Dial, 26*(2), 138-142. doi: 10.1111/sdi.12086

Grava-Gubins, I., & Scott, S. (2008). Effects of various methodologic strategies: survey response rates among Canadian physicians and physicians-in-training. *Can Fam Physician, 54*(10), 1424-1430.

Hingwala, J., Diamond, J., Tangri, N., Bueti, J., Rigatto, C., Sood, M. M., et al. (2012). Underutilization of peritoneal dialysis: the role of the nephrologist's referral pattern. *Nephrol Dial Transplant*. doi: 10.1093/ndt/gfs323

Jassal, S. V., Krishna, G., Mallick, N. P., & Mendelssohn, D. C. (2002). Attitudes of British Isles nephrologists towards dialysis modality selection: a questionnaire study. *Nephrol Dial Transplant, 17*(3), 474-477.

Jung, B., Blake, P. G., Mehta, R. L., & Mendelssohn, D. C. (1999). Attitudes of Canadian nephrologists toward dialysis modality selection. *Perit Dial Int, 19*(3), 263-268.

Kerr, P. G., Polkinghorne, K. R., & McDonald, S. P. (2008). Home hemodialysis in Australia: current perspective. *Hemodial Int, 12 Suppl 1*, S6-10. doi: HDI288 [pii]
10.1111/j.1542-4758.2008.00288.x

Kliger, A. S. (2007). Frequent nocturnal hemodialysis--a step forward? *JAMA, 298*(11), 1331-1333. doi: 298/11/1331 [pii]
10.1001/jama.298.11.1331

Kliger, A. S. (2009a). More intensive hemodialysis. *Clin J Am Soc Nephrol, 4 Suppl 1*, S121-124. doi: 4/Supplement_1/S121 [pii]
10.2215/CJN.02920509

Kliger, A. S. (2009b). New options to improve hemodialysis patient outcomes. *Clin J Am Soc Nephrol, 4*(4), 694-695. doi: CJN.00780209 [pii]
10.2215/CJN.00780209

Komenda, P., Gavaghan, M. B., Garfield, S. S., Poret, A. W., & Sood, M. M. (2012). An economic assessment model for in-center, conventional home, and more frequent home hemodialysis. *Kidney Int, 81*(3), 307-313. doi: 10.1038/ki.2011.338

Kondracki, N. L., Wellman, N. S., & Amundson, D. R. (2002). Content analysis: review of methods and their applications in nutrition education. *J Nutr Educ Behav, 34*(4), 224-230.

Korevaar, J. C., Feith, G. W., Dekker, F. W., van Manen, J. G., Boeschoten, E. W., Bossuyt, P. M., et al. (2003). Effect of starting with hemodialysis compared with peritoneal dialysis in patients new on dialysis treatment: a

randomized controlled trial. *Kidney Int, 64*(6), 2222-2228. doi: 10.1046/j.1523-1755.2003.00321.x

Mattern, W. D., McGaghie, W. C., Rigby, R. J., Nissenson, A. R., Dunham, C. B., & Khayrallah, M. A. (1989). Selection of ESRD treatment: an international study. *Am J Kidney Dis, 13*(6), 457-464.

McFarlane, E., Olmsted, M. G., Murphy, J., & Hill, C. A. (2007). Nonresponse bias in a mail survey of physicians. *Eval Health Prof, 30*(2), 170-185. doi: 10.1177/0163278707300632

McFarlane, P., & Komenda, P. (2011). Economic considerations in frequent home hemodialysis. *Semin Dial, 24*(6), 678-683. doi: 10.1111/j.1525-139X.2011.01007.x

Mehrotra, R., Kermah, D., Fried, L., Kalantar-Zadeh, K., Khawar, O., Norris, K., et al. (2007). Chronic peritoneal dialysis in the United States: declining utilization despite improving outcomes. *J Am Soc Nephrol, 18*(10), 2781-2788. doi: 10.1681/ASN.2006101130

Mendelssohn, D. C., Langlois, N., & Blake, P. G. (2004). Peritoneal dialysis in Ontario: a natural experiment in physician reimbursement methodology. *Perit Dial Int, 24*(6), 531-537.

Mendelssohn, D. C., Mullaney, S. R., Jung, B., Blake, P. G., & Mehta, R. L. (2001). What do American nephologists think about dialysis modality selection? *Am J Kidney Dis, 37*(1), 22-29.

Moran, J. (2009). Technical advances in home dialysis. *Adv Chronic Kidney Dis, 16*(3), 215-220. doi: 10.1053/j.ackd.2009.02.008

Mucsi, I., Hercz, G., Uldall, R., Ouwendyk, M., Francoeur, R., & Pierratos, A. (1998). Control of serum phosphate without any phosphate binders in patients treated with nocturnal hemodialysis. *Kidney Int, 53*(5), 1399-1404. doi: 10.1046/j.1523-1755.1998.00875.x

Nesrallah, G., & Mendelssohn, D. C. (2006). Modality options for renal replacement therapy: the integrated care concept revisited. *Hemodial Int, 10*(2), 143-151. doi: HDI86 [pii]
10.1111/j.1542-4758.2006.00086.x

Nesrallah, G. C., M.; Suri, R.; Moist, L.; Garg, A.; Pisoni, R.; Bragg-Gresham, J.; Robinson, B.; Port, F.; McDonald, S.; Hawley, C.; Lindasy, R. (2010). *Improved Survival of Patients Receiving In-center Nocturnal Hemodialysis vs. Self-Care Conventional Hemodialysis: A Longitudinal Cohort Study*. Paper presented at the Canadian Society of Nephrology, Montreal, Canada.

Nesrallah, G. E., Suri, R. S., Moist, L. M., Cuerden, M., Groeneweg, K. E., Hakim, R., et al. (2009). International Quotidian Dialysis Registry: annual report 2009. *Hemodial Int, 13*(3), 240-249. doi: HDI391 [pii]
10.1111/j.1542-4758.2009.00391.x

Nissenson, A. R., Prichard, S. S., Cheng, I. K., Gokal, R., Kubota, M., Maiorca, R., et al. (1997). ESRD modality selection into the 21st century: the importance of non medical factors. *ASAIO J, 43*(3), 143-150.

Ontario Renal Network. (2013). The Ontario Renal Plan. Retrieved July 11, 2013, 2013, from http://www.renalnetwork.on.ca/ontario_renal_plan/independent_dialysis/ -_.Ud68eBboghw

Oreopoulos, D. G. (1980). Chronic dialysis for uremia. *N Engl J Med, 302*(13), 755.

Pauly, R. P., Maximova, K., Coppens, J., Asad, R. A., Pierratos, A., Komenda, P., et al. (2010). Patient and Technique Survival among a Canadian Multicenter Nocturnal Home Hemodialysis Cohort. *Clin J Am Soc Nephrol*. doi: CJN.00300110 [pii]
10.2215/CJN.00300110

Pierratos, A. (1999). Nocturnal hemodialysis: dialysis for the new millennium. *CMAJ, 161*(9), 1137.

Pipkin, M., Eggers, P. W., Larive, B., Rocco, M. V., Stokes, J. B., Suri, R. S., et al. (2010). Recruitment and training for home hemodialysis: experience and lessons from the nocturnal dialysis trial. *Clin J Am Soc Nephrol, 5*(9), 1614-1620. doi: CJN.02440310 [pii]
10.2215/CJN.02440310

Russell, D. W. (2002). In Search of Underlying Dimensions: The Use (and Abuse) of Factor Analysis in Personality and Social Psychology Bulletin. *Personality and Social Psychology Bulletin, 28*(12), 1629-1646. doi: 10.1177/014616702237645

Schatell, D. (2006). Dialyzing at home: a look at the latest data on growth, trends. *Nephrol News Issues, 20*(2), 45.

Schlaeper, C., & Diaz-Buxo, J. A. (2005). Home hemodialysis and remote monitoring: current technology, requirements and capabilities. *Blood Purif, 23*(1), 18-22. doi: 10.1159/000082006

Su, C. Y., Lu, X. H., Chen, W., & Wang, T. (2009). Promoting self-management improves the health status of patients having peritoneal dialysis. *J Adv Nurs, 65*(7), 1381-1389. doi: 10.1111/j.1365-2648.2009.04993.x

Suri, R., Depner, T. A., Blake, P. G., Heidenheim, A. P., & Lindsay, R. M. (2003). Adequacy of quotidian hemodialysis. *Am J Kidney Dis, 42*(1 Suppl), 42-48. doi: S0272638603005377 [pii]

Suri, R. S., Nesrallah, G. E., Mainra, R., Garg, A. X., Lindsay, R. M., Greene, T., et al. (2006). Daily hemodialysis: a systematic review. *Clin J Am Soc Nephrol, 1*(1), 33-42. doi: CJN.00340705 [pii]
10.2215/CJN.00340705

Thodis, E. D., & Oreopoulos, D. G. (2011). Home dialysis first: a new paradigm for new ESRD patients. *J Nephrol, 24*(4), 398-404. doi: 10.5301/jn.2011.8374

U.S. Renal Data System. USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States. 2012, from http://www.usrds.org/atlas.aspx

U.S. Renal Data System. (2008). *USRDS 2008 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States*

Valderrabano, F., Jofre, R., & Lopez-Gomez, J. M. (2001). Quality of life in end-stage renal disease patients. *Am J Kidney Dis, 38*(3), 443-464. doi: S0272638601973688 [pii]

VanGeest, J. B., Johnson, T. P., & Welch, V. L. (2007). Methodologies for improving response rates in surveys of physicians: a systematic review. *Eval Health Prof, 30*(4), 303-321. doi: 10.1177/0163278707307899

Walsh, M., Culleton, B., Tonelli, M., & Manns, B. (2005). A systematic review of the effect of nocturnal hemodialysis on blood pressure, left ventricular hypertrophy, anemia, mineral metabolism, and health-related quality of life. *Kidney Int, 67*(4), 1500-1508. doi: KID228 [pii]
10.1111/j.1523-1755.2005.00228.x

Walters, B. A., Hays, R. D., Spritzer, K. L., Fridman, M., & Carter, W. B. (2002). Health-related quality of life, depressive symptoms, anemia, and malnutrition at hemodialysis initiation. *Am J Kidney Dis, 40*(6), 1185-1194. doi: 10.1053/ajkd.2002.36879
S0272638602002470 [pii]

Weinhandl, E. D., Foley, R. N., Gilbertson, D. T., Arneson, T. J., Snyder, J. J., & Collins, A. J. (2010). Propensity-matched mortality comparison of incident hemodialysis and peritoneal dialysis patients. *J Am Soc Nephrol, 21*(3), 499-506. doi: ASN.2009060635 [pii]
10.1681/ASN.2009060635

Widaman, K. F. (1993). Common Factor Analysis Versus Principal Component Analysis: Differential Bias in Representing Model Parameters? *Multivariate Behavioral Research, 28*(3), 263-311. doi: 10.1207/s15327906mbr2803_1

Woods, J. D., Port, F. K., Stannard, D., Blagg, C. R., & Held, P. J. (1996). Comparison of mortality with home hemodialysis and center hemodialysis: a national study. *Kidney Int, 49*(5), 1464-1470.

Young, B. A., Chan, C., Blagg, C., Lockridge, R., Golper, T., Finkelstein, F., et al. (2012). How to overcome barriers and establish a successful home HD program. *Clin J Am Soc Nephrol, 7*(12), 2023-2032. doi: 10.2215/CJN.07080712

Identification of Facilitators and Barriers to Home Dialysis Selection by Canadian Adults with ESRD

Authors:

Gihad Nesrallah[1,2,3]MD

Lianne Barnieh[4]PhD

David Mendelssohn[3]MD

Catherine Clase[2] MD, MSc

Braden Manns[4]MD, MSc

Stephen Walter[2] PhD

Gordon Guyatt[2] MD, MSc

[1] The Lawson Health Research Institute, Western University, 375 South Street, London, Ontario, Canada, N6A 4G5

[2] Department of Health Research Methodology, McMaster University, 1280 Main Street West, Rm. 2C12, Hamilton, Ontario, Canada L8S 4K1

[3] Department of Nephrology, Humber River Hospital, 200 Church Street, Toronto, Ontario, Canada, M9N 1N8

[4] Department of Medicine, Foothills Medical Center, 1403 - 29th St NW, Calgary, Alberta, Canada, T3Z 2T9

Submitted to: Clinical Journal of the American Society of Nephrology

ABSTRACT

Background: Home dialysis (home HD or home PD) remains underutilized in most jurisdictions. Physicians, advanced practice nurses, and policy makers working with chronic kidney disease populations can provide insights into patient, health care professional, and system-level barriers to home dialysis selection by suitable patients.

Methods: We used in-depth interviews, with a purposive sampling strategy until informational redundancy was achieved, to elicit barriers and facilitators to home dialysis selection from thirteen informants. We triangulated these data against qualitative data collected in a related survey of nephrologist attitudes. We used a modified grounded-theory approach to construct a taxonomy of barriers and facilitators.

Results: Informants included nephrologists (N=11), an advanced-practice nurse, and a health administrator with a provincial renal care organization. We constructed separate taxonomies of barriers and related facilitators that were specific to PD, specific to home HD, and common to both. We distinguished between factors favouring, modifiable factors opposing, and non-modifiable factors opposing home dialysis selection. Several major themes emerged, including: medical factors, home physical environment, psychological and cognitive factors (knowledge, attitudes, coping styles), social factors (supports, lifestyle), dialysis program, local hospital or regional factors (expertise, resources, local culture), health care professional-related factors (knowledge, attitudes, reimbursement), health system-related factors (funding models), and exogenous factors (late referral, technology).

Conclusions: We identified several modifiable practices at the level of patient, health care professional, dialysis facility, and healthcare system to increase appropriate use of home dialysis. We discuss potential facilitating factors, knowledge gaps, and priorities for future research, and propose potential applications for this novel taxonomy of determinants of dialysis modality choice.

INTRODUCTION

Hemodialysis (HD) and peritoneal dialysis (PD) provided in the patient's home (home dialysis) offer patients greater autonomy and satisfaction with health care than in-facility dialysis.(Fadem et al., 2011)Home dialysis therapies have also been associated with better patient survival and quality of life.(G. E. Nesrallah et al., 2012; Pauly et al., 2010)Many renal care organizations and health systems currently seek to ensure that patients who might benefit from these therapies are

given the opportunity to select them.(Kidney Health Australia, 2013; Ontario Renal Network, 2013b; Zuber, Davis, & Rizk, 2012)

Despite growing enthusiasm and available resources, home dialysis lags behind centre HD.(Charest & Mendelssohn, 2001; Jassal, Krishna, Mallick, & Mendelssohn, 2002; Jung, Blake, Mehta, & Mendelssohn, 1999; Mendelssohn, 2002; Mendelssohn, Mullaney, Jung, Blake, & Mehta, 2001) Variation in utilization patterns, as well as surveys of nephrologists' attitudes across a range of health systems suggest that dissociation exists between achievable and achieved home dialysis rates.(Hingwala et al., 2012; Mendelssohn, 2002)

Optimizing home dialysis utilization requires an understanding of contextual factors that operate at the levels of patient, health-care provider, and health-care system.(Mattern et al., 1989) Systematic approaches to PD selection have been developed,(Blake, Quinn, & Oliver, 2013)and opinion pieces specifically addressing barriers to home HD have been published.(Young et al., 2012) With the recent interest in and proliferation of home dialysis, however, patients and health care professionals approaching modality decisions need an integrated approach that considers the relative benefits and disadvantages of all home therapies.

Contemporary knowledge translation strategies offer methods for managing barriers at both the patient and health care professional level.(Cochrane et al., 2007; Legare, Ratte, Gravel, & Graham, 2008) An initial step in barrier management is the development of comprehensive framework or taxonomy of barriers, and strategies to overcome them (facilitators). A taxonomy can then guide the development of questionnaires, decision aids, and other knowledge translation tools. We therefore conducted this qualitative study to develop a taxonomy for the determinants of home dialysis selection.

METHODS

Study Overview and Design

This was a qualitative study in which we used in-depth interviews to gain insight into informants' experiences, knowledge, attitudes, and behaviours. The study was approved by the McMaster University (Hamilton, Canada) Research Ethics Board. We read a participant letter of information to each informant, and obtained and digitally recorded verbal consent before starting each interview. We de-identified interview transcripts to ensure confidentiality of responses.

Setting

In Canada, healthcare spending and policies related to renal care fall within the jurisdictions of ten provinces and three territories, within which there is considerable variability in population size, geography, proximity of patients to kidney care facilities,(Iliescu, Yeates, McComb, & Morton, 2006)case-mix,(Canadian Institute for Health Information, 2012)and availability of multi-disciplinary care.(Canadian Institute for Health Information, 2012)It was therefore necessary to include a broad and representative sample of informants in developing a taxonomy that is applicable on a national level.

Sample

We developed a maximum variation purposive sampling strategy which included practicing nephrologists, advanced-practice nurses, and administrators with experience in home dialysis.(Patton, 2002) To better understand barriers, we included nephrologists practicing in environments where the availability of home therapies is limited, in various Canadian provinces, in both university-affiliated and community programs.

Data Collection

Interviews

An experienced qualitative researcher (KO) conducted semi-structured in-depth interviews in person or by telephone. This interview format allowed for inquiry into pre-specified areas of interest, while allowing the flexibility to explore and probe deeper into the unique perspectives of our informants. We developed an interview guide based on a published dialysis modality decision aid,(G. Nesrallah, Blake, & Mendelssohn) and also included questions pertaining to scope of practice, dialysis prescription behaviours, attitudes towards home dialysis therapies, and perceptions regarding home dialysis barriers and facilitators. All interviews were digitally recorded and a medical transcriptionist transcribed interviews verbatim.

