Using a Measuring and Monitoring Safety Framework to Improve Patient Care with Peritoneal Dialysis and Peritoneal Dialysis Catheter Dysfunction Rate: *A Call to Action*

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ABSTRACT

The Saskatchewan Health Authority (SHA) - Kidney Health (KH) Program vision is to enhance the health, safety and quality of life of patients through a *home first* model of care, promoting peritoneal dialysis (PD) to better meet the health needs of patients in a collaborative manner, and to expand community partnerships. A current priority from the Saskatchewan Ministry of Health is to optimize care for persons within the community rather than in an institution or inpatient setting.

Historically, the utilization of PD in First Nations and Métis people is low. A holistic participatory evaluation framework honouring protocol, traditions, culture, and spirituality was used to better understand the lived interactions of patients and families with kidney disease. The *Truth and Reconciliation Calls to Action* guided this work, in tandem with advice and wisdom of Indigenous Elders. Kidney Health partnered with First Nations and Métis Health Services SHA to develop strategies to promote home based therapies in a culturally sensitive manner, develop new models of care for rural/remote communities, and address four '*Calls to Action*" items 19, 20, 22(iii), and 23. *Nîsohkamâtowak* (a Cree word meaning '*helping each other'*) sharing events were hosted in local communities from 2015-2017 to better understand the lived experience of First Nations and Métis patients and families. Sharing circles embraced conversational methods/storytelling to gather knowledge and wisdom regarding patient and family experiences living with kidney disease. Videos/short stories have been gathered to promote a better understanding of cultural competency, blending traditional and western medicine, and to improve the care experience for patients and families in their home communities. A participatory evaluation framework was used to identify themes, and action items were shared with the patients and families, and community partners (transcription of videos, flip charts, and focus group findings, analysis to identify common themes, mapping to *Calls to Action*).

As part of the *Nîsohkamâtowak* process, patients and family members were asked to provide guidance on priorities for action. The following priorities were highlighted: letting patients be in charge, more timely education, support in home communities, open communication, understanding and acceptance of kidney disease, more work with the youth, and cultural

competency training for staff and physicians. The concept of patient safety in the home and community was explored which led to an opportunity to participate in national collaborative on Measuring and Monitoring Safety Framework (MMSF) with the Canadian Patient Safety Institute/Healthcare Excellence Canada. A unique aspect of collaborative included the potential to expand MMSF in terms of cultural lens through our partnership with First Nations and Métis patients and families. The MMSF was an 18 month learning program (2018-2019 in person workshops and KH program application of safety principles).

The measurement and monitoring of safety in healthcare is an ongoing challenge and safety is not solely about measuring harm. The MMSF consists of five dimensions and associated questions that can be used to help understand the safety of care and service at multiple levels. The five dimensions are past harm, reliability, sensitivity to operations, anticipation and preparedness, and integration and learning. Through the MMSF national collaborative, the KH clinical improvement team (CIT) addressed a number of quality and safety barriers that prevent patients from successfully performing home PD and assisted patients to remain on PD when their functional status changed. Program enhancements are needed to better understand and serve these patients in their home communities.

Nationally, the target for primary PD catheter dysfunction (inability of the PD catheter to support adequate inflow and/or outflow, patient not able to train) for PD catheter insertions is set at <10% at 3 months. PD catheter dysfunction rates are associated with significant burden and hardship to the patient, and an overall increase in cost to the health system due to additional procedures/tests to diagnose and correct complications. Participation in the MMSF stimulated the development of the KH PD catheter outcomes database, and data collection was retrospectively set to 2016 to evaluate surgical and interventional radiology laparoscopic PD insertion techniques. Previous methods of PD catheter insertion resulted in high dysfunction rates at 3 months post procedure: PD catheter dysfunction rates (primary and secondary failure combined, secondary failure defined as patient able to train, but stopped due to PD catheter malfunction or flow, or non-catheter issues) were: 2016 25/62 (40.3%); 2017 19/71 (26.8%); 2018 11/50 (22.0%); 2019 12/54 (22.2%); and in 2020 5/57 (8.8%). Although PD dysfunction rates are improving, more work is needed to close this gap. Participation in the MMSF enabled

the ability for the CIT to translate real time data so that it is useful to take action, stimulate gap analysis for process improvement, identify strengths and weaknesses, and promote a culture of safety and continuous improvement. The success of the MMSF and the CIT team to imbed quality and safety into daily practice showed a positive shift in safety culture and mapping the patient and family experiences enabled opportunities to include the *Calls to Action* into Kidney Health programs and services. The Measuring and Monitoring of Safety Framework (MMSF) collaborative provided a unique mechanism to focus quality and safety efforts within Kidney Health in Saskatoon, and through organizational partnerships at the provincial level to spread these concepts.

ACKNOWLEDGEMENTS

I would like to express my gratitude for the support I received during the course of my PhD studies from my Research Advisory Committee (RAC). This was a unique opportunity for me to advance my skills and knowledge, improve patient and family centred care, and blend my academic and professional pursuits. Dr. Vivian Ramsden has known me throughout my career, and her support and guidance helped to shape this path. Dr. Paul Babyn and I had the opportunity to partner on strategic initiatives, which lead to this research in Kidney Health, clinical quality improvement, and patient safety. Dr. Babyn provided mentorship, helpful 'tips' to keep my writing moving forward, and to complete this academic journey. Dr. Rod Stryker and Dr. Joanne Kappel provided leadership and mentoring to shape the nature and scope of this work. Dr. Cory Neudorf kindly provided expertise and guidance on methods and approach to study design and population health perspective. I was humbled to have Mr. Gilbert Kewistep provide wisdom and a heartfelt approach to *Nîsohkamâtowak*, First Nations and Métis traditions, protocol and honouring *Truth and Reconciliation* and the *Calls to Action* in our work.

My RAC meetings intentionally and respectfully integrated First Nations and Métis traditional protocol with tobacco offerings, opening prayer, and the teaching of the four R's – respect, reciprocity, responsibility, and relevance. Gilbert Kewistep, Elder, Knowledge Keeper and research collaborator, offered these words in Salteaux "*Kitchi Meg-wetch Kahn-doh-tah-we-ang*" - a big thank you for listening to our voices.

This research was supported by Provincial Programs, Kidney Health, Saskatchewan Health Authority, and the St. Paul's Hospital Foundation. I would also like to thank our Clinical Improvement Team members. I am very grateful for the generous participation of First Nations and Métis patients and family members and their ongoing dedication to improving health in their communities. Our partnership to design and integrate a culturally sensitive *Home First* model of care into the daily operations of Kidney Health was a critical component of my PhD.

I would like to acknowledge the College of Medicine Health Sciences Program Graduate Chair and Staff, and the Office of the Vice Dean of Research as I progressed through my milestones, and for the opportunity to serve on the Health Sciences Graduate Program Committee.

I greatly appreciate the support of my husband Michael Scheibelhoffer, daughter Dylan and son Wilson throughout my studies and late evenings working on classes and papers.

DEDICATION

I dedicate this thesis in memory of my Grandmother Eileen Elizabeth Blair and my Father Sidney Stuart Blair. Their love and support to pursue my PhD was unwavering.

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LIST OF ABBREVIATIONS

Abbreviation	Description
CIT	Clinical Improvement Team
CKD	Chronic Kidney Disease
CORR	Canadian Organ Replacement Registry
CPSI	Canadian Patient Safety Institute
ESKD	End Stage Kidney Disease
HD	Hemodialysis
HHD	Home Hemodialysis
IR	Interventional Radiology
KH	Kidney Health
KHCP	Kidney Health Community Program
MMSF	Measuring and Monitoring of Safety Framework
n/a	Not Available
OR	Operating Room
PD	Peritoneal Dialysis
PDCA	Plan Do Check Act
SHA	Saskatchewan Health Authority
SPSS	Statistical Package for Social Sciences

SYMBOLS

Symbol	Description
<	less than
>	greater than
=	equal to

CHAPTER 1: Dissertation Overview

1.1 Dissertation Overview

This PhD dissertation examines improving peritoneal dialysis (PD) patient care within the Saskatchewan Health Authority. It explores two key initiatives: Nîsohkamâtowak, a culturally sensitive program engaging First Nations and Métis communities to increase PD uptake, and the Measuring and Monitoring Safety Framework (MMSF) collaborative, which aimed to reduce PD catheter dysfunction rates. The dissertation details the methodology, findings, and impact of both initiatives on patient outcomes, highlighting the importance of cultural competency and clinical practice redesign. This research resulted in a significant reduction in PD catheter dysfunction and improved patient experiences. A key contribution is the development of standardized definitions for PD catheter dysfunction to facilitate better data collection and benchmarking.

The Saskatchewan Health Authority (SHA) Kidney Health (KH) Program strives to enhance the health, safety, and quality of life of patients through a *Home First* model of care, promoting peritoneal dialysis (PD) to better meet patients' needs. Historically, the utilization of PD in First Nations and Métis people has been low. This research explores how a holistic participatory evaluation framework incorporating traditional First Nations and Métis protocols and the Truth and Reconciliation *Calls to Action* into the KH model of care, and a Measuring and Monitoring Safety Framework (MMSF) impacted the care experiences of patients and families with kidney disease.

This manuscript style dissertation is composed of the following:

- Chapter 1. Dissertation Overview – describes the research timeline, questions and objectives;
- Chapter 2. Introduction – provides an overview of the Home First and Home Based dialysis models of care and rationale for this research;

- Chapter 3. *Nîsohkamâtowak* (published manuscript) – describes the *Nîsohkamâtowak* initiative, outcomes and impact on the First Nations and Métis patient and families and the Kidney Health program and staff from 2015-2017;
- Chapter 4. Setting the Stage for the Measuring and Monitoring of Safety Framework (MMSF) and Link to Peritoneal Dialysis Failure Rate – describes how the two initiatives complement and add to the breadth of research from 2017-2020;
- Chapter 5: Using the Measuring and Monitoring of Safety Framework to Improve Peritoneal Dialysis Catheter Function and Patient Experience (manuscript submission in progress) – describes how the implementation of MMSF improved patient safety and clinical outcomes;
- Chapter 6: Discussion and Conclusions – provides perspective on research and impact.

This research addressed the following key themes:

- Understanding the lived interactions of patients and families with kidney disease within a culturally sensitive context informed by the Truth and Reconciliation *Calls to Action*;
- Exploring the concept of patient safety in the home and community through participation in the MMSF with the Canadian Patient Safety Institute/Healthcare Excellence Canada;
- Addressing quality and safety barriers that prevent patients from successfully performing home PD and helping patients remain on PD when their functional status changed;
- Evaluating PD catheter dysfunction rates and implementing improvements to enhance patient outcomes and reduce the burden on the healthcare system.

This dissertation highlights the importance of culturally sensitive care, patient safety, and continuous clinical improvement in enhancing the lives of patients and families living with kidney disease.

1.2 Research Timeline and Responsibilities

The *Nîsohkamâtowak* initiative occurred from 2015-2017, and the MMSF Collaborative from 2018-2020. The learnings from *Nîsohkamâtowak* helped to shape the development of a more culturally sensitive peritoneal dialysis (PD) model of care, with active participation from patient and families and the clinical improvement team (CIT). The development of a standardized database for prospectively tracking clinical outcomes over time was complemented by the MMSF metric set (mapped against framework dimensions). Data collection and analysis occurred over several phases, and the evaluation objectives allowed for an adaptive approach for interpretation. The research and evaluation methods are described in subsequent chapters.
For the *Nîsohkamâtowak* initiative, my research responsibilities were focused on participatory evaluation framework design, data collection, analysis, and report/manuscript preparation. I co-designed the questions used during the *Nîsohkamâtowak* events/sharing circles in partnership with First Nations and Métis patients and Elders and analyzed for themes. I lead the creative production of the videos in a storytelling format and prepared the manuscript for publication.

For the MMSF, my responsibilities included the development and standardization of the PD catheter outcomes database, facilitation of definition of PD catheter failure rate, implementation of the MMSF reporting and metrics cascade, clinical process improvement, and all duties related to data analysis and report/manuscript preparation. An overarching objective for my work was to integrate research and PD program operational initiatives.

1.3 Research Questions and Objectives

This research utilized principles of interventional research, integrating learnings about effective strategies for improving progress towards the *Calls to Action* in KH programs and addressing PD catheter dysfunction over time. This approach allowed for reflection and adaptation as the research progressed. The two manuscripts embedded in this dissertation are based on the following research questions and objectives.

Manuscript Title: Program Report: Nîsohkamâtowak - Helping Patients and Families Living With Kidney Disease in Northern Saskatchewan

Nîsohkamâtowak objectives:

- To identify factors which provide significant contributions to improved health status for patients who choose peritoneal dialysis as a treatment modality;
- In collaboration with First Nations and Métis people and Elders, improve access to peritoneal dialysis, within a well-designed culturally sensitive model of care;
- To engage healthcare teams in building cultural competencies, story-telling and active listening, and to participate in quality improvement with First Nations and Métis community partners;
- To better understand personal, family and community factors related to improved PD and quality of care outcomes;
- To honour the lived experience of patients and families, and the wisdom of the Elders.

Manuscript Title: Using a Measuring and Monitoring Safety Framework to Improve Peritoneal Dialysis Catheter Function and Patient Experience

MMSF research question:

- Will the implementation of MMSF improve PD catheter dysfunction and patient experience?

Kidney Health and Interventional Radiology Operational Objectives:

- To improve quality, safety and access to care for patients and families through the implementation of the MMSF;
- To facilitate more effective use of financial resources by redirecting existing surgical procedures for PD catheter insertion to Interventional Radiology;
- To integrate research and PD program operational initiatives;
- To improve patient and family home based PD care.

As part of the interventional research approach, the "So what" factor was used in the development of the research/evaluation strategy allowed for reflection and adaptation as my PhD progressed, in terms of impact, clinical practice improvement, and innovation[1]:

- "So what" is the prevalence of the problem and how is it modifiable through an intervention? – PD catheter dysfunction occured in 40.3% of patients (25/62) in 2016, and kidney failure affects a higher proportion of First Nations and Métis population
- "So what" will be the end outcome of the research/evaluation? – The *Calls to Action* will better tailor a culturally sensitive model of PD care, and IR PD insertion will improve PD catheter function rate
- "So what" difference will the research/evaluation make in improving health outcomes, costs, and patient and family/community outcomes? Patients will have better PD outcomes, their traditions and values will be respected, and less cost to the health system through more effective utilization of KH program and IR resources
- "So what" will others do with the research/evaluation outcomes? – Other PD programs can tailor their PD model of care and include the MMSF principles and *Calls to Action* directly into programs/services; adopt the definitions of PD catheter dysfunction and outcomes database
- "So what" will be the real time application of the results? – Improve uptake of PD and penetration rate of PD as a home based modality, and improve quality of life for patients with kidney failure
- "So what" is the chance that others will adopt and implement this intervention based on feasibility, reproducibility and cost?[1] – The adoption of MMSF represented a significant shift in patient safety culture, and required ongoing rigour for data collection, analysis, and clinical practice improvement and *Calls to Action* being embedded into the KH program. For other programs, this may be a significant challenge.

1.4 References

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CHAPTER 2: Introduction

2.1 Introduction

Central to good clinical care for people with chronic conditions is educating and empowering people to be more engaged in the self-management of their health and their care.[1,2] In current practice, patients with kidney failure may be passive recipients of care in in-hospital dialysis units, or satellite units. There is a need to shift toward stronger, patient centred care, empowering patients to make decisions and actively participate in their own care, and to recognize the importance of cultural differences in its success. A *Home First* model of care that recognizes and adapts to cultural diversity at an individual, family and community level will better serve patient needs, preferences and values. Innovation is defined as "the intentional introduction and application within a role, group, or organization, of ideas, processes, products or procedures, new to the relevant unit of adoption, designed to significantly benefit the individual, the group or wider society". [3] For this dissertation, innovation reflects the need to provide a better more robust way of providing home PD care.

To address these challenges, the Saskatoon Kidney Health program partnered with First Nations and Métis Health Services to implement the *Nîsohkamâtowak* initiative which sought to understand the reasons for low PD uptake among these communities, identify potential solutions to improve access and address the Truth and Reconciliation Commission of Canada's *Calls to Action*. One key aspect was designing a culturally sensitive model of care that acknowledges and respects the traditions and preferences of First Nations and Métis patients, aligning with the broader goal of improving quality care and outcomes for this population.

Benchmarking against external standards revealed that First Nations and Métis patients often experience a higher burden of kidney failure severity, utilize fewer home based dialysis therapies, and face longer travel distances living in rural and remote communities. Addressing these discrepancies and closing the gaps in care for First Nations and Métis patients with kidney failure formed a critical driver for this research.

While pre-emptive transplants are the preferred treatment for kidney failure, a *Home First* philosophy emphasizing home dialysis like PD or HHD should be considered when possible. This approach offers benefits such as tailored dialysis, freedom, flexibility, and improved quality of life for patients while also reducing costs and resource utilization for the healthcare system. However, despite being more cost-effective than in-center hemodialysis (HD), PD remains significantly underutilized, particularly among First Nations and Métis patients representing a gap in kidney failure quality care. The reasons for this disparity are complex and multifaceted.

Home First principles[1,2]

- Focus on patient-centred care and supporting patient self-management.
- Teamwork approach to care, with the patient as the central member of the team.
- Implementation of the evidence base, aiming to improve patient outcomes.
- Engagement at all levels of the health service, supported by a clear vision and both clinical and executive leadership.
- Capture patient and family, community, and staff stories to express the impact of co-design.
- Identify benefits and barriers for *Home First* model of care
- Culturally tailored to patient and family preferences and needs

Figure 2-1 shows the requisite attributes of a *Home First* model of care.

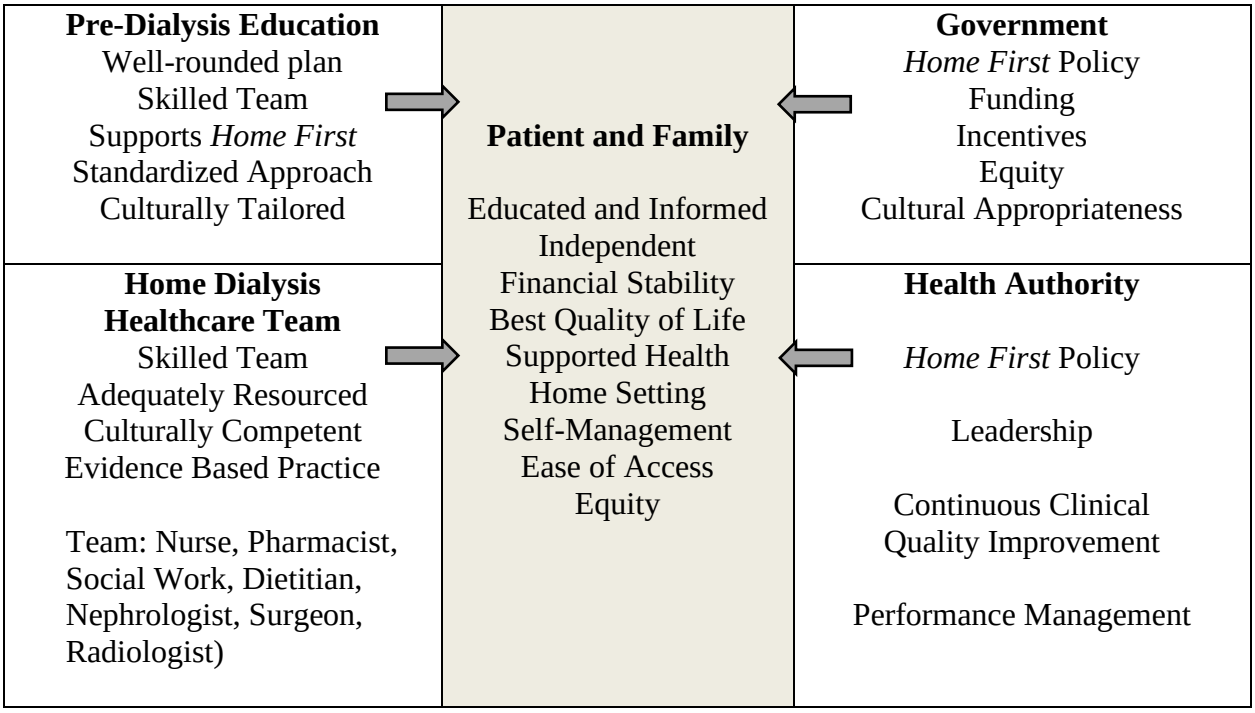

Figure 2-1. Requisite Attributes of *Home First* Model of Care.[1]

Peritoneal dialysis is an important model of a *Home First* therapy to avert or delay the need for HD and uses the peritoneum and dialysate solution to clean the blood. Home hemodialysis (HHD) is done in the patient's home, where blood flows from the patient's vascular access through a dialysis machine. The dialysis machine cleanses the blood of extra waste and fluids and sends the clean blood back into the body. PD and HHD have significant benefits to patients and families including not having to fit into rigid health service schedules, reduction in travel time and costs and improved quality of life. Benefits for the health system include cost savings as compared to hospital-based hemodialysis and lower resource utilization.[4-9]

Of note, kidney failure and its related comorbidities are more prevalent among First Nations and Métis than non-First Nations and Métis people, and at diagnosis, First Nations and Métis people present with more advanced disease.[10-12] In Saskatchewan, First Nations and Métis people had higher burden of kidney failure severity, utilized fewer home-based dialysis therapies, and had longer travel distances than their non-First Nations counterparts.[13] Clearly more research and innovative solutions are needed to design a culturally sensitive model of care, improve access and utilization of home based dialysis therapies, and better understand how personal, family and community factors relate to improved quality of care and safety outcomes.

The demand for dialysis services continues to increase, with projections and actual service utilization data suggesting an increase of approximately 5-6% annually.[7,14] Within the SHA where dialysis units are already operating at or above capacity, there is a need to rethink the usual model of care. Establishing a provincial *Home First* model is an overarching system priority and requires provincial, local and community commitment. However, it is not known to what degree this *Home First* dialysis approach will enhance patient and family choice for PD. *Home First* models prioritize empowering patients to self-manage their condition and their treatment, with an interdisciplinary team providing support, patient education, and help preparing the patient's home environment.[1]

1.2 Rationale

As part of the SHA Sustainability Plan, KH and IR partnered to achieve best practice for PD catheter insertions by providing a minimally invasive and timelier alternative to the predominant laparoscopic surgical insertion method. Advances in IR training and techniques have allowed for an increased number of procedures to be performed in the Medical Imaging Department rather than surgically. Current pressures for operating time have created wait times for peritoneal catheter insertion. A more responsive IR program promotes greater patient access, provides a less invasive procedure, and reduces the need for temporary vascular access and hemodialysis.

Nationally, the target for primary PD catheter dysfunction (inability of the PD catheter to support adequate inflow and/or outflow, patient not able to train) for PD catheter insertions is <10% at 3 months.[15] PD catheter dysfunction rates are associated with significant burden and hardship to the patient, and an overall increase in cost to the health system due to additional procedures/tests to diagnose and correct complications.[15]

High-quality PD catheter insertion pathways are essential for optimal access to the therapy.[16] Dialysis outcomes are influenced by a range of patient and centre-related factors, and there is a need to better understand these so that catheter insertion pathways can better match with individual circumstances.[16-19] Limitations include lack of standardization of facilities, availability of IR and surgical time for PD procedures, size of facility (reliability of operator, number of procedures/year), and staffing models.[16-19]

Previous methods of PD catheter insertion in Saskatoon resulted in high failure rates at 3 months post procedure for combined primary and secondary dysfunction rate: 2016 25/62 (40.3%); 2017 19/71 (26.8%); 2018 11/50 (22.0%); 2019 12/54 (22.2%); and in 2020 5/57 (8.8%). It was clear that there was an imperative to implement quality and safety efforts to address PD catheter failure rates for both primary and secondary PD catheter failure (patient able to train, but stopped due to PD catheter malfunction or flow, or non-catheter issues).

In 2018, the Kidney Health CIT was selected to participate in the MMSF[20] Collaborative. This opportunity aligned well with the SHA vision to enhance the health and quality of life of patients by allowing patients to perform life sustaining therapy in their own homes, to better meet the health needs of patients in a collaborative manner, and to expand community partnerships. The MMSF collaborative addressed a number of quality and safety barriers that prevent patients from successfully performing home PD and assisted patients to remain on PD when their functional status has changed. There is a lack of published research focusing on patient safety and PD.

With the transition to IR PD catheter insertion, and implementation of the MMSF, the failure rate has improved significantly from 40.3% in 2016 to 8.8% in 2020 which is below the national target. This transition was further advanced through the implementation of the Measuring and Monitoring of Safety Framework.

According to the report on *End-Stage Renal Disease among Aboriginal People in Canada: Treatment and Outcomes*,[10] kidney disease is more prevalent in First Nations and Métis people, occurs earlier and progresses more quickly; treatment of kidney disease (from prevention to dialysis and transplantation) is compromised for many First Nations and Métis people due to distance to treatment and cultural appropriateness (including traditional perspectives on transplantation and cultural insensitivity at the point of service); and there is limited information available on patient characteristics and treatment-related factors for end stage kidney disease. In general, First Nations and Métis patients have more co-morbidities, are less likely to initiate PD, have higher rates of technique failure requiring a switch to hemodialysis (HD) and higher rates of peritonitis.[21] Further culturally appropriate investigation regarding kidney failure screening and prevention, education initiatives, culturally appropriate care initiatives, and the reasons why these patients have higher rates of PD technique failure and lower PD use need to be better understood.[22-24] Further research should include measures of socioeconomic status, employment status, and other population health indicators that are known to affect health status.[24] In addition, the broad term Indigenous does not allow identification and appreciation of the unique profiles of First Nations and Métis patients and families.

In partnership with First Nations and Métis Health Services, the SHA Kidney Health program started work provincially with patients to better address The *Truth and Reconciliation Commission of Canada* [25] recommendations and close the gaps in kidney care. This document, released in 2015, lists 94 action items to "…readdress the legacy of residential schools and advance the process of Canadian reconciliation." Of the seven items under "Health", the Kidney Health Programs and local partners are collectively working to address four of these *Calls to Action*:

- *Item 19*: "identify and close gaps in health outcomes between Aboriginal and non-Aboriginal communities";
- *Item 20*: "recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal Peoples";
- *Item 22 (iii)*: "those who can effect change within the Canadian healthcare system…recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders…";
- *Item 23*: "Provide cultural competency training for all healthcare professionals".

Nîsohkamâtowak, the Cree word for '*helping each other*' was an initiative to close gaps in kidney health care for First Nations and Métis patients, their families and communities in northern Saskatchewan. *Nîsohkamâtowak* emerged from a collaboration between the Kidney Health Community Program and First Nations and Métis Health Services to find ways to deliver better care and education to First Nations and Métis people living with kidney disease while acknowledging *Truth and Reconciliation Calls to Action.*

Kidney Health program enhancements are needed to better understand and serve these patients in their home communities. Through this research, I developed strategies to promote home based therapies in a culturally sensitive manner, understand models of care that are better tailored to the needs of rural/remote communities, embed a quality and safety framework to improve patient care, and ensure more efficient use of existing resources. My dissertation describes the participatory framework undertaken and results achieved over time, and how the *Nîsohkamâtowak* learning positively impacted KH MMSF view of patient safety from a cultural inclusiveness lens. The First Nations and Métis patient advisors described being on PD as

"having a hospital in my home". The *Nîsohkamâtowak* videos and patient stories explored barriers to home based therapies and the need for staff to better understand traditional ways, healing practices, and highlighted the need for staff to receive training in cultural competency.

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CHAPTER 3: *Nîsohkamâtowak*

In 2015, the Kidney Health Community Program began a partnership with First Nations and Métis patients, their families and communities in northern Saskatchewan. The following chapter includes the published manuscript *Program Report: Nîsohkamâtowak - Helping Patients and Families Living With Kidney Disease in Northern Saskatchewan* in the *Canadian Journal of Kidney Health and Disease*. This manuscript describes the *Nîsohkamâtowak* program evaluation and how the *Truth and Reconciliation Calls to Action* were imbedded into the Kidney Health program to promote home based dialysis treatment options for First Nations and Métis patients, families and communities. I prepared the manuscript for publication.