Qualitative Survey Data

We used the penultimate version of our taxonomy to develop a survey of nephrologist attitudes towards barriers and related facilitator interventions. Survey development methods and findings are reported elsewhere; respondent characteristics are in Chapter 3, Table 1 of this thesis. Each survey domain was followed by a free-text field, and respondents were asked to propose additional factors that they felt impacted on modality choice. We triangulated our findings against this qualitative data.

Analysis

We used an analytical approach largely based on grounded theory.(Corbin & Strauss, 2008) Specifically, a first reading of the data identified a large number of open codes; we then grouped codes into categories (axial coding) that reflected the types of barriers and facilitators that limit or enhance the uptake of home dialysis. Since we could have framed factors either positively as facilitators, or negatively as barriers, we framed each factor as informants presented it. We then developed a taxonomy that reflected the lower and higher order codes, and directly addressed the research question. Through this process, we continued data collection until we reached saturation. Data analysis was recursive, moving from open to axial coding several times and leading towards saturation. The analysis departed from typical grounded theory approaches in that data collection and analysis was informed from the outset by targeted research questions, rather than a general topic of inquiry. We considered this hybrid approach appropriate, given our *a priori* knowledge, expertise, and knowledge of existing relevant literature. We extracted exemplar quotes verbatim, and summarized them in a tabular format.

RESULTS

Participants

Characteristics of study participants are in Table 1. All nephrologists were male. Four had proficiency in home HD, six in PD, one in neither, and two in both. We interviewed one nurse clinician and one administrator as well. We terminated interviews after achieving saturation.

Overarching Framework

Our final framework distinguished between factors specific to HD, factors specific to PD, and factors common to both. Informants felt that an intuitive and clinically applicable classification scheme should sub-divide factors into three broad categories: factors strongly favouring, modifiable barriers to, and insurmountable barriers to home HD or PD. This overarching framework is similar to that used in the Method to Assess Treatment Choices for Home Dialysis (MATCH-D) tool,(Home Dialysis Central, 2004) but further divides barriers into 9 domains. These include: medical factors, home physical environment, psychological and cognitive factors, social factors, dialysis program, local hospital or regional factors, health care professional-related factors (physicians, nurses, and allied healthcare staff), health system-related factors, and exogenous factors. Using this framework, we classified modality barriers (bold font) and facilitators (italic and in parentheses) as shown in Tables 3, 4, and 5.

General Approach to Patient and Modality Selection

No programs had a formal "PD first" policy in effect. All nephrologist informants (N=11) had specific views on the importance of personal practices regarding patient selection for home dialysis. While the majority (N=8/11, 73%) referred most or all patients for predialysis education, 3/11 (27%) reserved home dialysis education for younger patients or those with lower levels of comorbidity. One informant stated that home HD training was a scarce resource with a wait-list, and that triaging of younger or employed patients was necessary. Those who referred all or most patients for modality education felt that education was a key determinant of modality choice. Those who did not, felt that most patients were not able to undergo home dialysis.

Among those who referred all or most of their patients for modality education, a second key factor was perceptions regarding comparative effectiveness of home versus centre therapies, leading to different approaches to shared decision-making. Some placed a higher value on patient autonomy, and a lower value on the benefits of home dialysis:

"…we have to make sure we don't give up the fundamental ethical principle … which is to provide people choice in their health care, support them in those choices, even if we don't agree with those choices."

Others placed a higher value on benefits of home dialysis:

"…you know there are some nephrologists who feel that you should present the information unbiased and let the patients choose; my feeling is to present the information unbiased and then you should make fairly strong recommendations in favour of home dialysis if you think the patient is suitable. That is, we have an obligation to promote it, not just to be passive about it. That's my view."

Others expressed strong views about the benefits of home (intensive) dialysis and felt that physicians should present it as a better therapy; one informant recognized this approach to be potentially controversial:

"I don't think we are actually doing anyone any favours by presenting conventional in-center hemodialysis as though it were an equal option to intensive hemodialysis… I think it is so unpopular to actually say, you know what, 'In-center is a crappy option and you shouldn't even be thinking about this unless you have absolutely no alternative.' You know what, frankly it's, just very unpopular to even say such a thing in our culture…"

Factors Common to Home HD and PD

Table 2 contains exemplar quotes (labeled Q1, Q2, etc.), supporting major themes. Table 3 summarizes barriers and facilitators influencing both home HD and PD.

Factors Favouring Home Dialysis

Failure of the alternative home-based therapy, renal allograft failure, desire for independence (Q8), self-care ability, strong support structures (Q10), health-literacy, long distance from dialysis centres, impaired mobility, and need for flexible scheduling were identified as major patient-specific factors strongly favouring home dialysis choice. Facility and health-system factors strongly favouring home dialysis included facility expertise, patient selection practices (broad versus restrictive; Q11, Q12), multidisciplinary home dialysis rounds (Q13), processes for transferring patients from centre to home (Q14), and quality improvement initiatives promoting predialysis education. We identified several aspects of dialysis modality and predialysis education as favouring home therapies.

Potentially Modifiable Barriers to Home Dialysis

Disabilities, uncontrolled medical conditions, and lack of suitable housing were among well-recognized barriers cited by informants; related facilitating factors are in Table 3. Psychological and cognitive factors, including indecision (Q3), sick-role behaviours (Q4), dependency (Q5), caregiver burden, knowledge gaps (Q6), fear of home self-care (Q7), and reluctance to 'medicalize' the household (Q9) were identified as barriers potentially modified by more timely and effective pre-dialysis education and preparation of the patient and family. Potentially modifiable social factors included suitability of the home environment, adherence to medical advice, and hygiene.

Informants believed that program-specific barriers such as lack of physical space and personnel can only be addressed by payers, while attitudinal barriers, such as apathy and indifference to home therapies, might be overcome by recruitment of clinical experts and champions (Q17). Informants frequently cited the 'culture' of predialysis care as a major modifiable factor (Q15). Creating shared storage spaces or cluster dialysis facilities in more remote areas could overcome challenges posed by geographical constraints (Q16).

Informants proposed systematic administration of patient decision aids as a strategy to simultaneously address patient knowledge gaps, while ensuring that home therapies are included in all modality discussions. Finally, informants identified late referral to a nephrologist as a modifiable exogenous factor that could significantly affect modality choice.

Non-modifiable Barriers

These factors largely included potentially modifiable factors not responsive to appropriate intervention. Informants considered small program size, with failure to realize economies of scale a potentially insurmountable barrier.

Factors Specific to Home HD

Table 4 itemizes determinants of home HD selection.

Factors Favouring Home HD

Medical indications for home HD, included indications for longer or more frequent ("intensive") HD, such as: planned or current pregnancy, refractory volume excess, hypertension, and suboptimal clearance. Informants cited psychological factors, including personality traits as determinants of selection of and success with home HD. System-level factors included funding for equipment, staff, training, consumable materials, and monitoring. Informants felt that external forces, e.g. a secular trends and availability of equipment adapted for home HD could drive greater uptake of these therapies.

Potentially Modifiable Barriers to Home HD

Informants cited hearing impairment, contraindications to anticoagulants, limited vascular access flow, and difficult cannulation as modifiable barriers, with corresponding facilitating factors shown in Table 3. We identified several modifiable barriers related to water (Q2) and electricity. Informants considered fear of machines, blood, and needles, and other reasons for reluctance to self-cannulate potentially amenable to intervention. Frequent travel could represent a barrier to using a conventional home HD machine, which our informants suggested could be overcome with the use of a portable device with on-line dialysate generation of prefilled dialysate bags. We identified several health care professional-level knowledge and attitudinal barriers, which we summarize in Table 4. Notable among these, was the perception that only young and healthy patients are capable of undergoing home HD (Q18). One informant noted that the recent proliferation of satellite dialysis facilities in their catchment area was followed by a significant decline in home HD referral rates (Q19), suggesting that the availability of dialysis facilities closer to patients homes can impact on home HD utilization. Similarly, informants identified competition with an established PD program as a potential factor. We identified financial barriers related to several aspects of home HD provision. Components of home HD cost included training (Q20), equipment, consumables, medications, nursing, home visits, plumbing and electrical work, water, and electricity. Informants identified varying levels and mechanisms of funding for each of these items in their

jurisdictions. Informants cited the technical complexity of home HD machines as a major exogenous factor (Q21).

Non-modifiable Barriers to Home HD

Lack of vascular access, adequate water supply, and lack of funding for water and electricity were potentially insurmountable factors.

Factors Specific to PD

Factors specific to PD are in Table 5.

Factors Favouring PD

Medical factors favouring PD included absence of prior abdominal surgery, lack of vascular access or transplant options, and any medical contraindication to HD in a person seeking home therapy. A 'PD first' approach was identified as a system-level factor.

Potentially Modifiable Barriers to PD

We identified prior abdominal surgery, colostomy, hernias, polycystic kidneys and mechanical back pain as potentially modifiable barriers to PD; related facilitators are in Table 5. Informants did not consider loss of residual renal function an absolute contraindication to PD, but suggested that physicians would need to consider the feasibility of meeting clearance and ultrafiltration targets. Informants thought that barriers related to knowledge and attitude were common but potentially remediable. Informants did not consider lower physician reimbursement for PD a major factor. Informants cited local wait times and access to PD catheter implantation and support services as modifiable factors.

Non-modifiable Barriers to PD

We identified irreversible anatomical problems and PD-related complications (peritonitis, membrane failure, metabolic syndrome and loss of access) as insurmountable barriers.

DISCUSSION

Despite growing enthusiasm and availability of resources, Canadian prevalent rates for home HD (4.0%) and PD (17.1%) have lagged far behind centre HD (78.9%) rates over the last decade.(Canadian Institute for Health Information, 2013)Although recent Canadian figures are consistent with those of other developed nations, a prevalent rate of 30% for home dialysis in Australia suggests

that there is room for improvement.(Kidney Health Australia, 2012) While it is clear that not all patients are well-suited for home-based therapy, there is consensus within the renal community that the current modality distribution is not optimal.(Jung et al., 1999) In this study, we present a contemporary taxonomy of barriers and facilitators, which can inform research evaluating policies, services, and the development of knowledge translation tools to ensure that suitable patients have the opportunity to consider home dialysis.

Physician perceptions regarding the comparative effectiveness of home versus in center therapies surfaced as a key driver of modality choice. Some informants considered all dialytic therapies on par, while others considered intensive home HD superior, and worthy of promoting as the first-line therapy. Unfortunately, studies evaluating the comparative effectiveness of home (HD and PD) versus in-center therapies are limited by significant selection bias,(G. E. Nesrallah, Moist, Awaraji, & Lindsay, 2004) and clinical trials addressing these questions have not been feasible.(G. E. Nesrallah et al., 2012; Weinhandl, Liu, Gilbertson, Arneson, & Collins, 2012) Clinical experience and subjective interpretation of the literature therefore likely influence physician perceptions of modality efficacy. Nevertheless, a growing body of evidence suggests potential benefits with more intensive HD in specific populations,(Barua et al., 2008) a predominantly home-based modality in Canada.(G. E. Nesrallah et al., 2013)

Over the last decade, the largest rate of growth in the Canadian and US ESRD populations have been in those above 65 years.(Canadian Institute for Health Information, 2013; U.S. Renal Data System) Frailty and disability have become increasingly important considerations in understanding modality distribution. Our informants considered impaired mobility and long-term care residence to represent excellent opportunities for home dialysis. Some have advocated for assisted PD for more marginal populations, on the basis of potentially improved quality of life and lower cost,(Dimkovic et al., 2009; Oliver et al., 2007) while we and others have argued that the overall impact of such an approach may be small and the incremental costs not clearly justified.(Mendelssohn, 2007) Even less is known about the cost-effectiveness of assisted home HD, though assistance by an unpaid or informal caregiver is likely common and not associated with added health system costs.

Predialysis education emerged as a major patient-level factor since it is a prerequisite for informed decision-making,(Golper, Guest, Glickman, Turk, & Pulliam, 2011; G. Nesrallah & Mendelssohn, 2006) and since it promotes home dialysis selection.(Manns et al., 2005) Informants described polarized approaches to patient selection and modality education: virtually all versus the selected few, which may account for program and physician variance in home dialysis rates.(Hingwala et al., 2012) The Ontario Renal Network has recently established the provision of predialysis education to 100% of patients approaching dialysis as

a strategic priority and clinical performance measure.(Ontario Renal Network, 2013b)

Strategies to optimize the effectiveness of patient education interventions are also of interest, and priority questions include: how to accommodate various learning styles, personality types, health literacy levels, language barriers, levels of family or caregiver involvement, and cultural considerations.(G. E. Nesrallah & Mendelssohn, 2013) Practical aspects of the education intervention warrant further study – timing, frequency, and format (didactic versus interactive, individual versus group). Finally, contemporary knowledge translation strategies are theory-driven, and further insights into how to balance diverse patient needs with available education resources and expertise are needed.

Knowledge gaps also impact on health-care professional behaviours.(Kitson & Straus, 2010) Even in Canada, where enthusiasm for home dialysis is high, only 32% and 71% of 97 facilities offered home HD and PD training in 2011.(Canadian Institute for Health Information, 2013) The availability of funding for home therapies in all Canadian provinces argues against pervasive system-level factors. In a recent survey of Canadian nephrologists, 57 of 205 (28%) respondents had 2 or more months of training in home HD, versus 84% with PD (Chapter 3 of this thesis). Self-rated competency in home HD (15.8%) and PD (55.6%) are even lower in the US, where home dialysis rates are lower as well.(Berns, 2010) Collectively, these observations suggest that physician competency may be an important factor. The effectiveness of decision support systems and other knowledge translation strategies are of major interest in Canada.(The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET), 2013) Hiring of advanced practice nurses/case managers with dedicated training in modality education may overcome local knowledge gaps. The Ontario Renal Network has adopted this approach, and will study its effectiveness over time.

Funding and resources surfaced as major determinants of availability of home therapies. Recently, Ontario has gravitated towards a bundled payment system similar to the prospective payment system (PPS) adopted by the US Centres for Medicare & Medicaid Services (CMS) in 2011.(Department of Health and Human Services) While this funding model underwent public commentary between 2007-2009, the prevalent rate for PD in the US increased by 13.2%.(U.S. Renal Data System) This could be attributed to greater profitability of PD under the PPS,(Golper et al., 2011) and speaks to the effectiveness of financial incentives. Although Canadian facilities are primarily not-for-profit, growing financial pressures force them to realize efficiencies where possible, to defray the costs of under-funded services. Therefore, the introduction of bundles in Canada may improve PD utilization, though this remains to be seen. The picture for home HD is more complex. Although typically considered more costly than PD, recent

micro-costing data from Ontario demonstrate a narrowing gap between all home-based therapies.(Ontario Renal Network, 2013a)

Physician reimbursement rates for PD are lower than for HD in most of Canada. Since PD and HD physician reimbursement were set at par in Ontario in 1998, PD rates have remained near the national average.(Mendelssohn, Langlois, & Blake, 2004)In the US, where home dialysis prevalent rates are even lower, physicians receive a one-time payment upon a patients' completion of home dialysis training. This seems to have had little impact on home dialysis uptake, again supporting the notion that physician reimbursement may not be a major factor. On the other hand, PD is reimbursed at a lower rate over the longer term in the US, and this may be an important barrier. Regardless of the real impact of physician reimbursement, it seems likely that physicians would rather avoid being placed in a conflict of interest scenario – whether real or perceived – and parity across all modalities seems the best way to achieve this.

Strengths and Limitations

To our knowledge, this is the first study to apply rigorous qualitative methods to understand dialysis modality selection in Canada. Data obtained from nephrologists was corroborated by other health professionals, which led to saturation and provided data source triangulation. Although determinants of modality choice are likely to vary across health systems, our findings are likely generalizable beyond Canada.

A minor limitation is underrepresentation of some Canadian provinces and the territories. However our sample was representative of the various practice environments in Canada, including rural, urban, and remote areas.

Implications for Practice and Research

We identified a number of barriers and facilitators that are germane to modality decisions, but we cannot quantify the magnitudes of their relative effects. This study can therefore not directly inform practice or policy. The identification of these factors should instead, be viewed as a starting point for future research directed at improving home dialysis utilization.

Users of this framework can construct tools specific to their respective jurisdictions to assess local barriers, and the likelihood of success of candidate facilitator interventions. Using this taxonomy, we have developed a Canadian national survey of physician attitudes towards barriers and potential solutions (Chapter 3 of this thesis). The Ontario Renal Network has also incorporated this taxonomy into a measurement framework that will track "reason codes" for selection of in-center hemodialysis.(Ontario Renal Network, 2013c) Real-time

measurement of barriers operational in Ontario will allow us to better plan programs and services in the longer term.

This taxonomy may also serve as an educational tool for health care professionals seeking to better understand modality selection, and even to become more aware of their own inherent biases. Moreover, this framework can be used in the development of patient and health care professional educational materials, and clinical decision support tools.

CONCLUSION

The primary aim of this study was to identify barriers and facilitators to home dialysis adoption. We identified several potential barriers operational across the patient, health care professional, and health system levels, as well as several potential mitigating factors. The large number of factors highlights the complexity of modality decisions, and the breadth of expertise, services, and tools required by healthcare professionals in guiding their patients through modality choices. Global efforts informed by a systematic approach may be more successful in promoting home therapies in the long term.

ACKNOWLEDGMENTS

The authors wish to thank the study participants for sharing their knowledge and expertise.

DECLARATION OF COMPETING INTERESTS

None declared.

DISCLAIMER

The opinions expressed in this manuscript primarily represent the views of the study's informants, and do not necessarily reflect those of the study authors. It is beyond the scope of this descriptive study to endorse or refute the effectiveness, safety, appropriateness, or ethical soundness of described interventions.

REFERENCES

Barua, M., Hladunewich, M., Keunen, J., Pierratos, A., McFarlane, P., Sood, M., et al. (2008). Successful pregnancies on nocturnal home hemodialysis. *Clin J Am Soc Nephrol, 3*(2), 392-396. doi: 10.2215/CJN.04110907

Berns, J. S. (2010). A survey-based evaluation of self-perceived competency after nephrology fellowship training. *Clin J Am Soc Nephrol, 5*(3), 490-496. doi: 10.2215/CJN.08461109

Blake, P. G., Quinn, R. R., & Oliver, M. J. (2013). Peritoneal Dialysis and the Process of Modality Selection. *Peritoneal Dialysis International, 33*(3), 233-241. doi: 10.3747/pdi.2012.00119

Canadian Institute for Health Information. (2012). Treatment of End-Stage Organ Failure in Canada, 2001 to 2010—CORR 2012 Annual Report: Canadian Institute for Health Information,.

Canadian Institute for Health Information. (2013). Treatment of End-Stage Organ Failure in Canada, 2002 to 2011—CORR 2013 Annual Report. from https://secure.cihi.ca/estore/productFamily.htm?locale=en&pf=PFC1696

Charest, A. F., & Mendelssohn, D. C. (2001). Are North American nephrologists biased against peritoneal dialysis? *Perit Dial Int, 21*(4), 335-337.

Cochrane, L. J., Olson, C. A., Murray, S., Dupuis, M., Tooman, T., & Hayes, S. (2007). Gaps between knowing and doing: understanding and assessing the barriers to optimal health care. *J Contin Educ Health Prof, 27*(2), 94-102. doi: 10.1002/chp.106

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* (3 ed.). London, UK: Sage Publications Inc.

Department of Health and Human Services. Medicare Program; End-Stage Renal Disease Prospective Payment System, Quality Incentive Program, and Bad Debt Reductions for All Medicare Providers; Final Rule. *Federal Register, 77*(218), 67449-67531.

Dimkovic, N., Aggarwal, V., Khan, S., Chu, M., Bargman, J., & Oreopoulos, D. G. (2009). Assisted peritoneal dialysis: what is it and who does it involve? *Adv Perit Dial, 25*, 165-170.

Fadem, S. Z., Walker, D. R., Abbott, G., Friedman, A. L., Goldman, R., Sexton, S., et al. (2011). Satisfaction with renal replacement therapy and education: the American Association of Kidney Patients survey. *Clin J Am Soc Nephrol, 6*(3), 605-612. doi: 10.2215/CJN.06970810

Golper, T. A., Guest, S., Glickman, J. D., Turk, J., & Pulliam, J. P. (2011). Home dialysis in the new USA bundled payment plan: implications and impact. *Perit Dial Int, 31*(1), 12-16. doi: 10.3747/pdi.2010.00143

Hingwala, J., Diamond, J., Tangri, N., Bueti, J., Rigatto, C., Sood, M. M., et al. (2012). Underutilization of peritoneal dialysis: the role of the nephrologist's referral pattern. *Nephrol Dial Transplant*. doi: 10.1093/ndt/gfs323

Home Dialysis Central. (2004). Method to Assess Treatment Choices for Home Dialysis (MATCH-D). Retrieved July 11, 2013, 2013, from http://homedialysis.org/match-d

Iliescu, E. A., Yeates, K. E., McComb, J., & Morton, A. R. (2006). Modality choice among Aboriginal incident dialysis patients--influence of geographic location. *Perit Dial Int, 26*(4), 507-508.

Jassal, S. V., Krishna, G., Mallick, N. P., & Mendelssohn, D. C. (2002). Attitudes of British Isles nephrologists towards dialysis modality selection: a questionnaire study. *Nephrol Dial Transplant, 17*(3), 474-477.

Jung, B., Blake, P. G., Mehta, R. L., & Mendelssohn, D. C. (1999). Attitudes of Canadian nephrologists toward dialysis modality selection. *Perit Dial Int, 19*(3), 263-268.

Kidney Health Australia. (2012). A Model for Home Dialysis, Australia. Retrieved July 15, 2013, 2013, from http://www.kidney.org.au

Kidney Health Australia. (2013). Home Dialysis: a Support Resource for Your Home Dialysis Journey. Retrieved July 11, 2013, 2013, from http://homedialysis.org.au

Kitson, A., & Straus, S. E. (2010). The knowledge-to-action cycle: identifying the gaps. *CMAJ, 182*(2), E73-77. doi: 10.1503/cmaj.081231

Legare, F., Ratte, S., Gravel, K., & Graham, I. D. (2008). Barriers and facilitators to implementing shared decision-making in clinical practice: update of a systematic review of health professionals' perceptions. *Patient Educ Couns, 73*(3), 526-535. doi: 10.1016/j.pec.2008.07.018

Manns, B. J., Taub, K., Vanderstraeten, C., Jones, H., Mills, C., Visser, M., et al. (2005). The impact of education on chronic kidney disease patients' plans to initiate dialysis with self-care dialysis: a randomized trial. *Kidney Int, 68*(4), 1777-1783. doi: 10.1111/j.1523-1755.2005.00594.x

Mattern, W. D., McGaghie, W. C., Rigby, R. J., Nissenson, A. R., Dunham, C. B., & Khayrallah, M. A. (1989). Selection of ESRD treatment: an international study. *Am J Kidney Dis, 13*(6), 457-464.

Mendelssohn, D. C. (2002). Reflections on the optimal dialysis modality distribution: a North American perspective. *Nephrology news & issues, 16*(4), 26-30.

Mendelssohn, D. C. (2007). A skeptical view of assisted home peritoneal dialysis. *Kidney Int, 71*(7), 602-604. doi: 10.1038/sj.ki.5002153

Mendelssohn, D. C., Langlois, N., & Blake, P. G. (2004). Peritoneal dialysis in Ontario: a natural experiment in physician reimbursement methodology. *Perit Dial Int, 24*(6), 531-537.

Mendelssohn, D. C., Mullaney, S. R., Jung, B., Blake, P. G., & Mehta, R. L. (2001). What do American nephologists think about dialysis modality selection? *Am J Kidney Dis, 37*(1), 22-29.

Nesrallah, G., Blake, P. G., & Mendelssohn, D. *Modality Options for End-Stage Renal Disease Care* (2nd ed.). Philadelphia, Pennsylvania: Elsevier Saunders.

Nesrallah, G., & Mendelssohn, D. C. (2006). Modality options for renal replacement therapy: the integrated care concept revisited. *Hemodial Int, 10*(2), 143-151. doi: HDI86 [pii]
10.1111/j.1542-4758.2006.00086.x

Nesrallah, G. E., Lindsay, R. M., Cuerden, M. S., Garg, A. X., Port, F., Austin, P. C., et al. (2012). Intensive hemodialysis associates with improved survival compared with conventional hemodialysis. *J Am Soc Nephrol, 23*(4), 696-705. doi: 10.1681/ASN.2011070676

Nesrallah, G. E., & Mendelssohn, D. C. (2013). Reflections on education interventions and optimal dialysis starts. *Perit Dial Int, 33*(4), 358-361. doi: 10.3747/pdi.2013.00077

Nesrallah, G. E., Moist, L. M., Awaraji, C., & Lindsay, R. M. (2004). An international registry to compare quotidian dialysis regimens with conventional thrice-weekly hemodialysis: why, how, and potential pitfalls. *Semin Dial, 17*(2), 131-135. doi: 10.1111/j.0894-0959.2004.17210.x
SDI17210 [pii]

Nesrallah, G. E., Mustafa, R. A., Macrae, J., Pauly, R. P., Perkins, D. N., Gangji, A., et al. (2013). Canadian society of nephrology guidelines for the management of patients with ESRD treated with intensive hemodialysis. *Am J Kidney Dis, 62*(1), 187-198. doi: 10.1053/j.ajkd.2013.02.351

Oliver, M. J., Quinn, R. R., Richardson, E. P., Kiss, A. J., Lamping, D. L., & Manns, B. J. (2007). Home care assistance and the utilization of peritoneal dialysis. *Kidney Int, 71*(7), 673-678. doi: 10.1038/sj.ki.5002107

Ontario Renal Network. (2013a). 2013/14 Chronic Kidney Disease (CKD) FUnding Guide - Guide to CKD Program Reimbursement. Retrieved April 1st, 2013, from http://www.renalnetwork.on.ca

Ontario Renal Network. (2013b). The Ontario Renal Plan. Retrieved July 11, 2013, 2013, from http://www.renalnetwork.on.ca/ontario_renal_plan/independent_dialysis/ -.Ud68eBboghw

Ontario Renal Network. (2013c). Ontario Renal Reporting System (ORRS) Data Dictionary (pp. 35-37). Toronto, Ontario: Cancer Care Ontario.

Patton, M. (2002). *Qualitative Research and Evaluation Methods* (3rd ed.). Thousand Oaks, California: Sage Publications.

Pauly, R. P., Maximova, K., Coppens, J., Asad, R. A., Pierratos, A., Komenda, P., et al. (2010). Patient and Technique Survival among a Canadian Multicenter Nocturnal Home Hemodialysis Cohort. *Clin J Am Soc Nephrol*. doi: CJN.00300110 [pii]
10.2215/CJN.00300110

The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET). (2013). Advancing Kidney Care and Research in Canada. from http://www.cann-net.ca

U.S. Renal Data System. USRDS 2012 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States. 2012, from http://www.usrds.org/atlas.aspx

Weinhandl, E. D., Liu, J., Gilbertson, D. T., Arneson, T. J., & Collins, A. J. (2012). Survival in daily home hemodialysis and matched thrice-weekly in-center hemodialysis patients. *J Am Soc Nephrol, 23*(5), 895-904. doi: 10.1681/ASN.2011080761

Young, B. A., Chan, C., Blagg, C., Lockridge, R., Golper, T., Finkelstein, F., et al. (2012). How to overcome barriers and establish a successful home HD program. *Clin J Am Soc Nephrol, 7*(12), 2023-2032. doi: 10.2215/CJN.07080712

Zuber, K., Davis, J., & Rizk, D. V. (2012). Kidney disease education one year after the Medicare Improvement of Patients and Providers Act: a survey of US nephrology practices. *Am J Kidney Dis, 59*(6), 892-894. doi: 10.1053/j.ajkd.2012.02.324

TABLES

Table 1. Characteristics of study informants (N=13)

Participant / Characteristic	**Value**
Nephrologists (N=11)	
Years in practice, mean ± SD	16.1 ± 9.9
Years in practice, median (range)	12 (4-30)
Age in years, mean ± SD	48.2 ± 8.6
Age in years, median (range)	45 (38-60)
Female, N (%)	0 (0)
University-based practice, N (%)	5 (45)
Community-based practice, N (%)	6 (55)
Home HD proficiency, N (%)	4 (36)
PD proficiency, N (%)	6 (55)
No home dialysis proficiency, N (%)	1 (9)
Peritoneal and home HD proficiency, N (%)	2 (18%)
% Work hours spent in clinical activities, median (range)	65 (20-90)
% Clinical hours spent in dialysis, median (range)	54 (30-75)
Nurse clinician (N=1)	
Years in practice	27
Female, N (%)	1 (8)
Age in years	49
Renal care administrator (N=1)	
Years in practice	
Female, N (%)	1 (8)
Age in years	

Table 2. Exemplar quotes supporting major themes.

MEDICAL FACTORS
Q1: "I don't think we have ever declined someone on medical grounds. Okay, that's not entirely true. We did have someone who was nearly blind and didn't have the support of someone at home, and he just couldn't tell what fluid was in which chamber, and what line was being filled with what, to couldn't see the different colors on the screen, and he was just completely unsafe, so after several weeks of training, we just had to pull the plug."
HOME PHYSICAL ENVIRONMENT
Q2. "We also have other people coming in – referrals – their water quality is even worse… people that are living on the farms and use well water – that's another problem. About 500 litres per night, most of the sewage systems outside the city cannot handle that kind of volume every day. Another challenge is you can't consume that much water, or you can, but it costs too much."
PSYCHOLOGICAL AND COGNITIVE FACTORS
Q3. "the Ministry [of Health] ask 'why do we have these 50% 'crash starts'?' As a Clinical Nephrologist I've got to come back to them and say, 'You will never get rid of that because people don't decide until they're sick'."
Q4. "They come in here, get on the chair, stretch their arm out, and everything is done for them."
Q5. "Some people are more independent they want to be out of the hospital and others are dependent and want to be in the hospital."
Q6. "I don't think there is a true informed consent when it relates to dialysis … somehow we need to communicate in a meaningful way the ramifications of renal replacement modality to someone for whom this is really an abstract concept – and it will remain an abstract concept for that person until they are physically doing it."
Q7. "… 'I am safe in the hospital because if something happens to me the team will be there'."
SOCIAL FACTORS
Q8. "…encouraging them to talk to me about their lifestyle, what they do for a living, if they're retired … getting to know the person, finding what is important to them, and telling them to use that as their basis for deciding [on a modality]"
Q9. "…a working mother and divorced recently, I tried to get her on PD and thought she would have done very well, but she didn't want her children to see that she was on dialysis. She didn't want to bring it home…"
Q10. "…I think the home care system relies on the invisible work of family members…"

DIALYSIS PROGRAM, LOCAL HOSPITAL, OR REGIONAL FACTORS

Q11. "To push the barrier and get more patients at home you have to go away from the ideal [patients] and deal with the suitable ones, the ones that you can overcome whatever the barriers are."

Q12. "…our whole philosophy at this stage is that we should be dialyzing at home unless there is a reason not to…"

Q13. "Because we have these interdisciplinary meetings every two weeks so we ensure that every single patient that starts our programs completes the modality assessment process."

Q14. "We do not give up on people even though they started in our In-centre and as a result we have a pretty measurable transfer rate from HD to PD and sometimes home HD as well."

Q15. I believe CKD clinic 'culture' is critical to PD uptake. We have to promote a culture of self-dialysis (PD and home HD) from the earliest phases. We have to rebrand dialysis as PD/home rather than in centre HD as is currently the case."

Q16. "In the greater Northern Ontario one of the challenges is road access. So why not create a storage unit to store their supplies?"

HEALTH CARE PROFESSIONAL-RELATED FACTORS

Q17. "[The physician]…has to believe in the therapy whatever the therapy may be – it's not just about process – it's also about belief and I think a physician has to project as well as nursing leaders and other nurses that they truly believe in this therapy and that resonates throughout the program. Whether it is PD or home HD, people can sense when people don't believe it."

Q18. "There's still a perception that home hemodialysis is only there for the 'best' patients…the youngest, most physically, and cognitive capable patients. And I think that a lot of health care providers, who don't routinely care for hemodialysis patients, don't get that's not necessarily the case."

HEALTH SYSTEM-RELATED FACTORS

Q19. "One of our barriers is that the Ministry wanted us to put in a satellite, which we did; I have a feeling that we would have a significantly more home patients if we didn't put that satellite there…like a few of your patients they moved closer to the satellite. And they are quite happy to go down the street to their satellite unit and go back home and not have any fuss and bother. Okay. A similar patient that's twenty miles away, might say, "I'd rather do it at home because I don't want to face the traffic three times a week."

Q20. "The barriers are actually financial … we are only given budget to train a certain number of people."

EXOGENOUS FACTORS

Q21. "….the main barrier is that it is hard. You need to take a month or more to train somebody and it's frightening and difficult still. The machines are not made for home, the software is not patient friendly or easy, so it is frightening and challenging."

Table 3. Factors that influence home dialysis selection (factors common to home HD and PD)

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
MEDICAL FACTORS		
Mobility-impaired, frail, or bedridden patient who lives at home or long-term care *(PD or HD provided by formal or informal caregiver)* **Pending renal allograft failure**	**Significant disability:** • **Frailty** • **Visual impairment** • **Impaired manual dexterity** • **Cognitive impairment** *(PD or HD provided by formal or informal caregiver)* **Medical barriers:** • **Seizure disorder** • **Recurrent hypoglycemia** *(trial of medical therapy and reassess)*	**Significant disability and no assistance available:** • **Visual impairment** • **Impaired manual dexterity** • **Cognitive impairment** **Uncontrolled medical conditions:** • **Seizure disorder** • **Hypoglycemia** **Transplantation of suitable home dialysis candidates (desirable outcome)**
HOME PHYSICAL ENVIRONMENT		
	Homeless *(consider community or public housing; 'cluster', or self-care HD)* **Inadequate space for equipment and materials***(consider relocating; more frequent delivery of materials)*	**Homeless and no availability of non-facility-based HD**

Table 3 (continued).

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
PSYCHOLOGICAL AND COGNITIVE FACTORS		
Patient seeking independence **Strong self-management ability or health literacy**	**Patient indecision:** • **Denial** • **Reluctance to 'medicalize' household** • **Reluctance to place burden on family** *(timely and effective education, patient and family counselling, peer- or social-work support; inclusion of family members and other informal caregivers in modality planning and education; financial incentives for patients or caregivers e.g. tax credits for choosing home dialysis)* **Adoption of Sick-Role behaviour:** • **Culturally-based preference for dependence on health care professionals in decision-making** • **"Acclimatization" to in-centre or preference for "full-service" environment** • **Other factors predisposing to sick-role behaviour (secondary gain, coping style, personality traits)** *(strategies to reduce late referral; counselling and modality education for patients with unplanned starts may facilitate a transition to home dialysis e.g. by case manager; 'acute' PD catheter insertion and initiation of PD if medically appropriate)* **Difficulty comprehending or assimilating new knowledge related to modality choices** *(further research to identify optimal methods and timing for modality education; dedicated funding for patient education; gain efficiencies of scale by centralization or regionalization of educational programs)* **Perception that hospital-based therapies are safer or more sophisticated and therefore better** *(educational efforts that provide an unbiased description of pros and cons of home and centre dialysis)*	**Persistent debilitating mental health condition**

Table 3 (continued).