Program Report: Nîsohkamâtowak - Helping Patients and Families Living With Kidney Disease in Northern Saskatchewan

Blair T, Babyn P, Kewistep G, Kappel J, Stryker R, Ramsden VR, Neudorf C, Levandoski C. Program Report: *Nîsohkamâtowak* - Helping Patients and Families Living With Kidney Disease in Northern Saskatchewan. Can J Kidney Health Dis. 2022 Jan 5;9:20543581211067071. doi: 10.1177/20543581211067071. PMID: 35035983; PMCID: PMC8753229.

Abstract

Purpose of the Program: *Nîsohkamâtowak,* the Cree word for '*Helping Each Other*' is an initiative to close gaps in kidney health care for First Nations and Métis patients, their families and communities in northern Saskatchewan. *Nîsohkamâtowak* emerged from a collaboration between the Kidney Health Community Program and First Nations and Métis Health Services to find ways to deliver better care and education to First Nations and Métis people living with kidney disease while acknowledging *Truth and Reconciliation* and the *Calls to Action.*

Sources of Information: This article describes how traditional Indigenous protocols and story-telling were woven into the *Nîsohkamâtowak* events, gathering of patient and family voices in writing and video format, and how this work led to a collaborative co-designed process which

incorporates the *Truth and Reconciliation: Calls to Action* into kidney care and the benefits we have seen so far. The teachings of the four R's – respect, reciprocity, responsibility, and relevance, were critical to ensuring that *Nîsohkamâtowak* reports and learning were shared with participants and the communities represented in this initiative.

Methods: Group discussions and sharing circles were facilitated in several locations throughout northern and central Saskatchewan. Main topics of discussion were: traditional medicines, residential schools impact, community and peer supports for kidney disease patients, and cultural safety education for healthcare providers.

Key Findings: The general themes selected for improvement were: education, support within the local community, traditional practices and cultural competency, and delivery of services. To address these gaps in kidney care, the following objectives were co-created with First Nations and Métis patients, families and communities for Kidney Health: to provide culturally appropriate education and resources; to ensure appropriate follow-up support to include strengthening connections to communities and other health authorities; to incorporate traditional practices into program design; and to ensure appropriate service delivery across the spectrum of care with a focus on screening and referral, which is strongly linked to coordination of care with local health centers.

Implications: As a result of this work, the Kidney Health Community Program restructured the delivery of services and continues to work with *Nîsohkamâtowak* advisors on safety initiatives, and chronic kidney disease awareness, prevention, and management in their respective communities. The *Truth and Reconciliation Calls to Action* are honoured to close the gaps in kidney care.

Limitations: *Nîsohkamâtowak* is a local Kidney Health initiative that has the good fortune of having dedicated funding and staff to carry out this work. The findings may be unique to the First Nations and Métis communities and people that shared their stories. *Truth and Reconciliation* is an ongoing commitment that must be nurtured. Although not part of this

publication, the effects of COVID 19 have made it difficult to further advance the *Calls to Action*, with more limited staff resources and the inability to meet in person as in the past.

Keywords

Kidney Disease, Engagement, Calls to Action, Patients and Families, Indigenous

What was known before

The burden of kidney disease for people living in northern Saskatchewan is significant, and current models of care do not meet the needs, cultural values and preferences of First Nations and Métis patients and families.

What this adds

In collaboration with First Nations and Métis patients, families and Elders, Kidney Health partnered to design and integrate a culturally sensitive *Home First* model of care into the daily operations of the Kidney Health Community Program (KHCP). Together we worked to better understand how personal, family and community factors relate to improved quality of care outcomes. *Nîsohkamâtowak,* the Cree word for '*Helping Each Other*' is about recognizing and acknowledging the *Truth and Reconciliation Calls to Action*, and closing the gaps in kidney health care for First Nations and Métis patients, their families and communities. This article describes the traditional protocols and story-telling used, and how this work led to a collaborative co-designed process which incorporates the *Calls to Action* into kidney care and the benefits we have seen so far.

3.1 Purpose of the Program

The burden of kidney disease for people living in Canada is significant. According to the Kidney Foundation of Canada reports *Facing the Facts 2020*[1] and the Canadian Organ Replacement Register (CORR) annual statistics 2019[2] one in 10 adult Canadians has kidney disease, or 4 million people[3]. CORR statistics (excluding Quebec) show that the leading cause of kidney failure is diabetes at 38%, and the number of people living with end-stage kidney disease has grown 35% since 2009. Of note, more than 50,000 Canadians are being treated for kidney failure[4].

Overall measures of health and life expectancy from kidney disease are improving, but significant health inequities continue between population groups, socioeconomic levels and geographical areas, in health outcomes. As with many chronic conditions, chronic kidney disease (CKD) rates, morbidity and mortality worsen according to levels of disparity on social determinants on health. Populations with greater disparity have higher prevalence and are more likely to be hospitalized for care relating to CKD[5-9].

CKD and its related comorbidities are more prevalent among First Nations than non-First Nations people, and at diagnosis, First Nations people present with more advanced disease[10-12]. As reported by Thomas et al 2018, in Saskatchewan, First Nations' had higher burden of chronic kidney disease severity, utilized fewer home-based dialysis therapies, and had longer travel distances than their non-First Nations counterparts[13]. Clearly more research and innovative solutions are needed to design a culturally sensitive model of care, improve access and utilization of home based dialysis therapies, and better understand how personal, family and community factors relate to improved quality of care outcomes.

In partnership with First Nations and Métis Health Services, the Saskatchewan Health Authority (SHA) Kidney Health program started work provincially with patients to better address The *Truth and Reconciliation Commission of Canada* [14] recommendations and close the gaps in kidney care. This document, released in 2015, lists 94 action items to "…readdress the legacy of residential schools and advance the process of Canadian reconciliation." Of the seven items

under “Health”, the Kidney Health Programs and local partners are collectively working to address four of these *Calls to Action*:

- *Item 19*: “identify and close gaps in health outcomes between Aboriginal and non-Aboriginal communities”;
- *Item 20*: “recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal Peoples”;
- *Item 22 (iii)*: “those who can effect change within the Canadian healthcare system…recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders…”;
- *Item 23*: “Provide cultural competency training for all healthcare professionals”.

According to the report on *End-Stage Renal Disease among Aboriginal People in Canada: Treatment and Outcomes (*CIHI 2013 [15]), interventions to improve chronic care and end stage renal disease should include three categories: *create supportive environments* – incorporation of culturally appropriate practices to improve access; *strengthen community action* – identifying and planning for local needs to improve access and fostering patient and community empowerment in addition to collaboration between communities and between different levels of government toward innovative interventions; and *delivery system design and reorientation* – improving responsiveness to local needs; capacity building; culturally safe practices and providing service closer to home[15]. It remains imperative to address and close these gaps in kidney care for First Nations and Métis patients, their families and communities.

After many weeks of consultation, incorporating traditional protocol, Elder guidance and story-telling, *Nîsohkamâtowak*, the Cree word for ‘*Helping Each Other*’ was chosen to reflect the spirit of this initiative by friends and colleagues at First Nations & Metis Health Services, Kidney Health Community Program Improvement Team, and First Nations and Métis patients, families and community members. Reconciliation and addressing the *Calls to Action* is critical to guide this collaborative work, along with the Saskatchewan Health Authority (SHA) goal to provide the best patient and family centered care possible. Relationship building is a key component through which we can ‘help each other.’ This approach is intentional about following Indigenous traditional protocols and creating safe spaces for those relationships to grow.

This partnership served to co-create strategies to incorporate tradition and protocol in planning, delivery and evaluation of the *Nîsohkamâtowak* events, patient interviews and sharing circles, and actions plans to better address *Truth and Reconciliation*. The *Nîsohkamâtowak* initiative, results and impact on Kidney Health programming has led to a strong partnership with First Nations and Métis patient and families.

3.2 Home Based Dialysis – Peritoneal Dialysis and Home Hemodialysis

Currently, the uptake of home based dialysis therapies in First Nations and Métis communities is low in the Saskatoon Kidney Health program: peritoneal dialysis (PD) 17.2% (27 out of 157 patients on PD), and home hemodialysis (HHD) 12.0% (3 out of 25 patients on HHD). Peritoneal Dialysis is an important model of home based therapy to avert or delay the need for hemodialysis, and uses the peritoneum and dialysate solution to clean the blood. Home hemodialysis is done in the patient's home, where blood flows from the patient's vascular access through a dialysis machine. The dialysis machine cleanses the blood of extra waste and fluids and sends the clean blood back into the body. There are significant benefits from PD and HHD modality usage for the health system, including significant cost differences between hospital-based, satellite and home based dialysis and lower resource utilization with home dialysis[6,8]. Other substantial benefits for patients include not having to fit into rigid health service schedules and a reduction in travel time and costs[3,8]. Supporting the patient to choose the best home based modality has been shown to have a great impact not only on health-related outcomes but on quality of life[5]. Thus, it is important to consider the social implications of each modality on the patient's life, and tailoring a patient's care pathway will enhance the uptake of home based dialysis therapies and quality of life, should they choose either PD or HHD[6,9].

Program enhancements for PD and HHD are needed to better understand and serve these patients in their home communities. According to a recent publication by Richels et al 2020[16], home PD offers better quality of life, lessens the burden of travel, requires fewer dietary restrictions and is approximately half the cost of hospital-based dialysis yet remains significantly underutilized by First Nations communities[16]. The reasons for the disparity in utilization and the barriers to home

dialysis in First Nations communities in Saskatchewan need to be addressed to improve quality of care[17].

Unique challenges for PD and HHD in First Nations and Métis communities include rapidly growing populations with higher rates of end stage renal disease at a younger age, poor housing with a mix of urban, inner city, reserve, and remote homes, each with different challenges, poor water quality, socio-economic disadvantages, and limited access to treatment facilities[5,9,10,16]. Indigenous patients experience higher technique failure, less survival benefit, higher rates of peritonitis, higher PD dropout rate and transfer to hemodialysis, and a lack of culturally sensitive models of care[10,12,16,18,19]. There is also a lack of information and specific kidney health education for health centres on reserves, and the potential of home based therapies is not routinely talked about (*Nîsohkamâtowak 2017).*

3.3 Methods

KHCP held several *Nîsohkamâtowak* events at Wanuskewin, Meadow Lake and La Ronge, in partnership with the SHA, First Nations Improvement Team members, and Elders. These events were guided by a holistic participatory framework honouring Indigenous protocols, traditions, culture and spirituality. The events were advertised using posters and brochures. Patients and their families were invited to attend. Those that chose to attend, signed a SHA media consent and release form. Sharing circles embraced conversational methods/story-telling to gather knowledge and wisdom regarding patient and family experiences living with kidney disease. Videos/short stories were gathered to promote a better understanding of cultural competency, blending traditional and western medicines, to improve the care experience for patients and families in their home communities.

The teachings of the four R's – respect, reciprocity, responsibility, and relevance, also guide the Kidney Health Community Program Improvement Team. This preliminary work helped to inform how to tailor a culturally sensitive model of care for PD as a modality option for First Nations and Métis people. Of note, the *Nîsohkamâtowak* collaborative model has demonstrated positive outcomes related to the *Calls to Action*. It is also unique in terms of integration of

protocol, prayer, and Elder guidance in planning, community partnerships, traditional medicine teachings, and building cultural competency.

Nîsohkamâtowak objectives:

- To identify factors which make significant contributions to improved health status for patients who choose peritoneal dialysis as a treatment modality
- In collaboration with First Nations and Métis people and Elders, improve access to peritoneal dialysis, and design a culturally sensitive model of care
- To engage healthcare teams in building cultural competencies, story-telling and active listening, and to participate in quality improvement with First Nations and Métis community partners
- To better understand personal, family and community factors related to improved PD and quality of care outcomes
- To honour the lived experience of patients and families, and the wisdom of the Elders

Figure 3-1 shows some of the participants at the Wanuskewin Event in one of the group sessions that explored kidney health.

Figure 3-1. Photograph provided with consent, showing a group session at the Wanuskewin Event.

We cannot improve outcomes without the voice and perspectives of the people in which we serve. This requires active listening on the part of the healthcare professional. "*Reconciliation must inspire Aboriginal and non-Aboriginal peoples to transform Canadian society so that our*

children and grandchildren can live together in dignity, peace, and prosperity on these lands we now share" – Truth and Reconciliation 2015[14].

3.4 Key Findings

3.4.1 *Nîsohkamâtowak* 2015

In October 2015, the first *Nîsohkamâtowak*" event was held at a traditional ceremony site at Wanuskewin Heritage Park Saskatoon, Saskatchewan. The purpose of the event was to gather First Nations & Métis people living with kidney disease to co-develop a plan to deliver *better education, treatment, and care*. *Nîsohkamâtowak* helped develop a strong partnership to create action plans for better care. Figure 3-2 shows a representation of the feathers that were incorporated as part of the sharing circle, and were passed between participants when they told their stories.

Figure 3-2. Feathers symbolizing sharing circle theme.

Nîsohkamâtowak incorporates traditions, culture, and spirituality in a safe, open atmosphere that promotes equal opportunity for all to share and learn, where healthcare professionals listen versus teaching and talking. Audio and video professionals were present at the event. They recorded footage of the events and produced educational video clips for use by Kidney Health programs, and with First Nations & Métis Health Services assistance.