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
SOCIAL FACTORS		
Strong support structures (e.g. partner as dialysis helper) **Requires flexible dialysis schedule for:** • **School** • **Employment** • **Providing care for child, elder, other dependent person** • **Other reasons** **Lives significant distance from dialysis facility or unreliable transportation** **Requires portable therapy for work or leisure travel** *(portable HD devices, cycler, or CAPD)*	**Time (e.g. 6 weeks) required for training/time away from work** *(in-home training after-hours; begin with limited-care centre HD, graduate to fully independent home HD with reduced training time)* **Substance abuse disorder** *(trial of rehabilitation)* **Poor hygiene** *(educate and reassess)* **Non-adherence** *(may improve when patient regains autonomy)* **Unsanitary home environment** (*pets, plants, and other fomites should be removed from the dialysis treatment area, particularly during treatment)* **Homeless** *(consider community or public housing)* **Lives long term care facility** *(consider PD or HD training for nursing staff)* **Illiteracy or language other than local languages of instruction** *(consider developing multi-lingual educational materials, including educational videos demonstrating technical components or treatment delivery)*	**Persistent substance abuse disorder despite trial of rehabilitation** **Poor hygiene despite education** **Persistent or severe non-adherence** **Unsanitary home environment** **Homeless** **Unsafe or unstable home social environment:** • **Significant risk of domestic violence** • **Substance abuse disorder (patient or cohabitant)**

Table 3 (continued).

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
DIALYSIS PROGRAM, LOCAL HOSPITAL, OR REGIONAL FACTORS		
Local policies for mandatory review and consideration of all or most patients for eligibility for HHD or PD (e.g. via multidisciplinary rounds), including: • **Predialysis patients** • **New unplanned in-centre starts** • **Patients with anticipated graft or PD failure** **Availability of modality education for all or most pre-dialysis patients** **Human resources:** • **Provision of adequate "face time" with staff during modality education and selection process** • **Dedicated case manager, nurse educator, social workers, psychologist** **Program philosophy favouring 'home first' for all patients** **Quality improvement initiatives that evaluate practices and program factors that impact incident and prevalent (e.g. technique survival) rates**	**Local culture generally unenthusiastic about HHD or PD, resulting in inconsistent or negative messaging** *(KT initiatives targeting individual disciplines; clinical decision support tools; standardization of educational methods and materials)* **Lack of physical space for HHD training** *(relocate home dialysis unit to community/out-of-hospital setting; explore funding options)* **Lack of human resources (nurses and/or multidisciplinary care) for HHD or PD education or training** *(incentivized recruitment and training; certification programs; continuing professional development credits; explore funding opportunities)* **Local culture favours centre HD as default modality for most patients** *(recruitment of clinical leaders committed to home dialysis)* **HHD or PD not included in modality discussions – patient not aware of its existence** *(patient decision aides that include all modalities; policy mandating availability of and/or discussion of all RRT modalities for all patients approaching ESRD; standardized modality education materials that encompass all modalities)*	**Small program size precludes allocating resources to HHD or PD infrastructure**

Table 3 (continued).

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
DIALYSIS PROGRAM, LOCAL HOSPITAL, OR REGIONAL FACTORS (continued)		
Aspects of modality education: • **Timeliness** • **Provided by staff with training and expertise in patient education methods** • **Consistent messaging/standardization** • **Pace and style appropriate for learning ability (repetition, decomposition, immersion)** • **Incorporates primary caregivers** • **Use of patient peers** • **Multimedia, user-friendly** • **Multilingual, where needed** • **Group modality education** **Program experienced in HHD provision; program "maturity"** **Models of care:** • **Primary nurse model in predialysis clinic** • **Transition care (structured educational program in conjunction with new centre HD start, aimed at transition to home dialysis modality)**	**Suboptimal program size results in inefficient resource use, lack of expertise, or unsustainability** *(regional consolidation of small programs around a 'centre of excellence' with sharing of expertise and resources – improve quality and cost-efficiency of care)* **Referral centres with expertise operate at capacity and can not accept referrals for home dialysis training from smaller centres** *(develop local training programs if volumes justify; transition care [limited care setting] while awaiting training at referral centre; strategies to increase training capacity e.g. group training)* **Geography or climate preclude shipping supplies to patients' homes** *(carefully timed bulk shipments; cluster dialysis i.e. self-care in a nearby facility; local storage facilities for dialysis supplies)* **Failure to provide modality education to unplanned centre HD starts** *(case manager or multidisciplinary team to review all new starts and provide education; RightStart™ or similar multi-factorial interventions)*	

Table 3 (continued).

FAVOURING HHD OR PD	PERCEIVED OR MODIFIABLE BARRIER TO HHD OR PD	POTENTIALLY INSURMOUNTABLE BARRIER
HEALTH CARE PROFESSIONAL-RELATED FACTORS		
Perception that outcomes with home therapies are generally better than centre HD, and that patients should be encouraged to choose home on this basis	**Financial disincentives in jurisdictions where technical and/or physician fees are lower for HHD or PD** **Attitudinal barriers:** • **Unwilling to dedicate extra clinic time to modality planning discussions; particularly if patient not immediately interested** • **Perception that remuneration for modality counselling insufficient** • **Lack of motivation** • **Perception that home and centre therapies provide comparable outcomes, and that patients should not be pressured to choose one over the other**	
HEALTH SYSTEM-RELATED FACTORS		
	Lack of funding for assisted dialysis (nurse or other helper) for patients at home or in long-term care *(payers should consider pilot programs to study cost-effectiveness nurse-assisted dialysis in various home settings)* **Lack of support from hospital administration** *(education, engage hospital administrators in integrated KT strategies)* **Rapid proliferation of home therapies results in service volumes exceeding forecasted leading to a lag in funding** *(renegotiation with payers; transition to bundled payment system*	
EXOGENOUS FACTORS		
	Late referral for nephrologic care and modality planning *(develop KT strategies in conjunction with key stake-holders including primary care professional organizations, guideline panels, and educators)*	

Table 4. Factors that influence home HD selection

FAVOURING HOME HD	PERCEIVED OR MODIFIABLE BARRIER TO HOME HD	POTENTIALLY INSURMOUNTABLE BARRIER
MEDICAL FACTORS		
Requirement for longer or more frequent dialysis: • **Planned or current pregnancy** • **Large ultrafiltration requirements or hypervolemia** • **Suboptimal solute/electrolyte clearance on other modality (potassium, phosphate, urea)** • **Recurrent intradialytic hypotension e.g. Aortic Stenosis** • **Uncontrolled hypertension** • **Extraosseous calcification** **Patient seeking more intensive dialysis (longer or more frequent) with the belief that it will provide best outcome** **Failure of other modality in an independent patient:** • **Renal allograft** • **PD**	**Hearing impairment***(for nocturnal HD – informal caregiver, hearing aids, remote monitoring with telephone back-up, light or vibration-based alarms; not a barrier if patient is awake during dialysis)* **Contraindication to anticoagulants***(avoiding lower blood pump speeds e.g. <300 ml/min may be helpful)* **Low vascular access blood flow** *(longer dialysis duration allows utilizing slower pump speeds or single needle nocturnal dialysis, while maintaining adequate clearance)* **Difficult vascular access cannulation** (*patient once proficient, may cannulate better than multiple staff attempting to access)*	**No vascular access options***(consider PD or expedite transplantation)*

Table 4 (continued).

FAVOURING HOME HD	PERCEIVED OR MODIFIABLE BARRIER TO HOME HD	POTENTIALLY INSURMOUNTABLE BARRIER
HOME PHYSICAL ENVIRONMENT		
Patient owns home or has approval to make changes to electrical/plumbing or other renovations to accommodate HHD	**Inadequate plumbing or electrical supply** *(review local zoning and tenancy legislation – upgrade infrastructure where possible)* **Water supply:** • **Low pressure** *(consider lower dialysate flow rate or pre-mixed dialysate)* • **Poor water quality** *(consider alternative water purification equipment; pre-mixed dialysate; sorbent dialysis may be available for commercial use in the future)* • **Septic drain field with small water supply** *(consider lower dialysate flow or conventional thrice-weekly HHD; cluster care)*	**Insurmountable problems with water or electrical supply**
PSYCHOLOGICAL AND COGNITIVE FACTORS		
Personality traits lend themselves to HHD • **Agorophobia or fear of leaving home** • **Internal locus of control or self-efficacy, including narcissistic personalities which may benefit from being given the responsibility of HHD; such patients may have been considered "difficult" patients who challenge authority**	**Fear or phobia related to:** • **Needles** • **Blood** • **Machines** *(graded desensitization, counselling, treatment of associated anxiety disorders; cognitive behavioural therapy; consider formal or informal caregiver)* **Unable or unwilling to self-cannulate** *(cannulation by caregiver; buttonhole cannulation with topical antimicrobial prophylaxis; anaesthetic cream)* **Fear of cosmetic effect of vascular access** *(discuss values and preferences along with all available alternatives, including PD)*	

Table 4 (continued).

FAVOURING HOME HD	PERCEIVED OR MODIFIABLE BARRIER TO HOME HD	POTENTIALLY INSURMOUNTABLE BARRIER
SOCIAL FACTORS		
	No support person *(electronic life-line or remote monitoring or other ability to call in an emergency; restrict dialysis to awake hours)*	
	Support person (e.g. family member) available, but unwilling get involved *(inclusion of family members in predialysis education, counselling)*	
	Frequent travel e.g. between cottage and city every weekend or between various homes *(PD or portable HD device)*	

Table 4 (continued).

FAVOURING HOME HD	PERCEIVED OR MODIFIABLE BARRIER TO HOME HD	POTENTIALLY INSURMOUNTABLE BARRIER
HEALTH CARE PROFESSIONAL-RELATED FACTORS (*denotes factors specific to physicians)		
Perception that home HD is superior to centre HD, and that patients should be strongly encouraged to use it, when feasible	**Knowledge gaps:** • **Unawareness of existence of HHD** • **Unawareness of availability of funding for HHD** • **Unfamiliarity with technical aspects of HHD provision** • **Unfamiliarity with patient selection** *(nephrology fellowship training in HHD*; home dialysis program accreditation for HHD provision; KT initiatives and materials – physician certification programs at conferences, clinical practice guidelines, online courses, textbooks, mentorship programs through 'centres of excellence', clinical decision support tools; consider recruitment of medical and nursing staff with interest and expertise in HHD)* **Attitudinal barriers:** • **Perception that only the 'fittest' (younger, low comorbidity, high functional ability) patients should be offered HHD** • **Perception that HHD is too complex for most patients** • **Unconvinced regarding published evidence for efficacy (e.g. mortality and QoL outcomes)** • **Unconvinced re cost-effectiveness** • **Unwilling to dedicate extra clinic time to modality planning discussions; particularly if patient not immediately interested** • **Perception that remuneration for modality counselling insufficient*** • **Perception that HHD increases medical malpractice liability*** • **Lack of motivation**	

Table 4 (continued).

FAVOURING HOME HD	PERCEIVED OR MODIFIABLE BARRIER TO HOME HD	POTENTIALLY INSURMOUNTABLE BARRIER
DIALYSIS PROGRAM, LOCAL HOSPITAL, OR REGIONAL FACTORS		
	Proliferation of satellite dialysis units creates disincentives for HHD **Competition with PD program** *(patients eligible for both HHD and PD should receive unbiased education regarding both modalities; medical factors, patient values, preferences, and life-style needs should inform modality choice)*	
HEALTH SYSTEM-RELATED FACTORS		
Existing funding mechanisms for: • **Capital equipment costs** • **Consumable material costs** • **Training** • **In-home nursing support** • **On-call nursing support** • **Remote nocturnal monitoring**	**Lack of funding for more frequent dialysis e.g. incremental cost of consumable materials** *(varies with jurisdiction – where funding mechanisms exist for HHD, thrice weekly nocturnal HD can be provided at the same cost as conventional HD*) **Lack of funding for water and electricity** *(consider installation of solar panels and other 'green' technologies where appropriate; explore funding mechanisms)* **Inadequate human resources (nephrologists, nurses, other)** *(consider financial incentives or support for relocating to underserviced areas; align training program enrolment with human resource needs)*	**Lack of funding for any home HD (capital for equipment, training, home modification)**
EXOGENOUS FACTORS		
International secular trends favouring greater uptake of HHD **Increasing availability of dialysis equipment adapted for use at home**	**Dialysis equipment remains technologically complex and beyond the reach of many patients** *(simplified technologies continue to evolve)*	

Table 5. Factors that influence home PD selection

FAVOURING HOME PD	PERCEIVED OR MODIFIABLE BARRIER TO HOME PD	POTENTIALLY INSURMOUNTABLE BARRIER
MEDICAL FACTORS		
No prior abdominal surgery **No available vascular access or transplant options** **Patient seeking home therapy but has medical contraindication to HD**	**Prior abdominal surgery***(minor procedures are not barriers; if prior procedures more extensive, consider laparoscopic PD catheter insertion under direct visualization)* **Medical or anatomical barriers:** • **Colostomy** *(reversal of colostomy where appropriate)* • **Abdominal wall hernia** *(repair where feasible; lower fill volumes or avoidance of daytime exchanges)* • **Large polycystic kidneys** *(lower fill volumes and avoidance of day dwell)* • **Mechanical back pain** *(lower fill volumes and avoidance of day dwell)* **Loss of residual renal function** *(assess adequacy of dialysis and modify prescription accordingly; timely transition to other home modality)* **PD catheter malfunction** *(work with local surgeons and interventionalists to ensure timely intervention; financial incentives for timely intervention)*	**Anatomical barriers:** • **Colostomy not amenable to reversal** • **Irreparable hernia** • **Morbid obesity** • **Complex abdominal surgery** **Complications or failure of PD:** • **Membrane failure with reduced clearance, malnutrition of ultrafiltration failure** • **Recurrent peritonitis** • **Metabolic syndrome or excessive weight gain** • **Loss of PD catheter options** **Uncontrolled hyperglycemia**
HOME PHYSICAL ENVIRONMENT		
See Table 3		
PSYCHOLOGICAL AND COGNITIVE FACTORS		
See Table 3	**Fear of cosmetic effect of PD catheter** *(discuss values and preferences along with all available alternatives e.g. vascular access for home HD)*	
SOCIAL FACTORS		
See Table 3		

Table 5 (continued).

FAVOURING HOME PD	PERCEIVED OR MODIFIABLE BARRIER TO HOME PD	POTENTIALLY INSURMOUNTABLE BARRIER
HEALTH CARE PROFESSIONAL-RELATED FACTORS (*denotes factors specific to physicians)		
	Knowledge gaps: **Unfamiliarity with technical aspects of PD provision** **Unfamiliarity with patient selection** **Belief that PD is not adequate for larger patients** **Indirect effects of non-nephrologist (cardiology, endocrinology) biases against PD** *(nephrology fellowship training in PD*; home dialysis program accreditation for PD provision; KT initiatives and materials directed at renal and non-renal health care professionals – physician certification programs, clinical practice guidelines, textbooks, mentorship programs through 'centres of excellence', clinical decision support tools; recruitment of medical and nursing staff with interest and expertise in PD)* **Attitudinal barrier: perception that PD is an inferior therapy** **Lower technical and/or physician fees are for PD therapy** **Lower technical and/or physician fees for PD catheter implantation results in reduced training and expertise among operators**	
DIALYSIS PROGRAM OR LOCAL HOSPITAL-RELATED FACTORS		
Adoption of a PD-first integrated care model of care	**Excessive wait time for PD catheter implantation results in CVC insertion and HD***('buried' catheters; identify program-specific bottle-necks; collaborate with local interventional radiologists and surgeons; create care pathways that aim to provide optimal access at the optimal time for each patient; consider a bedside or acute PD catheter insertion program; financial incentives for timely PD catheter insertion)*	
HEALTH SYSTEM-RELATED FACTORS		
See Table 3		

Determinants of Home Dialysis Use: A Canadian National Survey of Nephrologists' Attitudes

Authors:

Gihad Nesrallah[1,2,3]MD

Lianne Barnieh[4]PhD

Braden Manns[4]MD, MSc

Catherine Clase[2] MD, MSc

David Mendelssohn[3]MD

Andreas Pierratos[3] MD

Gordon Guyatt[2] MD, MSc

[1] The Lawson Health Research Institute, Western University, 375 South Street, London, Ontario, Canada, N6A 4G5

[2] Department of Health Research Methodology, McMaster University, 1280 Main Street West, Rm. 2C12, Hamilton, Ontario, Canada L8S 4K1

[3] Department of Nephrology, Humber River Hospital, 200 Church Street, Toronto, Ontario, Canada, M9N 1N8

[4] Department of Medicine, Foothills Medical Center, 1403 - 29th St NW, Calgary, Alberta, Canada, T3Z 2T9

Submitted to: Kidney International

ABSTRACT

Barriers to and facilitators of home dialysis (peritoneal dialysis and hemodialysis) are numerous and complex. In order to better understand these factors in the Canadian context, we developed a *de novo* survey to measure nephrologists' attitudes and perceptions regarding determinants of home dialysis use. We used rigorous qualitative methods to develop a theoretical framework, which we then used to generate an initial survey item (N=60) pool. We used preference ratings followed by a Delphi process to reduce and refine candidate items into a 47-item survey, which we administered to all Canadian nephrologists providing dialysis and predialysis care to adult (>18 years) patients. We received 199 and 6 complete and partial responses (response rate 41%). We examined item-level responses and used factor analysis to reduce multiple items into domains. We used linear regression to explore relationships between respondent and practice characteristics with domain-level (composite) means scores. Factor analysis yielded an 11-factor solution explaining 67% of the variance across 41 item scores, denoting excellent construct validity; 6 items had factor loadings <0.4. Test-retest reliability was 0.70; Crohnbach's α was 0.60-.95. Domain-level median scores for barriers were generally low (12.5-18.8) indicating that typical respondents were unconcerned about most barriers. Facilitators related to nephrologist training, funding for personnel and infrastructure, and physician reimbursement had the highest domain-level scores, suggesting that nephrologists felt that initiatives in these areas were likely to be helpful. Practice setting, years in practice, gender, home dialysis program size, and province were significant explanatory variables in multivariable models. This study identified several potential target interventions for program planning and further research, and establishes the reliability and validity of a barrier assessment tool for potential use in other jurisdictions.