The short story telling videos can be viewed at:
https://www.stpaulshospital.org/foundation/donate/nisohkamatowak.php?page=270

- Video 1: *Nîsohkamâtowak*
- Video2: Chronic Kidney Disease Education
- Video 3: *Nîsohkamâtowak* Process
- Video 4: Challenges

Each day began and ended with a tobacco offering to an elder who prays in both English and his or her own native language. Traditional foods were served for breakfast, lunch, and snacks. As a thank you gift, participants were given a small fresh fruit basket, a coffee mug, and a bag of muskeg tea that was picked and blessed by an Elder from First Nations & Métis Health Services. Facilitators were present to guide and mediate discussions. The facilitators used small group discussion format, large group discussions, and sharing circles, providing a safe, trusting, and judgement free environment which made it easier for people to openly share ideas and stories. These activities link to the *Call to Action* items *19, 20, 22,* and *23*. Costs to host the events were provided by St. Paul's Hospital Foundation Saskatoon, Meadow Lake Tribal Council, Lac La Ronge Indian Band, and Peter Ballantyne Cree Nation. 27 First Nations and Métis kidney patients and family members participated in the Wanuskewin event.

The common themes expressed by participants included:

- The need for communication and culturally appropriate understanding and acceptance;
- Incorporation of western and traditional ways - medicines, foods, prayers and customs;
- Patients want to guide their own care;
- 'Up to date' and timely education;
- Peer support and workshops in their communities.
- Education - improved kidney health education, information delivery and print resources;
- Wellness – improved support for healthy diet and exercise; and
- Cultural Competency – better understanding by health providers, translation of education materials into indigenous languages, and as part of patient visits.

Many participants at the first event recommended that *Nîsohkamâtowak* workshops be held in communities throughout northern and central Saskatchewan. KHCP proceeded to host *Nîsohkamâtowak* events in Meadow Lake (Meadow Lake Tribal Council), La Ronge (Lac la

Ronge Indian Band) and Pelican Narrows (Peter Ballantyne Cree Nation), North Battleford, Saskatoon and Touchwood Agency Tribal Council. Participants at the 2015 *Nîsohkamâtowak* gathering also recommended that a follow up event should take place at Wanuskewin every two years. The themes for future events are chosen in collaboration with First Nations and Métis patients and their families, and will reflect current needs and preferences for enhancing kidney care.

3.4.2 Sharing Circles 2016 and 2017

In 2016, KHCP work focused on two of the common themes that emerged from *Nîsohkamâtowak* discussions: welcoming traditional medicine in a western medicine world; and learning from each other.

Nîsohkamâtowak Sharing Circles took place in Meadow Lake, La Ronge and Pelican Narrows. Overall, the events were a success with 54 participants in total. Major themes of community discussions mirrored those of the initial *Nîsohkamâtowak* event and included:

- Education - More education needed (healthcare staff, patients, families, those who don't already have kidney disease);
- Cultural training for healthcare providers to promote understanding and acceptance;
- Traditional medicine - there is a place for both western medicine and traditional medicine which can and should both exist in our world and must follow the land based teaching of the Elders;
- Communication issues - listen more and let the patient be in charge; and
- Continue our current work, but seek to partner more with existing healthcare staff, educators, and Elders from the communities we visit.

In follow up to the sharing circle discussions, four patients offered to share their healthcare experiences, and their words gave the team time to pause and reflect on the pressing need to advance the *Calls to Action*:

> *" I need fasting blood work and I have to book a medical taxi so far in advance or only at certain times of the day that I forget to keep fasting or I can't go hungry that long. I have no money or car to drive myself or I would do that".*

"When you go to the hospital and you get yelled at by doctors and told they aren't going to do anything for you so go home, you are afraid to go back".

"What rights do we have and who can we talk to that can advocate for us when we are treated poorly while getting healthcare services"?

"I have had diabetes for 30 years, so why has no one ever taken the time to teach me these things before? No one has ever explained why I need bloodwork done, they just get mad at me when I don't get it done. I don't even understand what's being tested so why would I do it"?

The sharing circles focused on opportunities to better understand why First Nations people do not generally use home-based dialysis therapies (peritoneal dialysis and home hemodialysis) and to develop some ideas for improving access and uptake. The themes that emerged from the sharing circles in 2017 were:

- Education and information about diet, diabetes and kidney disease is either non-existent, too general, anecdotal or not trusted (education and information need to be specific and culturally appropriate).
- Community Support is inconsistent (support needs to be consistent and mentors and role models need to be developed).
- Leadership and Culture - Elders, traditional medicines and foods and local leadership need to be more involved in kidney health.
- Training and Support provided by the program needs improvement as patients are frightened in the beginning, depressed and anxious or feel unprepared (assisted peritoneal dialysis options should be available; mentors and role models need to be developed; mental health supports need to be available).
- Logistics – housing, hygiene, storage and supply, water and electricity, travel are often inadequate (central storage; central locations for peritoneal dialysis; local walking programs should be considered)

The themes and findings from *Nîsohkamâtowak 2016* are similar to those reported by Richels et al 2020[16], in which the authors concluded that strategies to help improve home-based dialysis

included improved education, local support, integrated traditional medicine, cultural sensitivity, and leadership prioritization[16].

3.4.3 *Nîsohkamâtowak* 2017

Patients and family members, community health workers and the Improvement Team staff gathered at Wanuskewin in March 2017 to continue the collaboration designed to improve Kidney Health services for First Nations and Métis patients. *Nîsohkamâtowak* continued to evolve in process, tradition, and protocol based on trust, cultural diversity, and shared learnings.

Participants who attended *Nîsohkamâtowak* expressed that they learned a great deal from the workshop. Comments such as “this conference made me feel I am not alone”….”this helps me accept my sickness and learn how to take better care of myself in the native way”…and “when I attend these things I leave and want to share everything I learned with my home community” were very common. The exchange of knowledge and ideas, and helping others to feel they have support is the first step in better management of chronic kidney disease. Figure 3-3 is a picture of prairie crocus flowers chosen by the *Nîsohkamâtowak* team as a symbol to represent spring and family.

Figure 3-3. Wahpee Kwanees “Little Flower”

Participants had the honour of listening to the story of a Residential School Survivor, which truly empowered our hearts and minds. Gilbert Kewistep, Knowledge Keeper, offered these words in Salteaux "Kitchi Meg-wetch Kahn-doh-tah-we-ang". A big thank you for listening to our voices.

Table 3-1 and Table 3-2 below show the *Nîsohkamâtowak* 2017 discussion topics and themes that emerged from this patient and family community event.

Table 3-1: *Nîsohkamâtowak* 2017 Discussion Topics

Discussion Topics
• How do you feel about chronic kidney disease? • What are barriers to receiving kidney health services? • How can we fix these barriers? • What can the Kidney Health program staff do better? • How important to you is kidney health in the youth in your community? • How can traditional medicine be incorporated into Kidney Health programs?

Table 3-2: *Nîsohkamâtowak* 2017 Themes

Sharing Circle Themes that Emerged
• Patients in charge – let patients and families guide their own care • Education – more timely education at initial diagnosis and at all milestones along the continuum of kidney disease • Support – to accept diagnosis and progression of disease. Support groups in local communities and better education for healthcare providers on cultural needs, as well as the use of Elders • Communication – improvements are needed between patients/families and healthcare providers; between healthcare providers within our program; between our program and healthcare providers in our patients' communities • Understanding and acceptance – doctors and other healthcare providers need more education on traditional ways. Cultural training means a better understanding, leading to acceptance and compassion • Fear – patients and families are afraid to stand up for themselves regarding traditional ways • Youth – work more with schools to provide education on risks and causes of kidney disease, empower teachers to promote kidney health in youth

The general themes highlighted for improvement were: Education, Support, Traditional Practices and Cultural Competency, and Delivery of Services. To address these gaps in kidney care, the following objectives were co-created:

1. Kidney Health commitment to provide culturally appropriate education and resources for patients, families, and communities. This would include youth, adult, family, and community audiences. Areas of focus for education and resources include: awareness, prevention, screening, and treatment.
2. Kidney Health to ensure appropriate follow-up support for First Nations and Metis patients and families. This means connections to communities and other health authorities already made will be strengthened, as well as new connections and relationships formed.
3. Kidney Health to incorporate traditional practices into program design. This will involve partnering with Elders, redesigning clinic flow and follow up visits, and working with our clients to support the use of traditional medicines (alone or in conjunction with Western practices).
4. Kidney Health to ensure appropriate services across the spectrum of care. A key area of focus will be screening and referral, which is strongly linked to coordination of care with local health centers. There is also a need to redesign how treatment options education is delivered to patients and families, with a possible change in structure to being a "Passport to Kidney Health".
5. All Kidney Health staff should receive cultural competency training, and be provided with a variety of modes for self-learning and professional development in this area.

3.5 Implications - Closing the Gaps in Kidney Care

Since 2017, the KHCP has continued to work towards a more culturally tailored model of care. Recent comments from First Nations and Métis patients show that Kidney Health is making progress: "We are on the team", "My traditions and beliefs are respected", and "Staff care about me". Both the peritoneal dialysis and home hemodialysis programs have partnered with rural and remote communities to better support patients in their homes. Kidney Health is currently evaluating the impact of this work on clinical outcomes.

As listed in the *Truth and Reconciliation Commission of Canada Calls to Action 19, 20, 22, 23,* KHCP has made progress to close the gaps in healthcare for First Nations and Métis people at risk for developing or living with chronic kidney disease. KHCP cannot improve outcomes without the voice and perspectives of the people whom we serve. Having First Nations and Métis people involved in story-telling and sharing important lessons they have learned helps guide everyone in improving kidney care. Kidney Health teams have learned to listen more and let the patient/client be in charge, seek to understand all cultures and traditions and build relationships, that there is a place for both western and traditional medicine, to continue our current work, and seek to partner more with existing healthcare staff, educators, and elders from the communities we visit. Table 3-3 shows the *Nîsohkamâtowak Calls to Action* progress to date, and lists the accomplishments that bring a great sense of joy and pride for Kidney Health

Table 3-3: *Nîsohkamâtowak Calls to Action* Progress to Date

RECONCILIATION ITEM	**ACCOMPLISHMENTS**
19: "identify and close gaps in health outcomes between Aboriginal and non-Aboriginal communities"	• Seek the opinions and guidance of healthcare colleagues who are First Nations or Métis • Include First Nations and Métis Kidney Health patient representatives in planning and facilitation of World Kidney Day symposiums • KHCP, Saskatoon CKD Clinic team and CanSOLVE CKD Project Team (Improving Indigenous Patient Knowledge about Treatment Options for Failing Kidneys)[20] partnered with the community of Ile-a-la-Crosse in northern Saskatchewan to host a Community Kidney Wellness Day. Multiple Elders and a traditional medicine man were an integral to this event. Featuring Western and traditional foods, medicines and knowledge
20: "recognize, respect, and address the distinct health needs of the Métis,	• Kidney/heart/blood vessel health promotion projects with two First Nations communities that facilitated the connection of Youth and Elders

Inuit, and off-reserve Aboriginal Peoples." (*Not just on-reserve individuals)*	• Assist and support First Nations and Métis communities' healthcare teams to restructure kidney health support to suit their particular community's health needs • Support and mentor home dialysis patient with education and tools to teach peers, youth, and Elders in home community about kidney health and dialysis • Initial project with 3 Elders and 7 youth, plus one healthcare professional from each reserve; led to follow-up event at one reserve planned by 3 youth who invited 2 elders to co-teach workshop with KHCP for 13 youth attendees
22 (iii): "those who can effect change within the Canadian healthcare system…recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders…"	• Education sessions on traditional medicines (by Medicine Man and Bundle Keeper) for patients, families, and staff • Use of traditional foods and medicines is encouraged by KHCP staff in all community and healthcare provider presentations regardless of audience or location • Added prayer by First Nations Elder at annual patient memorial for those with kidney disease • Offering tobacco and inviting Elders to be part of planning events and education sessions that include and impact Indigenous people, as well as conduct prayers in both English and their traditional languages
23: "Provide cultural competency training for all healthcare professionals."	• Kidney Health staff encouraged and supported to attend presentations and Blanket Exercises by First Nations & Métis Health/Representative Workforce; 100% of staff attended • *Nîsohkamâtowak* videos shared as part of ongoing education and to showcase patients and families • CKD team attended Métis Culture Days • KHCP staff supported to complete U of S College of Medicine Continuing Education Course: *The Role of Practitioners in Indigenous Wellness*

	• Cultural competencies built into job descriptions, interview guides, and ongoing staff education • Redesign handouts and education materials in partnership with First Nations and Métis patients and families

3.6 Conclusion

The *Nîsohkamâtowak* initiative is not a research initiative, but an integral part of the daily operational plan for the KHCP. Formal qualitative and quantitative methods were not used, but the results achieved to date show the positive impact of community engagement and incorporation of the *Calls to Action 19, 20, 22, 23* into kidney care program planning, building healthcare team cultural competencies, and learning about the importance of respecting culture and traditional protocol. The *Nîsohkamâtowak* process, videos, staff commitment to cultural competency, and positive effect on patient, family and community experience and engagement have shown tangible progress towards closing the gaps in kidney care and addressing *Truth and Reconciliation*.

Kidney Health will continue to support First Nations and Métis patients, families and communities on their healing journey. The incorporation of the *Truth and Reconciliation Calls to Action* continue to be implemented throughout the process of delivering patient centered care for First Nations and Métis patients, their families and communities. We continue to strengthen relationships and friendships built during the planning and hosting of *Nîsohkamâtowak* events. The KHCP team works with patient and family advisors, Elders, and healthcare providers from First Nations and Métis communities to provide guidance in developing better teaching tools and culturally tailored models of care for home based dialysis therapies.

Future considerations brought forward during peer review include: community screening done by culturally competent health care professionals with community support by existing diabetes & support people in the community, the need to include more caregivers in the process, Sanyas or other training related to understanding the effects of colonization on communities for health care

professionals, and more work done with youth in terms of education & awareness of diabetes & CKD. These considerations are worth further exploration and align well with advancing Truth and Reconciliation and the Calls to Action, in partnership with patients, families, local communities and Kidney Health staff.

3.7 Limitations

Nîsohkamâtowak is a local Kidney Health initiative that has the good fortune of having dedicated funding and staff to carry out this work. The findings may be unique to the First Nations and Métis communities and people that shared their stories. *Truth and Reconciliation* is an ongoing commitment that must be nurtured. Although not part of this publication, the effects of COVID 19 have made it difficult to further advance the *Calls to Action*, with more limited staff resources and the inability to meet in person as in the past. It is hoped that 2022 will bring renewed opportunities to continue to collaborate with First Nations and Métis patients, families and communities.

3.8 Acknowledgements

This project is supported by Provincial Programs, Kidney Health within the Saskatchewan Health Authority, and the St. Paul's Hospital Foundation, Saskatoon, Saskatchewan. We are very grateful for the generous participation of First Nations and Métis patients and family members and their ongoing dedication to improving health in their communities. We look forward to continued work with them in the future. We would also like to thank our Improvement Team members, who support *Nîsohkamâtowak* and our patients, families, and communities: Kidney Health Community Program, First Nations and Métis Health Services, Employee Wellness, Chronic Disease Management, St. Paul's Hospital Foundation, and the Kidney Foundation, Saskatchewan Branch.

3.9 Ethics Approval and Consent to Participate

Consent to participate was obtained through the Saskatchewan Health Authority Media Consent and Release. Ethics approval was obtained from the University of Saskatchewan, Biomedical Research Ethics Board, Certificate # 2408 on January 6, 2021 - Use of Secondary Health Data, for the purpose of publication of the *Nîsohkamâtowak* initiative. Ownership, Control, Access, and Possession (OCAP) principles for engagement with First Nations communities was respected and followed.

3.10 Consent for Publication

We have the authors consent for publication.

3.11 Availability of Data and Materials

Data are available upon request.

3.12 Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the authorship, and/or publication of this article.

3.13 Funding

The author(s) disclosed that funding was received from the St Paul's Hospital Foundation in Saskatoon, Saskatchewan.

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3.15 Summary

The *Nîsohkamâtowak* initiative served to develop strong partnerships with First Nations and Métis patients, families and communities, and to better understand their challenges related to choosing a home based dialysis therapy. The KH PD model of care was tailored to promote patient choice, understand how best to match community needs (different between urban, rural and remote locations), and staff trained in cultural competencies. The videos were used to showcase patient stories. *Nîsohkamâtowak* broadened thinking around patient safety, and this blended well with the second phase of research utilizing the MMSF, and two of the patients who were part of *Nîsohkamâtowak* become members of the CIT, and their journeys mapped to provide a current state for the PD patient care, from kidney disease diagnosis, modality choice, PD insertion, recovery and training. The patient stories served to challenge staff assumptions about healthcare and KH program experiences.

Maintaining a community partnership such as *Nîsohkamâtowak* requires dedication and avenues to share findings and gain insights on future program directions. Since 2017, unfortunately the KH program was not able to host community engagement events to the same degree. SHA and KH leadership changed, as did program priorities. COVID 19 also had a significant impact on KH programs and altered the *Home First* strategy (significant restriction in in-person contact, uptake in home based dialysis therapies negatively impacted). Despite not being able to host community engagement events, work with individual First Nations and Métis patients and their families continued to provide culturally appropriate care in keeping with the TRC *Calls to Action*. The KH Community Program work with First Nations and Métis people has not stopped, it has simply taken a different route.

Although *Nîsohkamâtowak* served to improve the *Home First* model of care, the nature of this initiative shifted focus away from improving PD and HHD uptake for First Nations and Métis patients and families, in recognition that it takes significant time and attention to shift attitudes (fear) towards home based therapies, and to understand how best to address *Truth and Reconciliation Calls to Action*.

The intent of *Nîsohkamâtowak* is better described as objectives:

- Factors which make significant contributions to improved health status for patients who choose peritoneal dialysis as a treatment modality were identified;
- In collaboration with First Nations and Métis people and Elders, access to peritoneal dialysis was improved, and a culturally sensitive model of care was designed;
- Healthcare teams were engaged in building cultural competencies, story-telling and active listening, and to participate in quality improvement with First Nations and Métis community partners;
- Personal, family and community factors related to improved PD and quality of care outcomes were better understood;
- The lived experience of patients and families, and the wisdom of the Elders was honoured.

The 'So what" factor for the *Nîsohkamâtowak* was a novel approach to embedding the *Calls to Action* into KH programs, and to better understand First Nations and Métis patient and family preferences for home based dialysis therapies.

To provide context and link *Nîsohkamâtowak* to the importance of the MMSF, in 2016 the PD catheter failure rate was 40.3% (25/62). There was a clinical imperative to improve PD insertion technique, to enhance the reliability of this home based therapy, and build confidence with patients and families to choose this modality. The focus of the research shifted to stabilizing the PD insertion technique, tracking clinical outcomes over time, and enhancing the *Home First* model of care in a culturally sensitive manner.

My research responsibility included the development of the PD catheter outcomes database and analysis strategy to track clinical outcome, implementation of the MMSF safety framework to enhance focus on patient safety and reduce the PD catheter failure rate. Outcomes were reviewed on a case by case basis to inform clinical practice improvement and to set plan-do-check-act (PDCA) cycles.

CHAPTER 4: Setting the Stage for the Measuring and Monitoring of Safety Framework and Link to Peritoneal Dialysis Dysfunction Rate

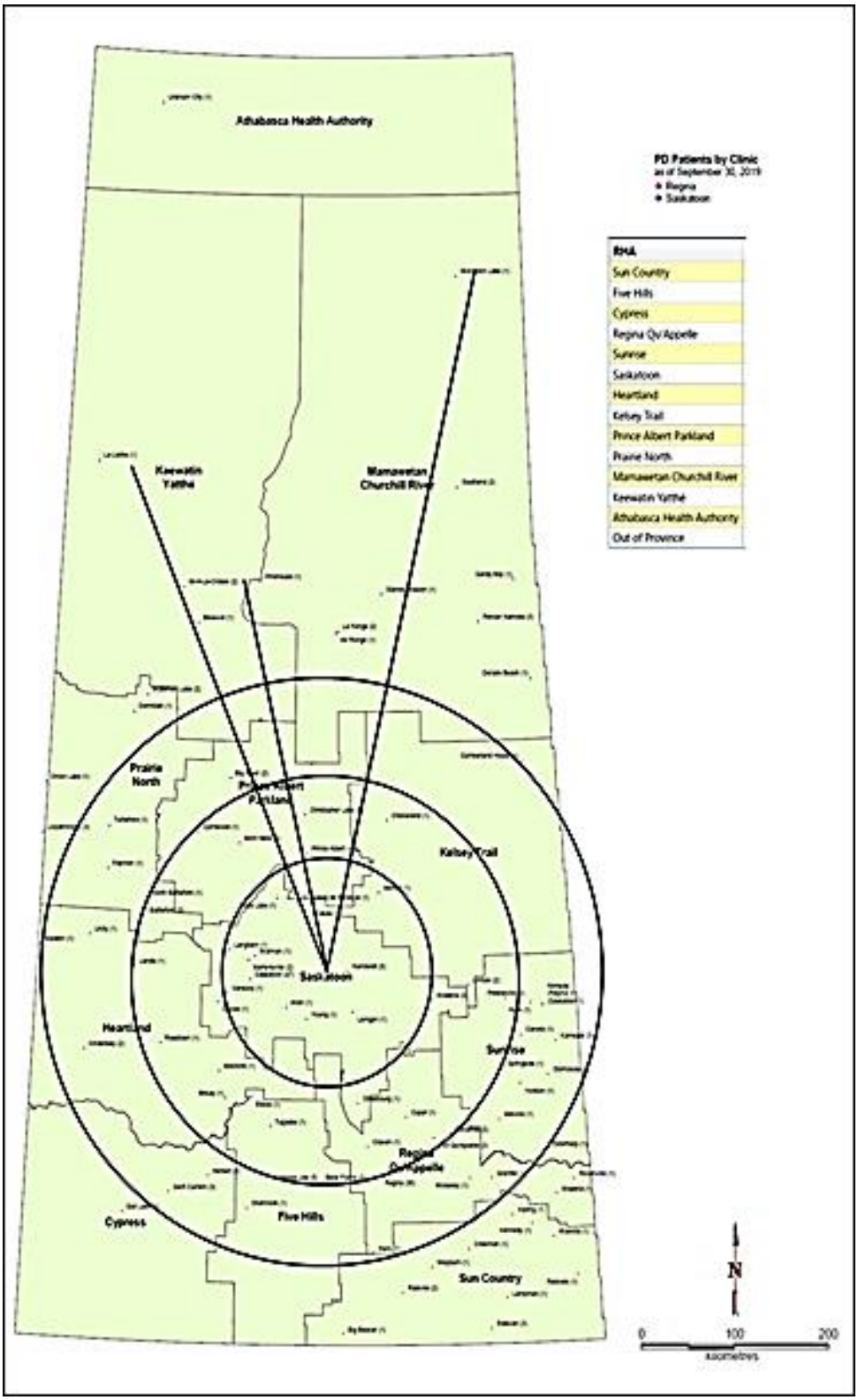
4.1 Introduction

Saskatoon KH partnered with First Nations and Métis Health Services to develop strategies to promote home based therapies in a culturally sensitive manner, develop new models of care for rural/remote communities, and address the *Truth and Reconciliation Calls to Action*. Peritoneal Dialysis is an important model of home based therapy to delay or avert the need for hemodialysis. The Kidney Health target was to have 30% of patients on home-based therapies. In 2017, there were 516 patients receiving dialysis treatments in the Saskatoon Kidney Health program. Of these, 147 patients (28.5%) were performing PD in urban, rural and remote areas of the province. Currently, the uptake for PD in First Nations and Métis populations is low. Program enhancements are needed to better understand and serve these patients in their home communities. Kidney Health developed strategies to promote home based therapies in a culturally sensitive manner, improved models of care for rural/remote communities, embedded a quality and safety framework to improve patient care, improved quality of life for patients and families, and ensured more efficient use of existing resources.

As outlined in the *Nîsohkamâtowak* manuscript, Kidney Health was collectively working to address four Calls to Action: Item 19: "identify and close gaps in health outcomes between Aboriginal and non-Aboriginal communities"; Item 20: "recognize, respect, and address the distinct health needs of the Métis, Inuit, and off-reserve Aboriginal Peoples." Item 22 (iii): "those who can effect change within the Canadian healthcare system…recognize the value of Aboriginal healing practices and use them in the treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders…"; and Item 23: "Provide cultural competency training for all healthcare professionals."[1] Cultural competency leads to safer, patient and family centred care.

In 2018 the Saskatoon Kidney Health Program was in a unique position to participate in the MMSF national collaborative. Saskatoon is one of only two PD units in Saskatchewan and is

responsible for providing PD services to the northern half of the province which lends itself well to roll out/dissemination of the safety framework over time. Figure 4-1 shows the capture range for PD patients across Saskatchewan.



Circles: distance from Saskatoon in 120 km increments.

Lines: northern communities

Figure 4-1. Map of PD Patient Range for Saskatchewan

Table 4-1 show the descriptive data tables for the PD patient population, followed prospectively over time.

Table 4-1 Descriptive Data Table Showing Age Breakdown, estimated glomerular filtration rate (eGFR) at time of insertion, Insertion Technique.

Age Breakdown - MALE								
	<50 yrs	50-59 yrs	60-69 yrs	70-79 yrs	>80 yrs	Total	Mean	Median
2016	9	13	7	6	1	36	56.3	57
2017	11	13	9	8	2	43	57.4	59
2018	11	3	6	4	1	25	53.6	54
2019	11	3	7	9	2	32	58.0	64
2020	8	6	7	14	1	36	61.3	66
Total	**50**	**38**	**36**	**41**	**7**	**172**	**57.7**	**59**

Age Breakdown - FEMALE								
	<50 yrs	50-59 yrs	60-69 yrs	70-79 yrs	>80 yrs	Total	Mean	Median
2016	9	11	3	3	0	26	52.6	54
2017	15	4	6	3	1	29	50.4	48
2018	9	2	5	8	1	25	57.0	54
2019	9	5	3	4	1	22	53.7	55
2020	8	7	3	3	0	21	53.2	66
Total	**50**	**29**	**20**	**21**	**3**	**123**	**53.3**	**55**

Age Breakdown - TOTAL								
	<50 yrs	50-59 yrs	60-69 yrs	70-79 yrs	>80 yrs	Total	Mean	Median
2016	18	24	10	9	1	62	54.7	55
2017	26	17	15	11	3	72	54.6	55
2018	20	5	11	12	2	50	55.3	60
2019	20	8	10	13	3	54	56.3	58
2020	16	13	10	17	1	57	58.3	59
Total	**100**	**67**	**56**	**62**	**10**	**295**	**55.8**	**57**

Level 4 (eGFR between 15-29) is poor kidney function, with moderate to severe kidney damage. Level 5 (eGFR below 15) is a sign of end stage kidney disease.

eGFR at the time of Insertion - MALE			
eGFR	Level 5	Level 4	n/a
2016	6	1	29
2017	21	1	21
2018	20	0	5
2019	22	0	10
2020	22	1	13
Total	91	3	78

Insertion Technique -- MALE			
	DI	Laparoscopic	Vascular Surgery
2016	8	7	21
2017	25	15	3
2018	20	5	0
2019	26	6	0
2020	32	4	0
Total	111	37	24

eGFR at the time of Insertion - FEMALE			
eGFR	Level 5	Level 4	n/a
2016	7	1	18
2017	17	1	11
2018	16	0	9
2019	16	0	6
2020	17	0	4
Total	73	2	48

Insertion Technique -- FEMALE			
	DI	Laparoscopic	Vascular Surgery
2016	4	8	14
2017	15	14	0
2018	14	10	1
2019	20	2	0
2020	19	2	0
Total	72	36	15

eGFR at the time of Insertion - TOTAL			
eGFR	Level 5	Level 4	n/a
2016	13	2	47
2017	38	2	32
2018	36	0	14
2019	38	0	16
2020	39	1	17
Total	164	5	126

Insertion Technique -- TOTAL			
	DI	Laparoscopic	Vascular Surgery
2016	12	15	35
2017	40	29	3
2018	34	15	1
2019	46	8	0
2020	51	6	0
Total	183	73	39

For the MMSF Collaborative, the CIT members were drawn from a variety of healthcare backgrounds/expertise, organization roles, staff and physicians from KH and IR, and two patient and family advisors. Patient and family involvement was represented at the Kidney Health Patient Family Advisory Council and through engagement with patients and families living with PD. The structure of the CIT served to ensure that patient care is based on a clinical best practice, overcome traditional 'department' boundaries, and better capture and understand patient and family care over time. The CIT oversaw the development, monitoring, and clinical practice redesign drawing upon evidence based best practice. My PhD research complemented the clinical practice improvement focus, and several RAC members also participated in the MMSF Collaborative. One of the key objectives was to to integrate research and PD program operational initiatives, and this was achieved through the PD catheter database being utilized as part of PD access and IR program workflow, routine PD clinic and follow visits, MMSF dashboard metric evaluation, and periodic assessments to evaluate outcomes and process improvement priorities.