INTRODUCTION

Home dialysis modalities are increasingly viewed as the best alternative to transplantation for patients with end-stage renal disease (ESRD). Both home hemodialysis (HD) and peritoneal dialysis (PD) were in widespread use during their earliest years of adoption, and their subsequent decline has resulted from the complex interplay between factors operating at the patient, health-care professional, and health-system levels. There is a growing consensus within the renal community on the need for strategies to increase uptake of home dialysis.

Given their position at the interface between patients and health-systems, nephrologists' perspectives on determinants of modality choice are germane to strategic planning and policy development. Healthcare agencies such as the Ontario Renal Network (ORN) and knowledge translation platforms, such as the Canadian Kidney Knowledge Generation and Translation Network (CANN-NET)

currently consider modality selection a priority for policy development and for research.(Ontario Renal Network, 2013b; The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET), 2013) We therefore surveyed Canadian nephrologists regarding their attitudes toward barriers and facilitators to use of HD and PD.

METHODS

Study Design

We performed a cross-sectional web-based survey. We measured respondents' perceptions regarding local barriers to adoption of home HD and PD, attitudes towards a range of candidate interventions to improve home dialysis adoption, and willingness to endorse or use resources directed at optimizing home dialysis use.

Ethical Review

The Hamilton Integrated Research Ethics Board affiliated with McMaster University, Hamilton, Canada approved the study. We assured respondents of anonymity.

Sample

We assembled a sampling frame consisting of nephrologists who practice in Canada, and provide predialysis care and dialysis services to adult (≥18 years old) patients. We obtained names and contact information from the Canadian Society of Nephrology listserv, provincial (Ontario and British Columbia) renal agency listservs, and provincial medical colleges. We supplemented and verified this information via email and telephone correspondence with dialysis facilities identified through the Canadian Organ Replacement Register. After excluding physicians practicing exclusively in pediatrics or transplantation (N=67), 506 nephrologists were eligible.

Instrument Development

We used in-depth interviews and a grounded-theory–informed approach to analysis to develop a taxonomy of determinants of dialysis modality choice, including barriers and facilitators (Chapter 2 of this thesis). For this phase of the work, our sample consisted of nephrologists, advanced practice nurses, and health administrators with varying levels of expertise in home dialysis. We classified items as barriers or facilitators (with positive versus negative wording) according to how informants described them during the interviews. We used the taxonomy to develop an initial item pool. A nationally representative panel of 20 content

experts then rated each item for importance on a 5-point unipolar adjectival scale. To further refine the items and establish face and content validity, we entered the highest-ranked 60 candidate items into a two-stage Delphi process. The final questionnaire, with 47 items, was administered to the sample of nephrologists described above.

For the final questionnaire, we constructed an ordinal level 5-point adjectival scale with the following anchors describing levels of agreement with statements describing barriers to and facilitators of home dialysis: “not at all”, “slightly”, “somewhat”, “very” and “extremely”. Five content areas were: 1) relevance of barriers to PD utilization, 2) relevance of barriers to home HD utilization,3) support for policies, practices, or interventions to increase the adoption of home HD,4) likelihood of using specific resources promoting home dialysis, and 5) likelihood of endorsing various initiatives or policies promoting home dialysis. We translated the instrument into French and back-translated to ensure fidelity.

Pilot Testing

We selected a purposive sample of 20 Canadian nephrologists with expertise in health services or survey research for pilot testing. Pilot testers provided free-text comments on clarity of wording and technical aspects of the web-based survey platform. Pilot testers completed the survey again 10 days later. We calculated test-retest reliability separately for barrier and facilitator items using Pearson’s r.

Survey Administration

We used a web-based platform (Fluid Surveys)(Fluidware, 2013) to administer the survey in May 2013, using the Tailored Design Method (with standard pre-notification, invitation, and 3 follow-up reminders).(Don A. Dillman, Jolene D. Smyth, & Leah Melani Christian, 2008) We used the entire sampling frame and a stratified (by province).

Analysis

We imported the data into SPSS 21.0 for Macintosh. We coded response types according to published standards.(The American Association for Public Opinion Research, 2011) We removed responders with early survey termination with no capture of usable data (“break offs”; N=6), and retained usable data from partial-responders (N=6).

We used exploratory factor analysis (principle axis factoring) with varimax rotation to assess the underlying structure of the final 47 survey items, and to construct item cluster domains. For the factor analysis, we transformed our 5-point scale to a 100-point scale for better interpretability, and retained a

meaningful zero, representing "absolute disagreement". We excluded items with factor loading coefficients less than 0.40 from domains, but retained and reported all item descriptive statistics. We used the Kaiser-Meyer-Olkin(KMO) measure of sampling adequacy and Bartlett's test of sphericity to confirm adequate (moderate) correlations between items. We considered factors with eigenvalues > 1.0 and interpreted these values in conjunction with a scree plot. We created domains consisting of all items loading on to a given factor. We computed Cronbach's α for each domain.

We calculated descriptive summary statistics for individual item scores, and reported frequencies for each response category. We used the Kolmogorov-Smirnov (KS) test to assess normality and the appropriateness of reporting item score means and standard deviations.

We used multiple linear regression to explore relationships between respondent and practice characteristics with responses. We used a simultaneous (forced-entry) regression model. In order to reduce the number of statistical comparisons (and the risk of type I error), we used mean scores within domains as the dependent variable. Since this survey will inform policy development in Ontario, we created a dichotomous predictor variable for Ontario versus other Canadian provinces. We examined all candidate predictor variables for collinearity using Pearson's r, and removed variables with $r>0.6$ from the regression models. We considered $p<0.05$ significant for the predictive model, and $p<0.01$ significant for the contributions of individual predictor variables within each model.

RESULTS

Respondent Characteristics

Table 1 summarizes respondent and practice characteristics. Of the 506 potential respondents, 211 initiated the survey, with 6 breakoffs, and 6 partial responses, yielding 199 complete responses (39%). Gender, practice setting, and province were similar for responders and non-responders ($p>0.5$ for all comparisons).

Exploratory Factor Analysis

Principal axis factor analysis yielded an 11-factor solution explaining 67% of the variance across 47 item scores. The assumption for independent sampling was met. The KMO statistic was 0.80, denoting sufficient items for each factor, and Bartlett's test was highly significant ($p<0.001$). Table 2 summarizes the 11 factors, which contain between two and seven items. Barriers related to home HD infrastructure explained 21.9% of the variance, while facilitators related to funding for home dialysis personnel and infrastructure explained 10.2% of the

variance. The remaining factors contained fewer items and explained less variance.

Composite Factor Scores

Composite scores for barrier-related factors were low and had skewed distributions (KS statistic $p<0.001$). Inadequate physician knowledge of home HD scored the lowest (median; interquartile range [IQR]) (12.5; 0.0-25.0) and competition between modalities, the highest (18.8; 6.3-34.4). Median composite scores for facilitators were generally higher: nephrologist fellowship training had the highest median score (75; 37.5-84.4), followed by funding for personnel and infrastructure (64.3; 50.0-78.6), and physician reimbursement (41.7; 25.0-75.0).

Domain Measurement Properties

With a sample of 20 pilot testers, test–retest reliability was 0.70 ($p<0.001$) for barriers and 0.71 ($p<0.001$) for facilitators. Table 2 summarizes internal consistency (Cronbach's α) for item clusters created by exploratory factor analysis. Cronbach's α ranged from 0.69 to 0.90 for barriers, and from 0.69 to 0.95 for facilitators.

Items Addressing Barriers to Home Dialysis

Table 3 presents score distributions for the 19 items in this category. Regression models were not significant for several domains; we report only significant predictor variables below.

Resources and Infrastructure for Home HD

Between 44 to 60% of respondents perceived that inadequacy of funding for home HD training, availability of home HD nurses, funding for consumables, start-up costs, capital equipment costs, installation, and technical support staff were "not at all relevant" barriers to home dialysis. Less than 15% of respondents perceived these to be very or extremely relevant barriers.

We constructed a simultaneous regression model with mean domain score as the dependent variable, and all of the variables in Table 1 as predictor variables. Respondent age was co-linear with years in practice ($r=0.87$; $p<0.001$), and PD program size was collinear with centre HD population size ($r=0.71$; $p<0.001$). We excluded age and PD program size from the final multivariable model. The R^2 value for the final adjusted model was 12.3%. Centers that referred patients elsewhere for home HD scored 22.9 points higher (95% CI 11.1 to 34.7; $p<0.001$) on the composite score than those who did not. Nephrologists who refer

elsewhere for PD scored 23.2 points lower than those who did not (95% CI -38.6 to -7.7; p=0.003).

Competition Between Home Dialysis Modalities

When considering factors leading to the preferential selection of PD over home HD among patients eligible for both, 64% of respondents perceived that "evidence or beliefs of better outcomes" with PD was not at all relevant, and 49% perceived "evidence or beliefs of lower costs" with PD as not at all relevant. Forty percent of respondents perceived the concept that a "local PD program attracts patients who would otherwise be candidates for home HD" was not at all relevant. Most respondents (60%) perceived the idea that "patients with high levels of comorbidity should not undergo HHD" as a slightly to somewhat relevant factor.

Physician Knowledge of Home HD Practices

Only 4% of respondents perceived that physician "lack of familiarity with home HD prescription" and "patient eligibility criteria" were very or extremely relevant barriers to home HD uptake in their practice environments. The majority (50 to 59%) perceived that these factors are not at all relevant.

Services and Infrastructure Specific to PD

Most respondents (58%) perceived that inadequacy of "funding for initial PD program start-up" (physical space, staff hiring, staff training) was not at all relevant, while 9% perceived this factor to be very or extremely relevant. Only 8% of respondents perceived "local technical expertise with PD catheter insertion" as a very or extremely relevant barrier in their practice environments. Eighteen percent of respondents perceived limited operating room time a very or extremely relevant barrier in their practice environments.

Barriers with Low Factor Loading Coefficients

Four items describing barriers to home dialysis had factor loadings < 0.40, and were therefore not included in composite scores or domains. Most respondents (75-88%) perceived that three items representing unrelated constructs were not at all relevant barriers: "lack of local nephrologist with expertise with PD prescription", physician bias that "[outcomes] with PD may not be as good as those with centre HD", and "unclear or limited liability protection for physicians prescribing home HD". Two or fewer percent of respondents considered these very or extremely relevant factors. Perceptions regarding the relevance of "availability of home care-assisted PD" varied widely, with response frequencies ranging between 18-24% across the five response categories.

Items Addressing Facilitators for Home Dialysis

Table 4 summarizes response frequencies for items related to home dialysis facilitators.

Home Dialysis Facilitators Related to Funding for Personnel and Infrastructure

Incremental "funding for nurse-assisted PD" was the highest-scored item in the survey with 63% of respondents indicating they were very or extremely supportive of this strategy. Respondents indicated that they were very or extremely supportive of several other interventions to promote home dialysis. These included "establishment of a local or regional long-term care facility with capacity for PD provision" (61%), limited-care nurse-assisted home HD (49%), full-care (50%) nurse and informal caregiver-assisted (51%) home HD, nurse case managers/modality coordinators accessible to all pre-dialysis patients (55%), and "government funding for electrical and water costs for home HD" (52%). The adjusted regression model explained only 4.9% of variance in this composite score, with borderline statistical significance (P = 0.048). The only predictor variable that was significant was practice setting – respondents based in academic centers scored an average of 10.3 (95% CI -18.9 to-1.7; p=0.019) points lower than their community-based counterparts.

Physician Reimbursement

Respondents rated three items related to physician reimbursement (for supervising home dialysis, supervising training for home dialysis, and for providing modality education) virtually identically, with 28-30% indicating that they were very or extremely supportive; 24-26% were not at all supportive. The multivariable regression model explained 6.8% of the total score variance for this item cluster. For every 10 years that a respondent was in practice, they scored the usefulness of physician financial incentives 6 points lower (95% CI -1.1 to -0.1; p=0.02).

Decision-support

Two items measuring perceived utility of electronic and paper-based decision support tools received moderate scores, with 26-27% not at all likely and 23-25% very or extremely likely to make use of these resources were they available. The multivariable model explained 5.7% of the score variance. Compared with respondents in other provinces, those practicing in Ontario scored decision support 12.1 (95% CI 0.3 to 24.0; p=0.04) points higher than non-Ontario residents. For every 10 patients on home HD at the respondents' centres, they rated decision-support two points lower on average (95% CI -0.4 to 0.0; p=0.018).

External Support Systems

Items related to external support interventions were among the lowest-rated facilitators. Forty-four percent of respondents were not at all likely to contact a"24-hour regional on-call physician support by local home HD expert, to assist with home HD prescription or other technical issues". Fifty-one percent of respondents were not at all likely to refer patients to a "regional center of excellence" that could provide support for body access, pre-dialysis education, and home dialysis training.

Facilitators with Low Loading Coefficients (<0.04)

We considered two items with low factor loadings separately. Fifty-two percent of respondents were very or extremely supportive of periodic multidisciplinary rounds to discuss modality selection. Forty-four percent were very or extremely supportive of "Acute" insertion of a PD catheter for unplanned starts who are medically suitable."

National and Provincial Policy Interventions

Table 5 summarizes the scores for three factors related to physician education (national scope) and health policy (provincial jurisdiction). Fellowship training and postgraduate continuing health education loaded onto separate factors.

Nephrology Training Programs

Fifty-eight and 51% of respondents were very or extremely supportive of mandatory nephrology fellowship training in PD and home HD, respectively. The multivariable model explained 6.9% of score variance and showed that male respondents scored this item cluster 14 points lower (95% CI -23.5 to -4.6;p=0.004) than their female counterparts.

Physician Continuing Health Education

Respondents rated postgraduate continuing health education (CHE) interventions lower than mandatory home dialysis rotations for nephrology trainees. Responses varied widely, with response frequencies ranging between 8-26% and 10-29% across all response categories (measuring support) for home HD and PD CHE programs, respectively.

Health System Policy Interventions

Three items evaluated support for facility-specific targets for home dialysis incident and prevalent rates. Targets linked to financial penalties received the

lowest support (37% of respondents were not at all supportive), while targets links to quality improvement initiatives received the highest support (37% of respondents were very or extremely supportive). Fifty-three percent of respondents were slightly or somewhat supportive of targets linked to financial incentives.

Fifty-one percent of respondents were very or extremely supportive of mandatory modality education and offering of home dialysis to virtually all patients. Support for external (provincial panel) program audits ranged widely with response frequencies ranging between 11-28%. The mandatory "PD-first" policy received the lowest support with 53% of respondents indicating that they were not at all supportive.

The multivariable model predicted 10.3% of the variance. For every 10 years in practice, respondents scored this item cluster four points lower (95% CI -7.0 to -1.0; p=0.014). Respondents practicing in academic settings scored this item cluster 14.9 points lower than their community-based counterparts (95% CI -22.9 to -6.9; p<0.001).

DISCUSSION

In this national survey, we found considerable support for a number of interventions that are already in use in some parts of Canada, including: nurse-assisted PD, capacity for PD in long-term care facilities, pre-dialysis case managers, and recurring multidisciplinary rounds that address modality selection. Respondents also expressed support for interventions that have not yet been widely adopted in Canada, including mandatory nephrology fellowship rotations in home HD, paid informal (lay) caregivers, nurse-assisted home HD, and funding for water and electricity for home hemodialysis. Respondents were largely unenthusiastic about facility-specific home dialysis targets, particularly those that are linked to financial penalties. There was also very little support for "mandatory use of PD first in all medically suitable patients". Respondents seldom expressed concern regarding most of the barriers included in the survey with the exception of an item related to the lack of availability of home care-assisted PD. Respondents differed considerably in their enthusiasm for physician financial incentives, decision support tools, postgraduate training, external program audits, and centre-specific targets linked to financial incentives.

We identified a number of respondent and practice environment characteristics that are associated with respondents' support for various policy interventions. We found that respondents practicing in academic settings were less concerned about funding for personnel and infrastructure than their community-based counterparts. Program size, and the ability to realize economies of scale may account for this

phenomenon. This observation should prompt policy-makers to further study the relationship between practice setting and the economics of home dialysis provision. A better understanding of these factors could lead to alternative funding models for community-based dialysis programs.

Respondents in university-based practices were also less supportive of physician financial incentives, provincial policies of mandatory pre-dialysis education, mandatory PD-first, and external panel review. Respondents from larger home HD programs were less interested in decision support tools. This likely reflects greater clinical experience with patient selection for home HD. However, overall enthusiasm for decision-support tools was only moderate, suggesting that widespread adoption could be unfruitful.

Respondents from the province of Ontario were more willing to endorse provincial policies to promote home therapies, as well as the use of decision support tools. This may be attributable in part to the ongoing activities of the Ontario Renal Network, for which home dialysis utilization is a leading strategic priority, and a focus of quality improvement efforts.(Ontario Renal Network, 2013b)

Finally, respondents with fewer years in practice were more supportive of physician financial incentives compared with their older counterparts. This may reflect differences in financial security or generational differences in attitudes and values.

Nurse-assisted PD in the home was the highest scored intervention, followed by nursing support for PD in long-term care facilities. There is no published experience with PD in nursing homes in Canada, though such programs exist. Potential advantages include lower-costs (including transportation), greater convenience, and improved patient quality of life.(Harris, Lamping, Brown, Constantinovici, & North Thames Dialysis Study, 2002) The availability of adequately trained nursing staff represents an important logistical challenge. Establishing a central pool of PD-trained nurses contracted through local home care agency could deal with this problem.

Assisted PD in the home is also currently available in a limited number of jurisdictions in Canada. Preliminary data seem promising,(Oliver et al., 2007) with benefits similar to those of nursing home assisted PD. One potential disadvantage is the risk of over-promoting PD in frail, marginally-eligible patients, thereby increasing the risk of hospitalization and technique failure.(Mendelssohn, 2007) The net balance of benefits and risks with assisted PD have yet to be established, and more rigorous studies seem warranted based on the strong endorsement by Canadian nephrologists.

Respondents strongly opposed two policy interventions. The "PD-first" approach has been debated since PD was first introduced in the 1970s. Proponents argue that PD is associated with better preservation of residual renal function, quality of life, and survival during the first 2-3 years of renal replacement therapy, while costing less than home and centre HD. More recent data from Canada, however, suggest that the use of central venous catheters (CVCs) accounts for poorer outcomes in the first few years of HD compared with PD. Since patients with CVCs are more likely to be unplanned starts, it may be misleading to compare them to patients who electively initiate PD. A recent Canadian analysis excluded patients with CVC, and found no survival advantage with PD compared with HD.(Perl et al., 2011) The validity of the economic argument has changed over time, as well. While PD is certainly less costly, the gap has narrowed considerably over the last few years, particularly if HD is provided in the home.(Ontario Renal Network, 2013a)

Does the lack of support for the PD-first approach represent a strong physician bias against PD? Eighty-three percent of respondents indicated that the notion that PD outcomes are inferior to HD outcomes is not at all relevant; a bias against PD therefore seems unlikely. Alternatively, respondents may have been averse to the "mandatory" nature of the PD-first intervention, as it was framed in the questionnaire. That a policy mandating PD first in the absence of a contraindication will lead to greater PD adoption rates has been demonstrated in Hong Kong where PD makes up 80% of the modality mix.(Li & Chow, 2013) Differences in societal and individual values on informed patient choice and autonomy may explain why Canadian nephrologists do not support mandating PD first.

A prior survey revealed that Canadian nephrologists strongly favoured 'promoting' rather than mandating home therapies.(Mendelssohn, Toffelmire, & Levin, 2006)However, neither this report, nor any other has proposed an operational definition for 'promoting' home dialysis. For a nephrologist, the act of promoting home dialysis could range anywhere from merely mentioning the range of dialysis options, through strongly encouraging home modalities. The relative impacts of these various approaches on patient decision-making are likely significant, but not formally studied.

Respondents were particularly averse to center-specific targets linked to financial penalties, and were only slightly more enthusiastic about targets linked to financial incentives. This model resembles the pay-for-performance paradigm recently adopted in the United States, and for which dialysis reimbursement has been a testing-ground. The quality incentive program (QIP) introduced by the US Centers for Medicare and Medicaid(Fishbane & Hazzan, 2012) services links reimbursement to metrics that are based on current practice guidelines, and that are for the most part, known or presumed to be achievable in the relevant practice

environments. There is no published data, however, to support this approach with home dialysis utilization as a performance measure. Home dialysis adoption rates are likely as much a function of a given patient population's characteristics as they are of facility practices and performance. This has led to the notion that targets should be facility-specific and should account for local case-mix. Regardless of these adjustments, it seems unlikely that financial penalties will help struggling dialysis programs to develop infrastructure and expertise to promote home dialysis in a public payer system.

Limitations of our survey include the response rate of 39%, though this is in keeping with other physician survey response rates.(Cull, O'Connor, Sharp, & Tang, 2005)Moreover, physician surveys tend to be less prone to non-response bias, compared with surveys of the general population.(McFarlane, Olmsted, Murphy, & Hill, 2007) Given the many ongoing nationwide efforts to promote home dialysis in Canada, the opinions addressed in this survey may be in a state of flux, and may change over time.

Strengths of the survey include rigorous methods to develop our instrument, and established face and content validity using a national panel of experts. High (0.5 to 0.8) factor loading coefficients, suggest adequate construct validity. Although we developed and validated the instrument in the Canadian context, many of the represented constructs are pertinent to modality decisions in other jurisdictions.

We would encourage other potential users of our instrument to add items based on relevance to their unique practice environments. In addition, we documented high internal consistency (Cronbach's alpha >0.9) suggesting redundancy of information in some factors. Items that represent very similar constructs can therefore be combined and the instrument abbreviated in future iterations.

This study provides a starting-point for developing policies to promote home dialysis utilization. Success is more likely for strategies that physicians enthusiastically support, and policy-makers should approach less-favourably viewed interventions with caution. Regardless of the prevailing sentiment surrounding each candidate intervention, all new policies should be phased in with a carefully crafted monitoring and evaluation framework in place. Among other things, this means that providers can guide the development of new policy interventions, but not without patients and the outcomes they care about at the core of the agenda.

REFERENCES

Cull, W. L., O'Connor, K. G., Sharp, S., & Tang, S. F. (2005). Response rates and response bias for 50 surveys of pediatricians. *Health Serv Res, 40*(1), 213-226. doi: 10.1111/j.1475-6773.2005.00350.x

Don A. Dillman, Jolene D. Smyth, & Leah Melani Christian. (2008). *Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method* (3rd Edition ed.). Hoboken, New Jersey: John Wiley & Sons.

Fishbane, S., & Hazzan, A. (2012). Meeting the 2012 QIP (Quality Incentive Program) clinical measures: strategies for dialysis centers. *Am J Kidney Dis, 60*(5 Suppl 1), S5-13; quiz S14-17. doi: 10.1053/j.ajkd.2012.07.002

Fluidware. (2013). FluidSurveys. Retrieved Jan 20, 2013, 2013, from http://fluidsurveys.com

Harris, S. A., Lamping, D. L., Brown, E. A., Constantinovici, N., & North Thames Dialysis Study, G. (2002). Clinical outcomes and quality of life in elderly patients on peritoneal dialysis versus hemodialysis. *Perit Dial Int, 22*(4), 463-470.

Li, P. K., & Chow, K. M. (2013). Peritoneal Dialysis-First Policy Made Successful: Perspectives and Actions. *Am J Kidney Dis*. doi: 10.1053/j.ajkd.2013.03.038

McFarlane, E., Olmsted, M. G., Murphy, J., & Hill, C. A. (2007). Nonresponse bias in a mail survey of physicians. *Eval Health Prof, 30*(2), 170-185. doi: 10.1177/0163278707300632

Mendelssohn, D. C. (2007). A skeptical view of assisted home peritoneal dialysis. *Kidney Int, 71*(7), 602-604. doi: 10.1038/sj.ki.5002153

Mendelssohn, D. C., Toffelmire, E. B., & Levin, A. (2006). Attitudes of Canadian nephrologists toward multidisciplinary team-based CKD clinic care. *Am J Kidney Dis, 47*(2), 277-284. doi: 10.1053/j.ajkd.2005.10.019

Oliver, M. J., Quinn, R. R., Richardson, E. P., Kiss, A. J., Lamping, D. L., & Manns, B. J. (2007). Home care assistance and the utilization of peritoneal dialysis. *Kidney Int, 71*(7), 673-678. doi: 10.1038/sj.ki.5002107

Ontario Renal Network. (2013a). 2013/14 Chronic Kidney Disease (CKD) FUnding Guide - Guide to CKD Program Reimbursement. Retrieved April 1st, 2013, from http://www.renalnetwork.on.ca

Ontario Renal Network. (2013b). The Ontario Renal Plan. Retrieved July 11, 2013, 2013, from http://www.renalnetwork.on.ca/ontario_renal_plan/independent_dialysis/ -_.Ud68eBboghw

Perl, J., Wald, R., McFarlane, P., Bargman, J. M., Vonesh, E., Na, Y., et al. (2011). Hemodialysis vascular access modifies the association between dialysis modality and survival. *J Am Soc Nephrol, 22*(6), 1113-1121. doi: 10.1681/ASN.2010111155

The American Association for Public Opinion Research. (2011). Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. (7th ed.).

The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET). (2013). Advancing Kidney Care and Research in Canada. from http://www.cann-net.ca

TABLES

Table 1. Characteristics of respondents and their practice environments (effective N=205)

Characteristic	Value
Age Stratum, N (%)	
>60	29 (14)
45-60	74 (36)
30-44	102 (50)
Years in Practice, median (IQR)	12 (7-13)
Gender, N (%)	
Male	142 (69)
Female	63 (31)
Language chosen for survey completion, N (%)	
English	192 (94)
French	13 (6)
Province, N (%)	
Ontario	80 (39)
Quebec	37 (18)
Alberta	31 (15)
British Columbia	26 (13)
Maritime provinces	14 (7)
Manitoba	11 (5)
Saskatchewan	6 (3)
Primary practice setting, N (%)	
University	156 (76)
Community	49 (24)
Home HD Training > 2 months, N (%)	
Yes	57 (28)
No	147 (72)
PD Training > 2 months, N (%)	
Yes	172 (84)
No	33 (16)
Services referred to other centres, N (%)	
Transplantation	92 (45)
Home HD	24 (12)
PD	12 (6)
Reimbursement for HD>PD, N (%)	84 (41)
Received incentive to complete survey, N (%)	86 (42)

Abbreviations: HD – hemodialysis; IQR – interquartile range; PD – peritoneal dialysis.

Table 2. Exploratory factor analysis with principal axis factoring and varimax rotation depicting 11 orthogonal factors explaining 66.6% of total score variance.

Factor Number	Factor Label (number of items)	Total Variance Explained	Cronbach's α	Score percentile (max=100)		
				25th	50th	75th
Barriers						
6	Competition between modalities (4)	4.0	0.69	6.3	18.8	34.4
1	HHD resources and infrastructure (7)	21.9	0.90	4.2	16.7	39.6
9	PD-specific services and infrastructure (3)	3.1	0.72	8.3	16.7	33.3
10	Physician knowledge of HHD practices (2)	2.8	0.86	0.0	12.5	25.0
Facilitators						
5	Nephrology Fellowship Program (2)	4.0	0.95	37.5	75.0	84.4
2	Funding for personnel and infrastructure (7)	10.2	0.85	50.0	64.3	78.6
3	Physician reimbursement (3)	6.2	0.94	25.0	41.7	75.0
4	Policies promoting home dialysis (6)	5.2	0.81	25.0	37.5	50.0
8	Decision support tools (2)	3.3	0.89	12.5	37.5	62.5
7	Physician Continuing Health Education (2)	3.3	0.95	25.0	31.3	75.0
11	External support systems (2)	2.6	0.69	0.0	25.0	37.5

Abbreviations: HHD – home hemodialysis; HD – hemodialysis; PD – peritoneal dialysis; SD – standard deviation; LCL – lower confidence limit; UCL – upper confidence limit.

Table 3. Item scores for questions addressing barriers to home hemodialysis and peritoneal dialysis (N=205 respondents); 5-point unipolar adjectival scale (not at all relevant →extremely relevant) median corresponds to 100-point scale with meaningful zero point. Range for all item scores = 100.

Item	Percentage of responses by category				
	Not at all	Slightly	Some what	Very	Extremely
Barriers related to home HD resources and infrastructure					
Lack of funding for HHD training	44	25	16	7	8
Lack of adequately trained dialysis nurses for HHD patient training, supervision and follow-up	45	23	19	8	5
Lack of funding for more frequent (>3 sessions per week – consumable costs) HD	45	21	22	6	5
Lack of funding for home HD program start-up (physical space for unit, hiring staff, training staff)	49	22	15	8	7
Lack of funding for HHD equipment and installation	47	23	17	5	8
Lack of adequately trained local support staff (biomedical/technologists)	60	19	15	2	4
Barriers related to competition between home modalities					
Evidence or belief that patients with high levels of comorbidity should not undergo HHD	27	34	26	11	2
Local PD program attracts patients that would otherwise be candidates for HHD	41	31	19	7	2
Patients who could do either HHD or PD are started on PD preferentially because of evidence or beliefs of lower costs	49	23	16	10	2
Patients who could do either HHD or PD are started on PD preferentially because of evidence or beliefs of better outcomes	64	22	9	4	1

Table 3 (continued).

Item	Percentage of responses by category				
	Not at all	Slightly	Some what	Very	Extremely
Barriers related to physician knowledge of home HD practices					
Lack of nephrologist's familiarity with patient eligibility criteria for HHD	50	29	17	3	2
Lack of nephrologist's familiarity with HHD prescription	59	26	10	2	2
Barriers related to PD-specific services and infrastructure					
Lack of local resources (operating or procedure room time) for PD catheter insertion	33	33	17	13	4
Lack of local technical expertise with PD catheter insertion (interventional radiologist, nephrologist, or surgeon)	52	28	12	4	4
Lack of funding for initial PD program start-up (physical space for unit, hiring staff, training staff)	58	22	10	6	3
Barriers with low loading coefficients (<0.04)					
Lack of availability of home care assisted PD (PD provided by visiting nurse)	24	22	19	17	18
Unclear or limited liability protection for physicians prescribing HHD	75	17	7	1	1
Physician perception that all other factors being equal, patient-important outcomes (survival, quality of life) with PD may not be as good as those with centre HD	83	11	5	0	1
Lack of local nephrologist with expertise with PD prescription	88	8	3	1	1

Abbreviations: HHD – home hemodialysis; HD – hemodialysis; IQR – inter-quartile range; PD – peritoneal dialysis.

Table 4. Item scores for facilitators to increase uptake of home dialysis (N=205 respondents); 5-point unipolar adjectival scale (not at all supportive →extremely supportive) median corresponds to 100-point scale with meaningful zero point. Range for all item scores = 100.

Item	Percentage of responses by category				
	Not at all	Slightly	Some what	Very	Extremely
Home dialysis facilitators related to funding for personnel and infrastructure					
Funding for nurse-assisted PD, specifically to set up cycler machines and/or assist with PD exchanges	4	9	24	35	28
Establishment of a local or regional long-term care facility with capacity for PD provision	10	11	19	25	36
Provincial funding for an informal caregiver (trained lay person) to provide full-care hemodialysis at home, assuming that it is shown to be cost-neutral or cost-saving	7	16	26	24	27
A dialysis modality coordinator who provides education (individual or group-based) to all pre-dialysis patients who are approaching the need for dialysis	8	15	22	33	22
Government funding for electrical and water costs for HHD so that patients don't have to pay	11	14	24	29	23
Provincial funding for a formal caregiver (nurse) to provide full-care hemodialysis at home, assuming that it shown to be cost-neutral or cost-saving	10	19	22	22	29
Funding for nurse-assisted home hemodialysis, specifically to assist patients with cannulation (patient or informal caregiver would be responsible for other components of dialysis prescription)	6	14	31	25	24

Table 4 (continued).

Item	Percentage of responses by category				
	Not at all	Slightly	Some what	Very	Extremely
Physician reimbursement					
Physician billing premium (over and above clinic visit fee) for dialysis modality education	24	23	26	17	12
Physician billing premium for supervising home-based dialysis therapies	26	21	24	17	13
Physician billing premium for supervising training for home-based dialysis therapies	25	22	25	17	12
Decision support					
An online clinical decision support tool to assist with patient selection for home dialysis	26	24	25	16	9
A paper-based clinical decision support tool (limited to 1 page) to assist with patient selection for home dialysis	27	29	21	15	8
External support systems					
24-hour regional on-call physician support by local home HD expert, to assist with home hemodialysis prescription or other technical issues	44	29	17	8	3
A regional 'centre of excellence' to whom your patients can be referred for modality education, home dialysis training and vascular or peritoneal access (while you remain most responsible physician during training and treatment)	51	17	15	10	8

Table 4 (continued).

Item	Percentage of responses by category				
	Not at all	Slightly	Some what	Very	Extremely
Facilitators with low loading coefficients (<0.04)					
Regularly scheduled local program meeting to discuss potential candidates for conversion to independent dialysis, including newly started patients on centre HD, patients with a failing renal allograft, or patients failing PD or HHD who could switch from one modality to the other	6	22	21	32	20
"Acute" insertion of a PD catheter for unplanned starts who are medically suitable, followed by initiation of dialysis with PD	14	19	25	23	21

Abbreviations: HHD – home hemodialysis; HD – hemodialysis; IQR – inter-quartile range; PD – peritoneal dialysis.

Table 5. Item scores for provincial or national policy interventions to increase uptake of home dialysis (N=205 respondents);5-point unipolar adjectival scale (not at all supportive →extremely supportive) median corresponds to 100-point scale with meaningful zero point. Range for all item scores = 100.

Item	Percentage of responses by category				
	Not at all	Slightly	Somewhat	Very	Extremely
Nephrology training programs					
Mandatory training in PD for nephrology fellows (e.g. minimum 3 months)	6	18	19	31	27
Mandatory training in HHD for nephrology fellows (e.g. minimum 3 months)	7	23	21	27	24
Nephrologist continuing health education					
Home hemodialysis certification program for physicians through the Canadian Society of Nephrology with course at annual general meeting; provided at a nominal cost	23	26	24	20	8
Peritoneal dialysis certification program for physicians through the Canadian Society of Nephrology, with course at annual general meeting; provided at a nominal cost	25	29	20	18	10
Health system policies					
Provincial policy of mandatory modality education in which all patients approaching dialysis are offered the opportunity to receive home HD or PD	10	18	21	33	18
Centre-specific target for independent dialysis rates (incident or prevalent) that is linked to quality improvement initiatives intended to identify and overcome local barriers	13	25	26	26	11

Table 5 (continued).