MMSF Dimensions[2]:

Past Harm - Has patient care been safe in the past?

- We need to assess rates of past harm to patients, both physical and psychological

Reliability - Are our clinical systems and processes reliable?

- This is the reliability of safety critical processes and systems but also the capacity of the staff to follow safety critical procedures

Sensitivity to Operations - Is care safe today?

- This is the information and capacity to monitor safety on an hourly or daily basis

Anticipation and Preparedness - Will care be safe in the future?

- The ability to anticipate, and be prepared for problems and threats to safety

Integration and Learning - Are we responding and learning?

- The capacity of the organization to detect, analyze, integrate, respond and improve from, safety information

To advance research capabilities for the PD program and research, an outcomes database was created to capture patient demographics, clinical outcomes, and PD catheter failure rate. The

database significantly advanced the ability to evaluate patient care and inform clinical process improvement strategies and enhance the integration of research and operational strategies. Establishing standardized definitions for primary and secondary PD catheter failure rate was achieved through an extensive literature review which is detailed in the MMSF manuscript in Chapter 5. The main areas of focus are: PD patient flow (from selection criteria, referral, procedure, training, to home), PD catheter dysfunction rate, mapping of PD patient safety indicators (determine core data set), and cultural appropriateness (at staff level). The PD Catheter Insertion Technique Description for IR and laparoscopic surgical insertion is described in Chapter 5 (page 65-66).

SHA Sustainability Plan was initiated in 2016, with the intent to provide best practice for PD catheter insertions through a minimally invasive and timelier alternative to open surgical insertion and increase the capacity of IR procedures. Benefits included:

- Improved quality and access to care and shorter hospital stay;
- More efficient use of resources (operating room time);
- Reduced need for general anesthesia, shorter recovery time, reduced risk of pain post procedure;
- IR insertion provides the opportunity for urgent PD insertion (not possible with short notice OR availability);
- Reduction of overall cost to the healthcare system;
- Reduced need for a patient to be placed on HD with a temporary vascular access representing greater risk and hardship to the patient;
- Reduction in additional intervention due to non-functioning PD catheter (KUB xray, sinogram, CT scan, emergency department visits, additional surgical procedures);
- Imperative to reduce high rate of PD catheter failure at 40.3% (25/62).

Although PD catheter dysfunction rates improved to 22.0% (11/50) in 2018, there was a definite need to focus efforts to reduce the PD dysfunction rate to the national benchmark of <10%. The MMSF Collaborative provided a unique opportunity to focus on clinical practice redesign. Chapter 5 describes how the MMSF was used to reduce the PD catheter dysfunction rate over time.

For the MMSF research, I utilized an integrative data analysis strategy over a four-year study period. The focus was on resolving or minimizing problems in home-based therapies practice and IR PD catheter insertion and introducing changes and innovation in healthcare practices. Focus groups and face-to-face semi-structured interviews were utilized to inform and guide clinical practice redesign through the MMSF collaborative workshops and action periods. A prospective cohort study design with quantitative assessment of patient and program outcomes was used. Clinical redesign principles were employed to close the gaps identified through the implementation of the MMSF to reduce PD catheter failure rate.

The PD catheter database design followed patient care over time from PD catheter referral, consultation, PD insertion, clinic visits, patient outcomes, PD training, complications/additional interventions, reason for stopping PD (catheter and non-catheter), and removal of PD catheter/switch to HD. The PD catheter database complimented the electronic medical record used by KH staff, and enhanced research opportunities. Chart reviews were performed to assess clinical outcomes.

A Certificate of Approval was received from the University of Saskatchewan's, Biomedical Research Ethics Board along with Operational Approval from SHA. Tri-Council Policy Statement (2) Chapter 9 Research Involving the First Nations, Inuit and Métis People of Canada were adhered to.

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CHAPTER 5: Using a Measuring and Monitoring of Safety Framework to Improve Peritoneal Dialysis Catheter Function and Patient Experience

The MMSF Collaborative aligned well with the SHA vision to enhance the health and quality of life of patients by allowing patients to perform life sustaining therapy in their own homes, to better meet the health needs of patients in a collaborative manner, and to expand community partnerships. The MMSF Collaborative addressed a number of quality and safety barriers that prevent patients from successfully performing home PD and assisted patients to remain on PD when their functional status has changed. The *Call to Action* for MMSF was driven by the need to improve PD catheter insertion success rate and patient care and outcomes.

The second manuscript focused on the implementation of the MMSF within the interdisciplinary clinical improvement team, to reduce the failure rate of peritoneal dialysis catheters and improve the outcomes and care experience for patients and families living with ESRD.

MANUSCRIPT IN PROGRESS: Submission to BMJ Quality and Safety

Title

Using a Measuring and Monitoring Safety Framework to Improve Peritoneal Dialysis Catheter Function and Patient Experience

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Key Words:

Peritoneal Dialysis, Patient Safety, Clinical Quality Improvement, Measurement, Catheter Dysfunction

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Abstract

Background: Peritoneal dialysis (PD) catheter complications are common and may cause significant adverse patient events, and require a switch to hospital-based hemodialysis. Reducing PD catheter insertion complications remains a major challenge to increasing PD technique survival/utilization and optimizing patient outcomes. It is important to identify and implement best practice solutions to ameliorate cause-specific PD complications that are

associated with a significant burden for the patient, and an overall increase in costs to the health system. Previous methods of surgical PD catheter insertion in our local PD program resulted in high PD catheter dysfunction rates in patients.

Methods: A local interdisciplinary PD clinical improvement team (CIT) participated in a national Measuring and Monitoring Safety Framework (MMSF) Collaborative. The team was challenged to improve the quality and safety of care for patients requiring PD utilizing clinical care pathways based upon best practice, overcoming traditional 'department' boundaries, and better capturing and understanding the patient and family care experience.

Results: Over time, through focused efforts, PD catheter complication rates decreased significantly from 40.3% to 8.8%. PD catheter dysfunction rates (primary and secondary failure combined) were: 2016 25/62 (40.3%); 2017 19/71 (26.8%); 2018 11/50 (22.0%); 2019 12/54 (22.2%); and in 2020 5/57 (8.8%). Clinical process improvements included development and implementation of a standardized workflow and PD assessment, exit site marking (interventional radiology), standardized IR room set up, patient safety questionnaire, quarterly reviews, ongoing case reviews, and standard patient outcome assessments.

Conclusion: The MMSF facilitated real time data to enable action, improve gap analysis, identify strengths and weaknesses, and promote a culture of safety and continuous clinical improvement. The MMSF changed the team mindset from thinking about the absence of harm, to assuring the presence of safety for PD patients and their families.

What is known about the topic

Reducing complications related to PD catheter dysfunction remains a major challenge to increasing overall PD insertion technique survival and utilization, as well as optimizing patient safety and clinical outcomes. The MMSF provides critical thinking and use of real time data to drive clinical quality improvement.

What this study adds

The application of the MMSF resulted in better interdisciplinary teamwork and a significant improvement of peritoneal dialysis catheter function and patient outcomes. Inclusion of patient partners was critical to the success of this research, and in promoting a culture of safety. Practical definitions of peritoneal dialysis catheter dysfunction and MMSF metrics enabled ongoing performance monitoring and operational planning. In addition, the clinical improvement team approach is critical to success.

How might this study affect research, policy and practice?

With stabilization in PD catheter insertion technique and complication rates, improvement efforts are shifting to address sub-optimal PD function. Embedding frameworks like MMSF takes organizational commitment and long-term vision, and strong partnerships with patients and families, frontline staff, leadership, physicians, and Board members. Lack of consensus and variation on the international definitions of PD catheter dysfunction affects the ability to benchmark and standardize local targets.

5.1 Introduction

Peritoneal dialysis (PD) and home hemodialysis (HHD) are well-recognized home based treatment modalities that offer significant benefits for patients with kidney failure. These benefits include tailored dialysis dose, improved clinical outcomes, greater freedom and flexibility, improved quality of life and reduced rates of depression.[1-3] There are also significant benefits to the health system, including overall cost reduction compared with hospital-based or satellite dialysis, and lower resource utilization.[4] Although pre-emptive transplant remains the preferred route for patient care whenever possible, in a fiscally responsible health system that recommends treatments with favourable outcomes, a *Home First* philosophy for home dialysis, either PD or HHD, should be considered initially, and hospital or satellite dialysis only offered when home based dialysis is contraindicated for patients with kidney failure.[1-4]

PD is more cost effective than conventional hemodialysis and represents a cost saving of approximately $55,000/patient year in Canadian dollars, compared with in-centre hemodialysis ($110,000 vs PD $55,000).[5] Furthermore, Klarenbach et al[5] found that using a cost-minimization framework, PD is the most efficient dialysis modality; however, PD is underused, particularly in high-income nations.

Creating a supportive team environment for the patient to choose the dialysis modality that best suits their need and preferences has been shown to have a great impact not only on health-related outcomes but on quality of life.[6-7] Thus, it is important to consider the social implications of each modality on the individual patient. It is apparent that tailoring a patient's care pathway with the patient can enhance the uptake of PD and quality of life, should they choose PD.[8-11] Of particular concern, First Nations and Métis patients with kidney failure often have a higher burden of chronic kidney disease severity, utilize fewer home-based dialysis therapies, and have longer distances to travel than their non-Métis and non-First Nation counterparts.[12-14] This study was intentional in recruiting two patient First Nations and Métis partners to learn from their experiences. The reasons for the disparity in utilization and the barriers to home dialysis need to be addressed to improve quality of care[12-14].

This initiative focused on improvements in patient outcomes and experience, and clinical process improvements to reduce PD catheter dysfunction (failure) rates achieved through the Measuring and Monitoring of Safety Framework (MMSF) Collaborative:

- Research question: Will the implementation of MMSF improve PD catheter dysfunction and patient experience?

The core of the MMSF is to help people think differently and holistically about safety. The objectives are:

- To improve quality, safety and access to care for patients and families through the implementation of the MMSF;
- To facilitate more effective use of financial resources by redirecting existing surgical procedures for PD catheter insertion through Interventional Radiology;
- To integrate research and PD program operational initiatives;
- To improve the patient and family experience, and provider satisfaction.

5.1.1 Saskatchewan Health Authority – Saskatoon Kidney Health

To improve the PD model of care, the Saskatchewan Health Authority's Sustainability Plan included a partnership between Saskatoon Kidney Health and Medical Imaging/Interventional Radiology (IR) to achieve best practice for PD catheter insertions by providing a minimally invasive and a timely alternative to current surgical PD catheter insertion.

Advances in IR training and techniques have allowed for an increased number of procedures to be performed in the Medical Imaging Department rather than in the Operating Room (OR). Current pressures for OR time has created wait times for surgical peritoneal catheter insertion. A more responsive IR program promotes greater patient access, provides a less invasive procedure, and reduces the need for temporary vascular access and hemodialysis.

Improving PD insertion/function rate remains a major challenge to optimizing outcomes for patients and increasing PD utilization.[15] It is important to identify and implement best practice solutions to ameliorate cause-specific PD technique dysfunction to optimize clinical practice.[16]

Strategies to increase uptake of home based therapies have not been well documented.[1,4,6-7] Patient eligibility, available capacity, reimbursement, patient preferences, awareness and education about modalities and quality of life considerations should be considered before treatment is implemented.[4,17]

5.2 Methods

A Certificate of Approval was received from the University of Saskatchewan's, Biomedical Research Ethics Board along with Operational Approval from the local Health Authority. A prospective cohort study design was utilized, for adult patients with kidney failure enrolled in the Kidney Health PD Program (PD catheter insertions: 2016 n=62, 2017 n=71, 2018 n=50, 2019 n=54, 2020 n=57; average 59 patients). SPSS software version 26.0 [18] was used for data analysis to compare PD catheter insertion technique (surgical vs interventional radiology) for primary and secondary PD catheter dysfunction outcomes. Outcome assessments were performed at monthly intervals, including case reviews to identify complications. Potential causes for PD drop out and transfer to hemodialysis were assessed (modality related, system related, patient related). A data collection tool was developed to align the clinical, quality and process outcomes related to patient demographics, PD catheter referral criteria, scheduling and waitlist management, PD catheter insertion type, PD catheter success and dysfunction (failure) type, sub-optimal outcomes and interventions.

5.2.1 Clinical Improvement Team

The interdisciplinary clinical improvement team (CIT) oversaw the development, monitoring, and continuous improvement of clinical pathways drawing upon evidence-informed best practice. CIT members came from a variety of healthcare backgrounds/expertise, organization roles, and included staff (Nursing, Pharmacy, Social Work, Dietitian), Nephrologists from Kidney Health, Interventional Radiology, Surgery, Senior Leadership, a Quality and Safety Board Member and two Patient Advisors. Of note, this local program had a single Radiologist that performed this procedure, and a single Surgeon. Efforts are underway to train more physicians to perform this life sustaining dialysis procedure. The team employed a holistic

approach which involved staff, clinicians, patients and families at all levels. This structure served to ensure that patient care was based on a clinical pathway, overcame traditional 'department' boundaries and better captured and understood the patient and family care over time.

5.2.2 Patient and Family Participation

Patient Advisors were invited to participate as members of the CIT. Patient and family participation increased awareness and understanding of the patient and family perspective and assisted in designing systems and processes that enhanced the quality and safety of the care experience. There was clear, open and respectful communication at all times. Staff responded to the diverse needs of patients, families and communities with sensitivity, and patient partners were enabled to provide critical feedback on clinical care and service delivery. The CIT included two First Nations and Métis patient partners and a spouse. Both patients' journeys were captured on process maps, served to identify improvement opportunities, and created a shared vision for safe, patient-centred care. The concepts of cultural appropriateness of MMSF and patient safety in the home and community were explored.