Item	Percentage of responses by category				
	Not at all	Slightly	Somewhat	Very	Extremely
Health system policies (continued)					
Regular external (e.g. provincial agency) panel review to provide your program with feedback on where to target interventions to improve your local PD and home HD adoption rates	18	25	28	20	11
Centre-specific target for independent dialysis that is linked to facility reimbursement for dialysis technical fees with increased incremental funding if targets are met	27	27	27	12	8
Provincial policy of mandatory use of PD first in all medically suitable patients	53	16	12	13	7
Centre-specific target for independent dialysis that is linked to facility reimbursement for dialysis technical fees with claw-backs for failure to meet targets	55	25	13	5	3

Abbreviations: HHD – home hemodialysis; HD – hemodialysis; IQR – inter-quartile range; PD – peritoneal dialysis.

Randomized Trial Assessing the Impact of a Charitable Donation on Survey Response Rates

Authors:

Gihad Nesrallah[1,2,3]MD

Lianne Barnieh[4]PhD

Braden Manns[4]MD, MSc

Catherine Clase[2] MD, MSc

David Mendelssohn[3]MD

Gordon Guyatt[2] MD, MSc

[1] The Lawson Health Research Institute, Western University, 375 South Street, London, Ontario, Canada, N6A 4G5

[2] Department of Health Research Methodology, McMaster University, 1280 Main Street West, Rm. 2C12, Hamilton, Ontario, Canada L8S 4K1

[3] Department of Nephrology, Humber River Hospital, 200 Church Street, Toronto, Ontario, Canada, M9N 1N8

[4] Department of Medicine, Foothills Medical Center, 1403 - 29th St NW, Calgary, Alberta, Canada, T3Z 2T9

Submitted to: Journal of Clinical Epidemiology (Brief Communication)

ABSTRACT

Objective: Strategies to improve physician survey response rates are needed. We addressed the effectiveness of charitable donations about which evidence is currently limited.

Study Design and Setting: We conducted a randomized trial comparing the effect of a $40 charitable donation to the Kidney Foundation of Canada with no incentive on nephrologist response rates. We developed a web-based survey to measure Canadian nephrologists' attitudes towards home dialysis utilization. Our primary outcome was response rate (complete and partial); our secondary outcome was time-to-response, analyzed with Cox regression. We tested for interactions between group allocation and respondent characteristics using logistic regression.

Results: Among 484 eligible participants, 81/241 (33.6%) versus 93/243 (38.3%) responded in the intervention and control groups respectively (RR=1.10, 95% CI 0.85-1.42; p=0.46). The hazard ratio was 1.15 (95% CI 0.83 to 1.48; p=0.51); we found no significant interaction between respondent characteristics and the intervention.

Conclusions: A charitable donation to the Kidney Foundation did not improve nephrologist response rates in this national survey. This study adds to the growing evidence that donation incentives do not motivate physicians to participate in surveys.

INTRODUCTION

Surveys are an important tool for studying physician concerns, attitudes, and behaviours in areas that are germane to health service and policy development. Email surveys have become increasingly common, with advantages over postal surveys, including reduced social desirability bias, less errors, fewer omissions, and longer free-text responses to open-ended questions.(Seguin, Godwin, MacDonald, & McCall, 2004) Despite these advantages, Internet surveys have lower rates of response compared with postal surveys,(Cull, O'Connor, Sharp, & Tang, 2005) particularly among physicians.(Asch, Jedrziewski, & Christakis, 1997; Cummings, Savitz, & Konrad, 2001) Several strategies to improve physician response rates have been evaluated, including monetary incentives, shorter questionnaires, pre-notification letters, follow-up mailings, and other non-monetary interventions.(Edwards et al., 2009)

Surveyors have long recognized the opportunity costs that surveys of all formats carry for physicians and other professionals. Moreover, the growing volume of

unsolicited requests may further lower participation rates over time.(Moore, Post, & Smith, 1999) Monetary incentives that directly compensate physicians for clinical time have proven successful.(Keating, Zaslavsky, Goldstein, West, & Ayanian, 2008) The effectiveness of offering donations to charities rather than to the participant has been studied in the general population,(Robertson & Bellenger, 1978) but to a more limited degree in physicians.(Deehan, Templeton, Taylor, Drummond, & Strang, 1997; Gattellari & Ward, 2001) Such an approach is intended to appeal to the respondent's sense of altruism, by supporting an organization with which they share common goals and values.(Robertson & Bellenger, 1978)

The Kidney Foundation of Canada (KFOC) is a large patient advocacy organization that seeks to improve the lives of patients with kidney disease by improving access to renal care, education, and peer support, and by supporting research.(The Kidney Foundation of Canada, 2013) We conducted a clinical trial to determine whether a modest ($40 CAD) charitable donation to the KFOC would improve survey response rates among practicing Canadian nephrologists.

METHODS

Study Design

This study was a randomized trial embedded in a national survey of nephrologists' attitudes towards barriers to home dialysis utilization. Our objective was to compare response rates among nephrologists who received standard survey notifications (pre-notification, invitation, and two reminders – control group), with those who received identical letters that also included a promised incentive (intervention group). The incentive consisted of a $40 CAD charitable donation to the KFOC, with no direct financial incentive (e.g. tax receipt) for participants. We hypothesized that participants receiving the incentive would have a higher response rate than those who received the standard notifications. This study was conducted in collaboration with the Canadian Kidney Knowledge Translation and Generation Network (www.CANN-NET.ca).(The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET), 2013)

Ethical Review

The Hamilton Integrated Research Ethics Board affiliated with McMaster University, Hamilton, Canada approved the study. We assured participants of anonymity in each notification, but did not inform them of this secondarystudy evaluating the effectiveness of the donation incentive.

Participants and Eligibility

Our sampling frame consisted of all practicing nephrologists in Canada, using provincial medical college registers, provincial renal agency listservs (Ontario and British Columbia), and by directly contacting nephrology departments and individual nephrologists' offices to confirm accuracy of contact information, including e-mail addresses. Since the survey pertained to dialysis prescription for adults, we included only nephrologists with adult nephrology with dialysis as their scope of practice; nephrologists with a primarily pediatric or transplant-based practice were excluded.

Interventions

We used a modified Tailored Design Method,(Don A. Dilman, Jolene D. Smyth, & Christian, 2009) with pre-notification (May 22nd, 2013), invitation (May 24th, 2013), first reminder (June 3rd, 2013), and final reminder (June 11th, 2013) letters sent by e-mail to both groups simultaneously. Letters were identical for both groups with the exception of the following phrase, which was added to the incentive arm: "By completing the survey, and in compensation for your time, a charitable donation of $40 CAD will be made, on your behalf, to the Kidney Foundation of Canada, by our study sponsors (Fresenius Medical Care, Baxter Healthcare, and Gambro Canada)". We used a commercial web-based survey platform (Fluid Surveys) to distribute notification letters containing links to the web-based survey.

Instrument Design

We developed a *de novo* questionnaire, measuring nephrologists' perceptions regarding the importance of barriers to home dialysis use (as compared with hospital-based dialysis), and their willingness to endorse policy and knowledge translation interventions to optimize home dialysis use in Canada. The instrument consisted of 47 items scored with a unipolar 5-point adjectival scale. Key domains included barriers due to funding, physician attitudes, and competition between dialysis therapies; facilitators of interest included funding policy interventions, physician reimbursement, physician training, and knowledge translation strategies. Detailed methods and instrument development are published presented in Chapter 3 of this thesis.

Outcomes

Our primary outcome was the final response rate (proportion providing complete or partial responses) at the end of the study (28 days after initial invitation), and using standard definitions for complete and partial responses.(The American Association for Public Opinion Research, 2011) Our secondary outcome was time

to response. We performed exploratory analyses to examine the relationships between participant and practice characteristics with time to response, and response versus nonresponse.

Sample Size Determination

We sought to enrol the entire Canadian nephrologist population, and therefore did not restrict our sample size based on statistical criteria.

Randomization

We used a computerized random number generator and stratified by province of residence to randomize nephrologists in a 1:1 ratio to receive the incentive versus standard notifications, which included no incentive. One author who did not know the study participants (LB) performed the randomization, preparation of electronic mailing lists, and preparation (including removal of identifying information) of the analytical files. A second author (GN) analyzed de-identified datasets, and was blinded to the identities of participants.

Statistical analyses

We exported data from Fluid Surveys into an Excel (Office 2011 for Macintosh) spreadsheet, and then imported data into IBM SPSS 21.0 for Macintosh for cleaning and analysis. We examined descriptive statistics using stem and leaf plots and box plots to identify outliers and potentially erroneous values. We analyzed all participants according to original group assignment. For the primary outcome, we used the χ^2 statistic to compare response rates between treatment groups, and computed the relative risk. For the secondary outcome, we plotted Kaplan-Meier curves of time-to-response in the intervention and control groups, and computed a Mantel-Cox log rank statistic for the entire study period. We also used Cox regression with forward conditional selection (p for entry <0.05, p for removal <0.1) to compute an adjusted hazard ratio. We used log minus log plots to test the proportionality assumption for all covariates. Covariates included group allocation (incentive versus none), gender, practice location (Ontario versus other provinces), dialysis program size (home and hospital hemodialysis), years in practice, and practice setting (university versus community).

We tested whether the effect of the intervention differed according to all of these predictor variables, and considered an interaction p<0.1 significant.

RESULTS

The study proceeded according to protocol, with no *post-hoc* changes in design, eligibility criteria, conduct, or analysis methods.

Eligibility and Enrolment

Figure 1 summarizes patient flow. Our sampling frame consisted of 573 nephrologists practicing in Canada. While we were assembling contact information, two nephrologists declined participation. We excluded 20 nephrologists involved in survey pilot testing from randomization, and 67 nephrologists whose scope of practice did not include adult patients on dialysis. Four hundred and eighty four nephrologists were eligible for randomization: 241 and 243 in the intervention and control groups, respectively. All randomized participants were included in the analysis.

Participant Characteristics

Table 1 summarizes participant characteristics. Gender, practice setting, and practice location (province) were well-balanced between groups.

Primary Outcome

Figure 2 shows overall response rates in the two groups. Among participants in the intervention group, 81/241 (33.6%) responded, compared with 93/243 (38.3%) of control participants (Pearson's χ^2 = 1.14; p=0.29). The relative risk was 1.10 (95% CI 0.85 to 1.42; p=0.46).

Secondary Outcome and Exploratory Analysis

Figure 3 depicts time to response in the control and intervention groups. The Mantel-Cox Log Rank test statistic was χ^2 =0.60, df=1, p=0.45. The unadjusted hazard ratio was 1.15 (95% CI 0.83 to 1.48; p=0.51). There was also no statistically significant interaction between the intervention and any of the variables tested (all p>0.1).

DISCUSSION

Contrary to our hypothesis, providing an incentive to survey response with a $40 charitable donation to the Kidney Foundation of Canada did not increase response rates among Canadian nephrologists. We found no interactions between participant or practice characteristics with the intervention.

Prior studies of the effectiveness of donation incentives have provided mixed results in the general population.(Gendall & Healey, 2008; Raymond Hubbard & Eldon L. Little, 1988; Raymond Hubbard & Eldon L Little, 1988) Very few studies have evaluated the effectiveness of donations in physician populations. In a study of family physicians, Deehan *et al.* found direct monetary incentives (£5

or £10) were more effective than charitable donations in the same amounts, while both approaches were more effective than no incentive.(Deehan et al., 1997) Gattellari *et al*., in a study of Australian surgeons, found that a promised charitable donation of $10 AUS to their professional college decreased the response rate.(Gattellari & Ward, 2001) In the Australian study, the control group response rate was 70%, providing little room for improvement, and the success of the other strategies to increase response rates may have obscured any additional effect related to the intervention, i.e., a 'ceiling-effect'. Moreover, unlike our study, the Australian study provided monthly reminders over a four-month period. This approach resulted in greater separation between groups over time. This suggests that multiple successive reminder prompts impacted negatively on participants' enthusiasm for supporting the study (or the charity) over time.

In contrast, we followed a published method which involved four points of contact over a 4-week period.(Don A. Dilman et al., 2009) We deliberately restricted our study period and number of prompts to avoid antagonizing participants in our fairly small national community. A more persistent approach may have yielded a higher response rate. Survey fatigue among Canadian nephrologists and a lack of interest in the survey topic may also explain our suboptimal response rates. The perception that Canadian nephrologists already adequately support the Kidney Foundation through other means may be a reason for the ineffectiveness of the incentive. Up-front, rather than promised (upon completion of the questionnaire) incentives have historically resulted in higher response rates among physicians, and this may also have been relevant.(Delnevo, Abatemarco, & Steinberg, 2004) The absence of effect was consistent across gender, practice setting and location, years in practice and dialysis program size. The available data do not provide additional insights into the reasons for our low response rate and apparent lack of effect with our intervention.

Strengths of this study include its randomized design, adequately-balanced respondent characteristics between groups, and the use of a comprehensive (and hence, representative) sample. Limitations include unknown generalizability beyond the Canadian nephrology community, and suboptimal sample size.

This study adds to a small but important body of evidence that suggests that promised charitable donations might not be effective in improving the response rates in e-mail surveys of physicians. With the growing demands placed on physicians' time, better strategies to engage them in survey research are needed and worthy of further study.

FUNDING

Three major dialysis equipment manufacturers (Fresenius Medical Care, Baxter Healthcare, and Gambro Canada) provided equal financial support for the study.

Each sponsor paid a 1/3 share of a $40 donation directly to the KFOC for each survey response we received. Funding was provided by CANN-NET, who is supported jointly by CIHR (FRN# 251048) and the Kidney Foundation of Canada for support of LB's work on survey administration.

REFERENCES

Asch, D. A., Jedrziewski, M. K., & Christakis, N. A. (1997). Response rates to mail surveys published in medical journals. *J Clin Epidemiol, 50*(10), 1129-1136.

Cull, W. L., O'Connor, K. G., Sharp, S., & Tang, S. F. (2005). Response rates and response bias for 50 surveys of pediatricians. *Health Serv Res, 40*(1), 213-226. doi: 10.1111/j.1475-6773.2005.00350.x

Cummings, S. M., Savitz, L. A., & Konrad, T. R. (2001). Reported response rates to mailed physician questionnaires. *Health Serv Res, 35*(6), 1347-1355.

Deehan, A., Templeton, L., Taylor, C., Drummond, C., & Strang, J. (1997). The effect of cash and other financial inducements on the response rate of general practitioners in a national postal study. *Br J Gen Pract, 47*(415), 87-90.

Delnevo, C. D., Abatemarco, D. J., & Steinberg, M. B. (2004). Physician response rates to a mail survey by specialty and timing of incentive. *Am J Prev Med, 26*(3), 234-236. doi: 10.1016/j.amepre.2003.12.013

Don A. Dilman, Jolene D. Smyth, & Christian, L. M. (2009). *Internet, Mail, and Mixed-Mode Surveys: The Tailored Design Method*. Hoboken, New Jersey: John Wiley & Sons, Inc.

Edwards, P. J., Roberts, I., Clarke, M. J., Diguiseppi, C., Wentz, R., Kwan, I., et al. (2009). Methods to increase response to postal and electronic questionnaires. *Cochrane Database Syst Rev*(3), Mr000008. doi: 10.1002/14651858.MR000008.pub4

Gattellari, M., & Ward, J. E. (2001). Will donations to their learned college increase surgeons' participation in surveys? A randomized trial. *J Clin Epidemiol, 54*(6), 645-649.

Gendall, P., & Healey, B. (2008). Alternatives to Prepaid Monetary Incentives in Mail Surveys. *International Journal of Public Opinion Research, 20*(4), 517-527. doi: 10.1093/ijpor/edn048

Hubbard, R., & Little, E. L. (1988). Promised contributions to charity and mail survey responses: replication with extension. *Public Opinion Quarterly, 52*(2), 223-230. doi: 10.1086/269096

Hubbard, R., & Little, E. L. (1988). Promised Contributions to Charity and Mail Survey Responses: Replication With Extension. *The Public Opinion Quarterly, 52*(2), 223-230.

Keating, N. L., Zaslavsky, A. M., Goldstein, J., West, D. W., & Ayanian, J. Z. (2008). Randomized trial of $20 versus $50 incentives to increase physician survey response rates. *Med Care, 46*(8), 878-881. doi: 10.1097/MLR.0b013e318178eb1d

Moore, M., Post, K., & Smith, H. (1999). 'Bin bag' study: a survey of the research requests received by general practitioners and the primary health care team. *Br J Gen Pract, 49*(448), 905-906.

Robertson, D. H., & Bellenger, D. N. (1978). A New Method of Increasing Mail Survey Responses: Contributions to Charity. *Journal of Marketing Research (JMR), 15*(4), 632-633.

Seguin, R., Godwin, M., MacDonald, S., & McCall, M. (2004). E-mail or snail mail? Randomized controlled trial on which works better for surveys. *Can Fam Physician, 50*, 414-419.

The American Association for Public Opinion Research. (2011). Standard Definitions: Final Dispositions of Case Codes and Outcome Rates for Surveys. (7th ed.).

The Canadian Kidney Knowledge Translation and Generation Network (CANN-NET). (2013). Advancing Kidney Care and Research in Canada. from http://www.cann-net.ca

The Kidney Foundation of Canada. (2013). from http://www.kidney.ca

TABLES AND FIGURES

Figure 1. Participant inclusion flow diagram.