5.2.3 Measuring and Monitoring of Safety Framework

In 2018, the Kidney Health Program was invited to participate in the Canadian Patient Safety Institute (CPSI) MMSF National Collaborative and was successful in being selected as part of the cohort. This Collaborative was a one-year training program with in-person sessions, webinars, mentoring from CPSI coaches, and practical applications of the MMSF as described in the CPSI MMSF Evaluation Report.[19] Team members attended including patients and families, staff, physicians, management, senior leadership, and Board Members. A priority from the Ministry of Health was to optimize care for persons within the community rather than in an institution or inpatient setting.

The MMSF model consists of five 'dimensions' and associated questions that can be used to understand the safety of care and service at multiple levels, as depicted in online supplemental

Figure 5-1 utilized with permission as part of the MMSF National Collaborative.[20] The MMSF has five fundamental questions which set the context for this study:

- Past Harm: *Has patient care been safe in the past*? We need to assess rates of past harm to patients, both physical and psychological – identified need to establish definitions and outcomes to track over time, and prospectively prevent PD catheter complications
- Reliability: *Are our clinical systems and processes reliable*? This explores the reliability of safe critical processes and systems but also the capacity of the available staff to follow safety procedures – identified need to standardize PD insertion referral criteria, procedures, and model of care
- Sensitivity to Operations: *Is care safe today*? This is the information and capacity to continuously monitor safety on an hourly or daily basis given any changes of staff and resources – identified need to start with team huddle to determine safety of procedure, exit site patient teaching, and staffing model
- Anticipation and Preparedness: *Will care be safe in the future*? The ability to anticipate and be prepared for problems and threats to safety – identified need for daily huddles, monthly and quarterly reviews, and clinic feedback loop for improvement cycle planning
- Integration and Learning: *Are we responding and improving*? The capacity of the organization to detect, analyze, integrate, respond, and improve from safety information - identified need to interdisciplinary team meetings, ongoing process mapping, and report out to Senior leadership

Figure 5-1 – Measuring and Monitoring of Safety Framework[20]. Used with permission.

For the MMSF Collaborative, PD catheter dysfunction was selected for the targeted improvement work. To guide clinical practice improvement efforts, the CIT reached consensus on the definitions for PD catheter reliability, success, PD catheter dysfunction (primary and secondary failure), and sub-optimal catheter function as listed in Table 5-1A/B, and shows the variation from International PD catheter dysfunction definitions.

Table 5-1A/B. PD Catheter Function Rate and Operational Definitions.

Table 4-A. PD Catheter Function Rate and Operational Definitions	
PD Catheter Category	PD Catheter Operational Definition – MMSF Collaborative
Reliability of PD Catheter Function	Probability of PD catheter functioning correctly over a period of time, under a given set of conditions (<30 days)
PD Catheter Success	Patient able to train and perform PD with no catheter flow issues
Primary Failure of PD Catheter	Inserted PD catheter cannot be used/flushed and patient is not able to train due to PD catheter flow related issues; national target for primary failure is <10% at 3 months[30]
Secondary Failure of PD Catheter	Patient is trained but ultimately has to stop PD due to major issue • due to catheter: catheter flow issue • not due to catheter: catheter is in good position by imaging but drainage is poor (typically due to "fecal loading") • due to complication: leak at insertion site
Sub-Optimal PD Catheter Function	Patient advanced past training stage but patient continues to have catheter issues • Catheter related: drain pain, drainage flow issues, cycler alarms, hernia/leak • Hernia/leak not related to catheter • Local audit metrics (see Table 5)
Table 4-B. International PD Malfunction/Catheter Failure Rate Definitions	
International References	PD Malfunction/Catheter Failure Rate Definition
Ontario Renal Network Committee[16] PD Catheter Primary Malfunction	The inability of the PD catheter to support adequate inflow and/or outflow of peritoneal dialysate despite aggressive medical management requiring either procedural revision/manipulation, removal or transfer to hemodialysis
International Society for Peritoneal Dialysis guidelines[15,21]	Aim is 1 year catheter patency of 80%
Peppelenbosch[22]	Early complications (<30 days): bowel and organ perforation; bleeding: catheter dysfunction/outflow failure by kink in the subcutaneous tunnel, clots or fibrin in the catheter, omental wrapping, presence of adhesions in the abdomen, catheter tip migration; tunnel infection, peritonitis. Late complications (>30 days): tunnel infections; peritonitis; catheter dysfunction/outflow failure by clots or fibrin in the catheter, catheter tip migration or winding in epiploon; leaks, hernias.
International Society for Peritoneal Dialysis Guidelines/Recommendations for Creating and Maintaining Optimal Peritoneal Dialysis Access in the Adult Patient: 2019 Update[21] Recommended audit metrics for PD catheter insertion outcomes and clinical goals	PD catheter patency at 12 months >95% for advanced laparoscopic placement and >80% for all other catheter insertion methods; <5% exit-site tunnel infection within 30 days of catheter insertion; <5% peritonitis within 30 days of catheter insertion; <1% visceral injury (bowel, bladder, solid organ); and <1% significant hemorrhage requiring transfusion or surgical intervention. Complications of PD catheter placement: death, transplantation, infection, pericatheter leakage, or transfer to hemodialysis because of inadequate dialysis, psychosocial reasons or medical
United Kingdom Catheter Study[23]	Catheter related event definitions and causes: further operative procedures related to catheter function (catheter repositioning, omentectomy/omentopexy, PD catheter removal, new/recurrent hernia) Catheter-related infections (exit-site/tunnel infection, peritonitis) Failure of catheter function due to any cause leading to an interruption of either planned or continued use: mechanical (defined as >3 days disruption/delay to treatment and/or requirement of temporary or permanent hemodialysis or required PD catheter removal (e.g., infections; hospital admission for catheter related problems
Peritoneal Dialysis Outcomes and Practice Patterns Study[15] PD Technique Failure	Seven primary causes: infection-related, catheter-related, problems with solute/water clearance, peritoneal leaks/hernia, psychosocial/medical, risk of or diagnosis of encapsulating peritoneal sclerosis

5.2.4 PD Catheter Insertion Technique Description

The following sections describe the PD catheter insertion technique for IR and laparoscopic surgical insertion.

Interventional Radiology (IR) insertion utilizes conscious sedation and local anesthesia as a day surgery procedure. Sennokot/lactulose is given for 7 days prior to insertion and the patient is asked to void prior to the procedure. Ultrasound guidance is used for the abdominal wall puncture with fluoroscopic guidance for catheter tip positioning. The abdomen is marked by the PD nurses to demarcate the belt line and preferred exit sites. After local anesthetic an approximately 3cm incision is made over the peritoneal cavity which is then accessed using a 22g needle. Iodine contrast media injection confirms intraperitoneal location. Access is then changed to a 5 French Kumpe catheter that is used to fluoroscopically maneuver into the pelvis/pouch of Douglas. The dual cuff curl tip PD catheter is then placed through a 16 French peel away sheath, the deep cuff is not embedded into the rectus sheath, it is placed to the level of it. 500 to 1000ml of dialysate is then instilled and drained from the peritoneal cavity. If there is poor drainage the catheter is manipulated in an attempt to ensure adequate drainage. If the interventional radiologist does not feel the catheter will ever drain well another access point is chosen, often lower on the abdomen to allow for a deeper position of the tip. Once catheter function is deemed to be adequate a subcutaneous tract is then created with the tunneler device. The incision is closed with interrupted deep 3.0 Vicryl (absorbable) sutures and the skin is closed with interrupted 3.0 Prolene sutures that are removed in 2 weeks.

Laparoscopic Surgical Insertion: The individual is brought into the operating room and placed in a supine position. General anesthetic is administered. The abdomen is prepped and draped in a sterile fashion and then opened using a Hasson technique and pneumoperitoneum achieved. The abdomen is inspected for adhesions and adhesion lysis is performed if necessary. A working port is placed in the left lower quadrant under direct visualization. A single cuff catheter is measured from the pelvis to the abdominal wall. A tunneled 5.5 mm port is placed through the pre marked location through the rectus sheath, into the abdominal cavity. The single cuff catheter is then introduced through the 10/12 trocar into the abdominal cavity. The tip of the catheter is

positioned in the pelvis. The distal end of the single cuff catheter is exteriorized through the tunneled port. The pneumoperitoneum is removed. The umbilicus is repaired with figure-of-eight 0 Vicryl stitch. Skin incisions are closed with Monocryl. Approximately 500ml of dialysate is instilled via the catheter into the abdomen to confirm patency of the catheter. The catheter is capped off and individual is transferred to post anesthesia care unit when appropriate. The surgeon used single cuff catheters with tunneling through the rectus sheath (switched from curled tip catheter to straight catheter over time).

5.3 Results

5.3.1 Primary and Secondary PD Catheter Dysfunction Rates

Previous methods of PD catheter insertion in this local program had resulted in high dysfunction rates at 3 months post procedure for combined primary and secondary rates: 2016 25/62 (40.3%) and 2017 19/71 (26.8%). Transition to IR and laparoscopic PD catheter insertion coupled with participation in the MMSF Collaborative showed improvement over time: 2018 11/50 (22.0%); 2019 12/54 (22.2%) and 2020 5/57 (8.8%). Results show a significant improvement in dysfunction from 40.3% to 8.8% which was below the national target of <10%[21]. Table 5-2 shows a summary year to year comparison, and Figure 5-2 shows PD catheter insertion results against the national target. The number of insertions has stayed consistent at an average of 59 patients/year. There has been a significant shift to IR as the primary insertion technique.

Table 5-2. PD Catheter Insertion Outcomes – Year to Year Comparison

Year		2016	2017	2018	2019	2020
Volume	# PD Patients with PD Catheter Insertions	62	71	50	54	57
Insertion Technique (%)	Interventional Radiology	12 (19.3%)	39 (55.6%)	34 (68.0%)	46 (85.2%)	51 (89.5%)
	Laparoscopic	15 (24.2%)	29 (40.3%)	15 (30.0%)	8 (14.8%)	6 (10.5%)
	Blind Surgical Insertion	35 (56.5%)	3 (4.2%)	1 (2.0%)	0 (0.0%)	0 (0.0%)
PD Dysfunction Outcomes	# Patients with Primary Failure	8 (12.9%)	9 (12.5%)	3 (6.0%)	7 (12.9%)	3 (5.3%)
	Catheter function	*n/a	4 (44.4%)	1 (33.3%)	4 (57.1%)	2 (66.7%)
	Peritonitis	n/a	2 (22.2%)	2 (66.7%)	0 (0.0%)	0 (0.0%)
	Exit/Tunnel Infection	n/a	1 (11.1%)	0 (0.0%)	0 (0.0%)	1 (33.3%)
	Hernia/Leak	n/a	2 (22.2%)	0 (0.0%)	2 (28.6%)	0 (0.0%)
	Patient Choice	n/a	n/a	n/a	1 (14.3%)	0 (0.0%)
	# Patients with Secondary Failure	n/a	n/a	n/a	0 (0.0%)	0 (0.0%)
	# Patients with Secondary Failure - Due to Catheter Placement	9 (14.5%)	0 (0.0%)	1 (2.0%)	2 (3.7%)	0 (0.0%)
	Catheter function	n/a	n/a	1 (100.0%)	2 (100.0%)	0 (0.0%)
	Peritonitis	n/a	n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Exit/Tunnel Infection	n/a	n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Hernia/Leak	n/a	n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)
	# Patients with Secondary Failure - NOT due to Catheter Placement	5 (8.1%)	5 (6.9%)	5 (10.0%)	3 (5.5%)	2 (3.5%)
	Catheter function	n/a	0 (0.0%)	0 (0.0%)	2 (66.7%)	0 (0.0%)
	Peritonitis	n/a	0 (0.0%)	3 (60.0%)	1 (33.3%)	0 (0.0%)
	Exit/Tunnel Infection	n/a	0 (0.0%)	1 (20.0%)	0 (0.0%)	0 (0.0%)
	Hernia/Leak	n/a	3 (60.0%)	1 (20.0%)	0 (0.0%)	2 (100.0%)
	Inadequate Dialysis/Volume Control	n/a	2 (40.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	# Patients with Secondary Failure - Due to Complications	3 (4.8%)	5 (6.9%)	2 (4.0%)	0 (0.0%)	0 (0.0%)
	Catheter function	n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Peritonitis	n/a	1 (20.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	Exit/Tunnel Infection	n/a	0 (0.0%)	0 (0.0%)	0 (0.0%)	0 (0.0%)
	Hernia/Leak	n/a	4 (80.0%)	1 (50.0%)	0 (0.0%)	0 (0.0%)
	TOTAL PD Failure Rate	25/62 40.3%	19/71 26.8%	11/50 22.0%	12/54 22.2%	5/57 8.8%
	Sub-optimal	6 (9.7%)	19 (26.4%)	10 (20.0%)	16 (29.6%)	22 (38.6%)
	* n/a – data not available					