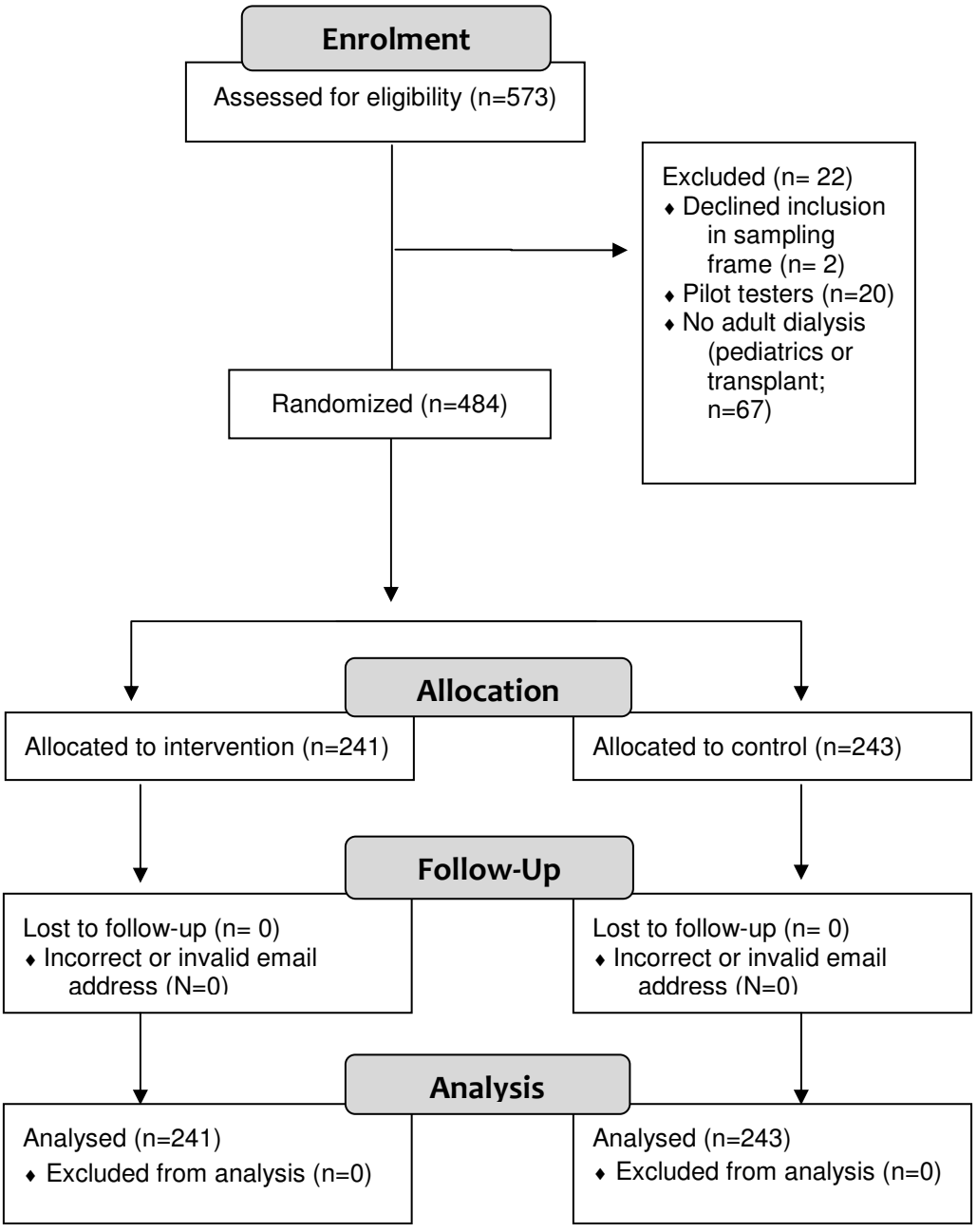


Table 1. Participant characteristics

	Intervention (N=243)		Control (N=241)	
	N	%	N	%
Female gender	75	31.1	73	30.0
Practice setting				
University	78	32.4	79	32.5
Community	149	61.8	147	60.5
Missing	14	5.8	17	7.0
Province				
Alberta	27	11.2	26	10.7
British Columbia	29	12.0	31	12.8
Manitoba	10	4.1	8	3.3
Maritimes	18	7.5	19	7.8
Ontario	86	35.7	84	34.6
Quebec	61	25.3	66	27.2
Saskatchewan	5	2.1	6	2.5
Missing	5	2.1	3	1.2

Figure 2. Response rates among incentive recipients and controls.

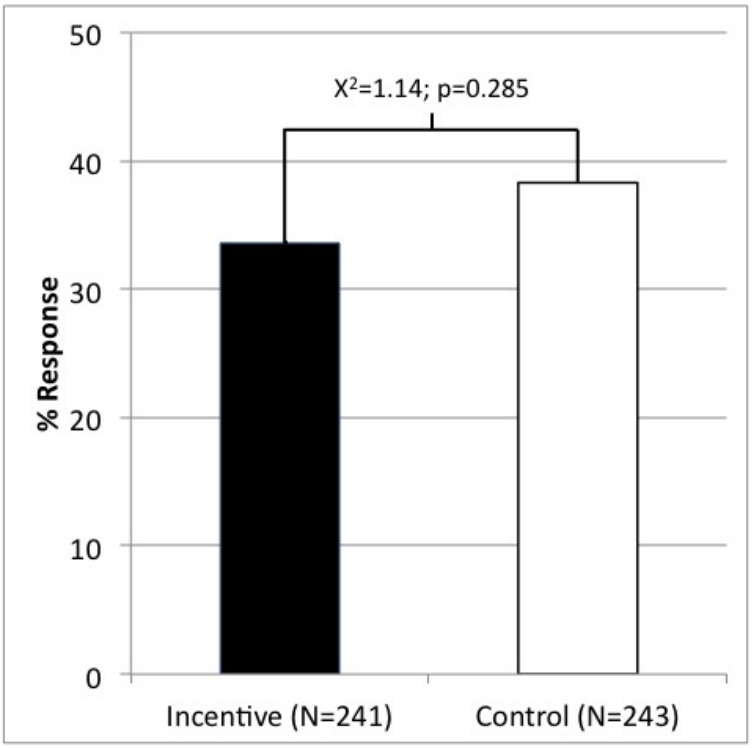
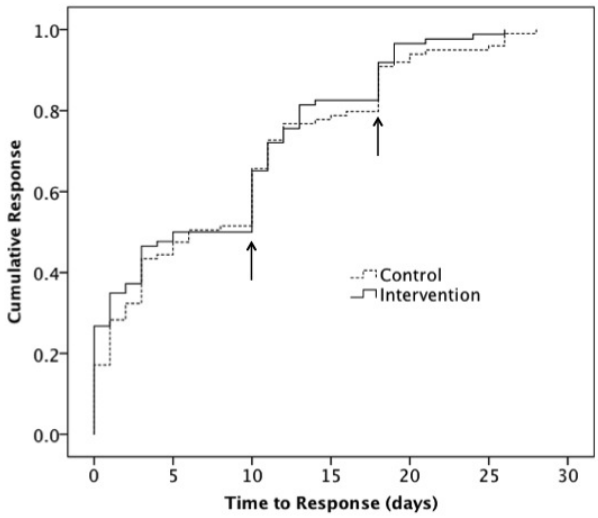


Figure 3. Cumulative response rate. Arrows denote timing of reminder notifications. Log Rank (Mantel-Cox) statistic=0.579; p=0447, df=1



THESIS CONCLUSIONS

The first two papers that comprise this thesis contribute useful new knowledge about determinants of dialysis modality choice, and approaches that policy-makers and the renal community should consider in approaching dialysis modality selection. In addition, the third study, evaluating the effectiveness of the promised charitable donation, adds to the growing body of evidence suggesting that this incentivization strategy is not effective with physicians.

Paper 1: Identification of Facilitators and Barriers to Home Dialysis Selection by Canadian Adults with ESRD

This paper builds on prior studies of determinants of dialysis modality choice. Expert opinion and experience formed the basis for prior conceptualizations,(Golper et al., 2011; Young et al., 2012); this is therefore the first study to apply rigorous qualitative methods to gain a deeper understanding of the factors that impact on home dialysis selection. This study also uniquely addresses the Canadian context, and thus informs future research related to policy development and service planning in Canada. Healthcare professionals can use the framework as a learning tool, and policy-makers and researchers can use the framework to develop barrier assessment, knowledge translation, and other measurement tools.

Summary of Key Findings

This paper classifies barriers to home dialysis use as 'modifiable' versus 'non-modifiable', and presents barriers in conjunction with their related facilitator strategies. This approach carries two advantages for knowledge users. First, as an educational tool, it illustrates that many factors that users may traditionally view as insurmountable barriers are in fact amenable to intervention. The framework encourages non-experts in home dialysis to seek innovative approaches to enabling suitable patients to receive home dialysis. Secondly, it provides clear guidance for abandoning efforts to provide home therapy where such attempts are very likely to be futile or potentially harmful. Finally, the framework also classifies many factors as 'ideal' circumstances for home HD or PD. Again, this format allows knowledge users to see factors that they may have considered barriers to home dialysis from a new perspective, e.g., many users may not initially recognize that long-term care residents, or those with impaired mobility could, with appropriate resources, be well positioned to undergo dialysis at home.

Informants identified two key determinants of modality choice that were likely relevant to all pre-dialysis patients, rather than sub-populations. These two factors also happen to be subject to significant between-physician variance in practices: 1) nephrologist perceptions of the comparative effectiveness of home

versus centre dialysis therapies, and 2) the referral of highly-selected versus unselected (virtually all) patients for modality education. The wide variance in physician attitudes and practices with respect to patient eligibility and modality comparative effectiveness speak to the considerable uncertainty surrounding these questions in the current published literature.(Hingwala et al., 2012; Pauly, Klarenbach, & Komenda, 2011) This observation highlights the need for more rigorous studies comparing modalities among different patient subgroups, which provide more definitive for patients and their providers.

In addition to cataloguing an exhaustive array of barriers to home dialysis selection, the framework systematically describes facilitator interventions and policies. These include broadening support systems (cluster dialysis, formal and informal caregivers, nursing home dialysis), educational interventions (for patients and healthcare professionals), financial incentives (for patients, facilities, and healthcare professionals), policy interventions (mandatory modality education, targets), and decision support tools.An important limitation is the paucity of studies confirming the effectiveness of facilitating factors described by the study informants, and most cannot be recommended for large-scale adoption without further study.

Knowledge Translation Strategy and Future Directions

This work is of major interest to the Ontario Renal Network (ORN) Independent Dialysis Advisory Group, and the Canadian Kidney Knowledge Translation and Generation Network (CANN-NET). Strategies to improve patient knowledge of and access to home dialysis therapies are strategic priorities for both organizations. Both the ORN and CANN-NET have been active knowledge user partners in the development of this work, and will be actively involved in implementing the recommendations that arise from this work. The framework developed in this study will inform the many initiatives that are underway, including the development of:

1. A national survey of physician attitudes towards barriers and facilitators of home dialysis use (Paper 2/Chapter 3 of this thesis; ORN/CANN-NET collaboration);
2. Attitudinal surveys (provincial or regional scope) of other health care providers, including advanced-practice and front-line nurses who provide dialysis modality education and predialysis care (CANN-NET);
3. Home dialysis barrier and suitability assessment questionnaires for patients (CANN-NET); and
4. A measurement framework that captures ‘reason codes’ for all patients initiating and remaining on dialysis in-centre in Ontario (ORN). This will allow for real-time monitoring of modifiable barriers operational in Ontario, and will guide related policies and recommended practices.

Paper 2: Determinants of Home Dialysis Use: A Canadian National Survey of Nephrologists' Attitudes

Though last studied over a decade ago, physician perspectives on determinants of home dialysis use have been of major interest to the Canadian nephrology community.(Jung, Blake, Mehta, & Mendelssohn, 1999; Mendelssohn, 2002) This study builds on prior research by including home HD as a prominent home dialysis option, alongside PD, and is timely given the recently heightened interest in home dialysis among nephrologists and policymakers in Canada and abroad.

Summary of Key Findings

In this study, respondents considered a wide range of potential barriers to home dialysis. Most respondents did not consider lack of funding and infrastructure, physician expertise, and competition with PD as relevant barriers to home HD. Similarly, most respondents did not perceive funding for PD, local expertise, or local resources for PD catheter insertion (operating room time) important barriers. Respondents strongly endorsed (e.g. stated that they were very or extremely supportive) a wide range of facilitators, including funding for nurse-assisted PD, nursing home dialysis, caregiver-assisted home dialysis (HD and PD), case-managers in renal clinics, and others. Some facilitators received very little support, including a mandatory "PD-first" policy, while others received widely variable scores, including decision support tools, postgraduate training, and external program audits. The study also identified provider subgroups that may be more or less likely to welcome some of the facilitator strategies.

Knowledge Translation Strategy and Future Directions

The next step in applying these findings is to present them to key stakeholders, then identify, and prioritize initiatives. Following the publication of this thesis, the author will begin work with the ORN Independent Dialysis Advisory Group, and a CANN-NET Ad Hoc Working Group for Home Dialysis. Stakeholders will consider projected levels of endorsement for various strategies against projected impacts, opportunity costs, availability of resources, and program-specific or regional needs. Where appropriate, survey responses will be analyzed at the provincial level, and will guide further investigation of local (facility-level) barriers, by way of surveys and focus groups.

Both CANN-NET and the ORN apply standard knowledge translation methodologies, including the Knowledge-to-Action Cycle to planning policies and services related to dialysis modality selection.(Cochrane et al., 2007; Kitson & Straus, 2010) This study provides insights into barriers to knowledge use and attitudinal gaps. For example, only 23-27% of respondents were very or

extremely likely to use paper or electronic decision support systems for modality selection. CANN-NET is contemplating a cluster-randomized trial evaluating one such tool. Our findings indicate that lower levels of enthusiasm for decision support tools may represent a barrier to successful use of the study intervention, and this will need to be considered in refining the study protocol. This study's findings also inform the creation of tailored knowledge tools (e.g. mandatory fellowship rotations in home dialysis). Educators will need to consider the potential utility of this approach by engaging stakeholders, and by further studying the relationship between nephrology training and success with home dialysis uptake. Pilot projects can then be developed, and the intervention adopted with appropriate evaluation mechanisms in place.Additionally, consideration of provincial-level responses may allow knowledge (e.g. best practices) to be adapted to local contexts, and the external quarterly review focus group currently used by the ORN could serve as a forum for deeper exploration of facility-specific barriers and needs. Finally, this study provides a baseline measure for ongoing efforts to drive knowledge related to modality selection into practice, and follow-up measures over time will allow efforts to be re-focused as needed.

Paper 3: Randomized Trial Assessing the Impact of a Charitable Donation on Survey Response Rates

This study failed to demonstrate any measurable impact on nephrologist response rates with a promised charitable donation of $40 CAD to the Kidney Foundation of Canada. Reasons for the lack or effect can only be speculative; yet, at least two other studies in physician populations corroborate these findings.(Deehan, Templeton, Taylor, Drummond, & Strang, 1997; Gattellari & Ward, 2001)

The knowledge translation strategy for this study includes submission to the Journal of Clinical Epidemiology for publication as a brief report.

REFERENCES

Cochrane, L. J., Olson, C. A., Murray, S., Dupuis, M., Tooman, T., & Hayes, S. (2007). Gaps between knowing and doing: understanding and assessing the barriers to optimal health care. *J Contin Educ Health Prof, 27*(2), 94-102. doi: 10.1002/chp.106

Deehan, A., Templeton, L., Taylor, C., Drummond, C., & Strang, J. (1997). The effect of cash and other financial inducements on the response rate of general practitioners in a national postal study. *Br J Gen Pract, 47*(415), 87-90.

Gattellari, M., & Ward, J. E. (2001). Will donations to their learned college increase surgeons' participation in surveys? A randomized trial. *J Clin Epidemiol, 54*(6), 645-649.

Golper, T. A., Saxena, A. B., Piraino, B., Teitelbaum, I., Burkart, J., Finkelstein, F. O., et al. (2011). Systematic barriers to the effective delivery of home dialysis in the United States: a report from the Public Policy/Advocacy Committee of the North American Chapter of the International Society for Peritoneal Dialysis. *Am J Kidney Dis, 58*(6), 879-885. doi: 10.1053/j.ajkd.2011.06.028

Hingwala, J., Diamond, J., Tangri, N., Bueti, J., Rigatto, C., Sood, M. M., et al. (2012). Underutilization of peritoneal dialysis: the role of the nephrologist's referral pattern. *Nephrol Dial Transplant*. doi: 10.1093/ndt/gfs323

Jung, B., Blake, P. G., Mehta, R. L., & Mendelssohn, D. C. (1999). Attitudes of Canadian nephrologists toward dialysis modality selection. *Perit Dial Int, 19*(3), 263-268.

Kitson, A., & Straus, S. E. (2010). The knowledge-to-action cycle: identifying the gaps. *CMAJ, 182*(2), E73-77. doi: 10.1503/cmaj.081231

Mendelssohn, D. C. (2002). Reflections on the optimal dialysis modality distribution: a North American perspective. *Nephrology news & issues, 16*(4), 26-30.

Pauly, R. P., Klarenbach, S. W., & Komenda, P. (2011). Comparative survival literature in intensive hemodialysis: limitations and future directions. *Semin Dial, 24*(6), 629-633. doi: 10.1111/j.1525-139X.2011.01000.x

Young, B. A., Chan, C., Blagg, C., Lockridge, R., Golper, T., Finkelstein, F., et al. (2012). How to overcome barriers and establish a successful home HD program. *Clin J Am Soc Nephrol, 7*(12), 2023-2032. doi: 10.2215/CJN.07080712