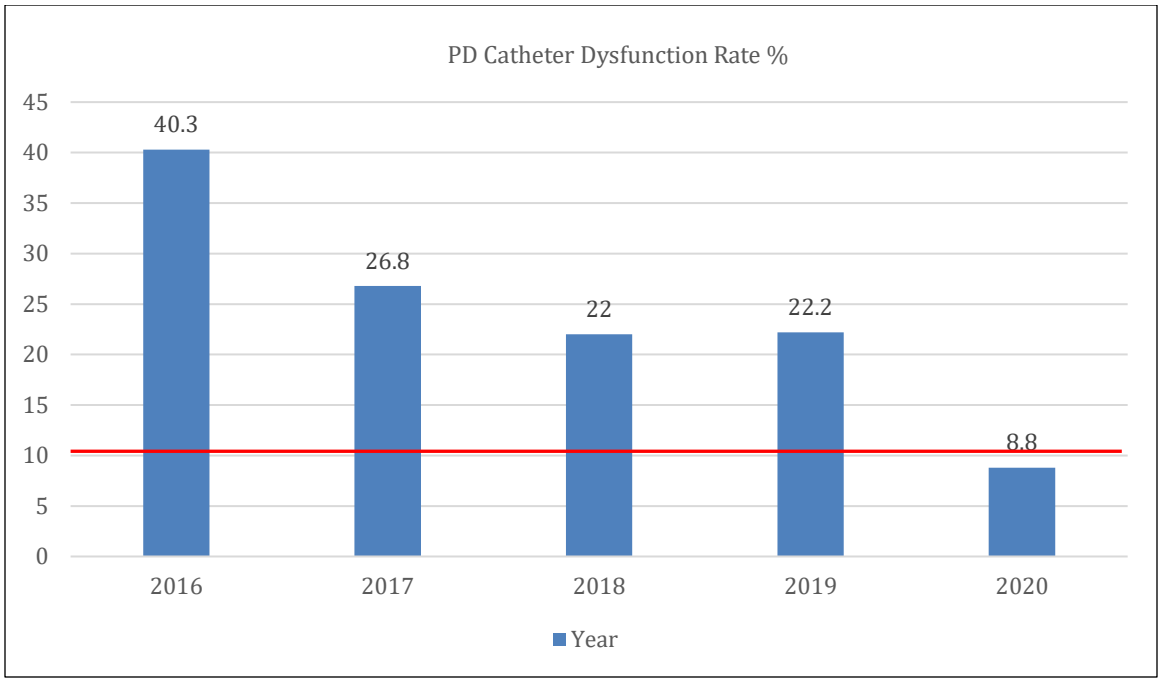

Figure 5-2. PD Catheter Dysfunction Rate % (primary and secondary failure combined, national target shown in red <10%[21])

Major IR PD technique changes that resulted in improvement:

- Tunnel length = less cuff extrusion and infection
- 2 procedures/day max = focus on technique for the operator, decrease time pressure
- Discontinued need for foley catheter = no increase to primary failure and increase in patient satisfaction
- Case review = every failure was tracked and evaluated
- MMSF collaborative = robust data and evaluation

5.3.2 Model for Improvement – Clinical Outcomes

Using the Model for Improvement[24] Plan-Do-Check-Act (PDCA) cycle, the CIT was able to implement over 72 process improvements from 2018 to 2020, to reduce the PD catheter dysfunction, and to improve patient care. Process improvements were selected and implemented by the CIT, to complement mapping the patient and family experience over time. Without the training and focus provided by the Collaborative, this clinically significant result would not have been achieved. The following quote from the Interventional Radiologist speaks to improvements in technique over time, and whether the MMSF made a difference in practice: "Yes very much so. I was able to give feedback on scheduling, room set up, and patient preparation. For IR we started with a very strict inclusion criteria for patients selected for IR insertion in order to optimize initial success and get some "early wins". As I became more comfortable with the procedure some of these parameters were expanded, in particular BMI as well as the history of previous abdominal surgery or previous peritoneal dialysis catheter". Table 5-3 shows selected improvements over time with link to the MMSF.

Table 5-3. Improvement Achieved by Year

Year	Improvements Implements using PDCA Cycles	Theme and Link to Measurement and Monitoring Framework Dimension
2018	• 2nd Access Nurse Clinician hired to support IR expansion and workflow • Revised patient letter and procedure instructions • Referral form revised, Nephrologist and Access Clinician review • PD Catheter database implemented • Quarterly Review meetings with Nephrology, IR and Surgery • Standardized workflow and PD assessment • Exit site marking for interventional radiology only • Standard room set up • Safety risk – adjustment to 2 IR cases/day • Check bloodwork with IR and surgical cases to avoid cancelled cases • Patient and family members recruited as partners • IR Patient safety questionnaire (rate on a scale of 1 to 10 – main theme from patient feedback "shorter wait times" - How safe did you feel during your time at the hospital today? - What was the most unpleasant part of your experience today? - What was the best part of your experience today - Any suggestions for us to continue to improve the care we provide to patients? • Implement new regime for exit site care (post op dressing @ 1 week, then exit site teach @ 2 weeks) to allow more healing time and prevent early PD exit site infections	Early improvement cycles focused on stabilizing referral criteria, increasing Access Nurse Clinical staff levels, PD procedural standardization IR PD Insertion exclusion criteria: 2nd catheter, previous hernia repair, minor laparoscopic procedures, nephrectomy, failed transplant Reliability: PD database and standard definition and outcomes established Past Harm: Safety metrics were established to monitor outcomes and provide an interdisciplinary learning environment Sensitivity to Operations: Standard workflow and room set up implemented Patient partners joined as team members Integration and Learning: Safety questionnaire designed and incorporated into daily practice
2019	• Adjusted referral form and criteria for 2/3 IR and 1/3 surgical insertions (expansion of criteria) • IR accepted greater patient BMI and inserted longer catheters • Tracking of time to referral – PD catheter insertion – patient trained • Training adjusted to 8 weeks post-surgical insertion (less incidence of leak) • Manipulation prior to train, wait 1-2 weeks before initiating patient train • Flushing protocol weekly instead of bi-weekly (more frequent assessment of catheter function)	Integration and Learning: Operator experience and PD failure rate improved Inclusion criteria for IR PD catheter insertion expanded to uncomplicated laparoscopic surgery, previous hernia repair, current hernia (with understanding hernia would be repaired surgically at a later date if needed), patients who previously has a PD catheter and BMI > 40 Reliability: Referral criteria for IR insertion expanded Sensitivity to Operations: PD patient care pathway adjusted to stabilize outcomes
2020	• Consider swan neck catheter usage to address tube migration • Increase infra umbilical placement for patients who require additional catheter length • Consider presternal catheter placement in larger patients requiring additional length • Developed more robust information management system/database • Follow up for bowel care prior to surgery • Review utility of PD catheter manipulation vs replacement • Provincial standardization and scorecard (clinical and operational outcomes)	Anticipation and Preparedness: Deeper understanding of PD catheter technique contributors for failure rate, and subsequent procedural improvements implemented Reliability: PD database refinements for data collection and reporting 3 years of focused improvements and implementation of the Measuring and Monitoring Framework lead to a PD catheter complication rate decrease from 40.3% to 8.8%

Table 5-4 shows an example of a case review undertaken at the quarterly clinical quality improvement meeting between the CIT, other Kidney Health staff, Physicians, Surgeons and Senior Leadership. Case reviews were selected if there was an adverse outcome (death, disability, harm, injury, process or system issues). These meetings provided feedback for quality improvement plans for the next quarter – reflecting a learning health system.

Table 5-4. Summary of PD Catheter Results in 2019 (sample year)

Total # of PD Patients 2019 - 147; 87% (128/147) of catheters were draining well # of PD catheter insertions 2019 = 54 6/54 unable to train (2=unable not due to catheter; 4/54=due to catheter, primary failure) → 4/52 = 7.7% primary failure 4/52 – stopped PD training due to catheter drainage issue 38/52 – drain well = 73% 14/52 – drain sub-optimally or have leak/hernia/etc. = 27% 48/52 - able to do PD = 89.0% success		
IR 44/54	Primary PD Catheter Failure 2/44	Themes - patient specific, not insertion - never drained well - catheter removed
Surgery 10/54	Primary PD Catheter Failure 2/10	Themes - exit site leak - fecal incontinence
Sub-Optimal 14/54	PD Catheter Issues after train	Themes - Poor catheter flow and drainage at 30-90 days - Manipulations – are they working, replace catheter - Leaks - ? Adequacy of dialysis - Patient factors (burn out)

The MMSF was utilized to create a cascade of metrics, as shown in Table 5-5. This dashboard continues to be used to drive further improvement and standardization in the local program.

Table 5-5. Cascade of Metrics by MMSF Dimension used for Performance, Reporting and Learning

MMSF Dimension	Cascade of Metrics
Past Harm	1^{o} and 2^{o} PD catheter failure Historical data of kidney failure Extra tests due to complications Death rate Transfer to hemodialysis Peritonitis rate Exit infection rate
Reliability	Standardized patient education Standard order sets (pre / intra / post procedure) PD assessment / modality choice Referral process standardized Exit site marking Standard clinic visit with follow-up
Sensitivity to Operations	Daily staff huddle to address concerns Exit site teaching for patient Follow-up appointments / care plan Staffing model
Anticipation and Preparedness	Daily team huddles Discharge plan / teaching Quarterly meetings Access referral Clinical feedback loop for PDCA planning
Integration and Learning	Quarterly meetings - full team Monthly clinical team meetings Process mapping and improvement Report to Senior Leadership and Board

Participation in the MMSF Collaborative resulted in a strong CIT approach, with a collective goal of embedding patient safety into every point of care. Continuous quality improvement has led to patient driven quality of care. Our First Nations and Métis patient partner shared this quote: "*It is important that this work be brought out to the reserves, to let patients know that there is help, that people care about you and your safety. People like me can promote PD, and it's important that you listen to our stories, good and bad, to improve our lives and health*." This patient now serves a member of the Kidney Health Patient Advisory Council and delivers education sessions on kidney health friendly lifestyles in the community. The focus of this study was to improve PD catheter function, and the patient voice speaks to the need to further explore culturally sensitive models of care.

Throughout the Collaborative, feedback was gathered from the core CIT, patients, families, and Senior Leadership. Summary statements are listed below that reflect how the MMSF was perceived by participants:

- The core of the framework is to help people think differently and holistically about safety;
- Putting patients and families first;
- The framework moves us from thinking about the absence of harm, to the presence of safety;
- Using the framework is as much about the conversation about safety as the measures you use;
- Using the framework is not a one-time exercise, but part of ongoing business;
- There's great potential, and we're learning as we're sharing;
- Continuous process improvement to streamline workload and workflow;
- Hospital leadership needs to be on board to support PD insertion program;
- Business plan, resources, and new technology;
- Serves to translate real time data so that it is useful to take action, gap analysis for process improvement, identifying strengths and weaknesses, and promoting a culture of safety and continuous improvement.

Patient Partner Perspective

- We are on the team.
- My traditions and beliefs are respected.
- Staff care about me.
- Doing PD is like having a hospital in my home.

Table 5-6. shows the elements of MMSF and the cascade of critical thinking across organizational levels.

Table 5-6. Elements of MMSF and Cascade of Critical Thinking

Kidney Health	Critical Thinking Be Open, Be Thoughtful, Be Reflective, Be Inquisitive
Individual Staff	Reflect on the value of daily safety conversations (near miss/harm), and identify opportunities to collect more meaningful data about the safety of services – broaden thinking
Manager and Staff - Daily Huddle	Work with clinical staff to ensure that learning, feedback and action are prioritized following the review of safety information – reflect on 'where we are' – see flaws in the current system and challenge roles
Director - Operations	Ensure that staff and clinicians have the time and resources to explore new measures so that safety information they ask for and receive is meaningful – a structure to analyze what they were doing, stimulate thinking about safety, and help make the connection between safety measures and activities
Senior Leadership/Boards - Provincial Transition	Design systems for oversight and regulation that allow organizations to demonstrate their safety, rather than compliance with prescriptive, centrally mandated measures – know what is important to frontline staff for improving safety in real time

5.4 Discussion

5.4.1 Defining PD Catheter Dysfunction

One of the most difficult components of this initiative was to establish operational definitions for primary and secondary PD catheter dysfunction rates. There are many inconsistencies in the literature (see Table 5A/1B). Definitions vary in terms of clinical outcome, timeframe (30 days to 12 months patency), and complication types making it difficult to compare results. The CIT chose to define the PD catheter complications in a manner that was practical and reflected the following components: reliability, success, PD dysfunction rate, and sub-optimal outcomes. The goal was to measure and monitor what matters most to the patient and operational staff and reflects excellence in patient care. Through focused efforts, PD catheter dysfunction rates were reduced from 40.3% in 2016 to 8.8% in 2020 which is less than the national target of 10%. The CIT continues to focus on sub-optimal outcomes for further improvement. This study represents the experience of a single interdisciplinary program and may not be generalizable to other programs. The MMSF focus and training was a significant contributor to the success of this study.

Comprehensive peritoneal dialysis programs include clinical quality improvement and implementation of best practices, but there is limited published literature that employs a patient safety framework to drive success in PD. Two recent publications that employed continuous quality improvement methods to decrease PD catheter dysfunction showed that tracking, outcome reporting, defining PD catheter dysfunction and access insertion pathway development yielded positive results, but comparison across studies is difficult due to lack of standardization of definitions for PD dysfunction and data/outcomes.[25,26] In Radiology, quality improvement and lean methods provide an empirical approach to reducing variability, medical errors, and improving workflow (primarily imaging appropriateness, diseases registries and key performance indicators), but there is considerable diversity in how these approaches are implemented and reported.[27,28] The MMSF Collaborative provided the unique lens to apply patient safety principles over time to improve PD catheter success and patient outcomes.

5.4.2 MMSF – Shift to Safety

A key element in MMSF is to focus on learning from failure and potential failure rather than success and to implement process improvements to create a more reliable, safer model of care. The MMSF dimensions were combined to better represent the links to clinical process improvement cycles:

- Sensitivity to Operations: How the job is being carried out in the real world, *with*
- Anticipation and Preparedness: Identify safety risks and improvements, *leads to*
- Integration and Learning: Feedback to ensure learning and drive improvement.

The CPSI MMSF Evaluation Report[19] described this framework as providing a broader view of the information needed to create and sustain safer care and is conceptually different in that it can be applied to any problem. The MMSF broadens thinking around harm, the basic question "How safe is our care?" in healthcare settings. The importance of measuring and monitoring safety from frontline staff, management and boards/government creates a much-needed patient safety conversation. In comparison to other types of patient safety frameworks, the MMSF's attention to the different domains expanded our views on how to understand and address safety concerns and events.[20] The MMSF Collaborative provided a unique opportunity to advance local team skills and knowledge related to safety measurement and monitoring. Participation enhanced the learning and capacity, allowing the team to apply this approach to the strategic priority of improving the success rate of IR PD catheter insertions.

Consistent with innovative models for Kidney Health, the CIT believes "that a dedicated and experienced PD team, a structured patient training program, continuous patient support, establishing and utilizing standardized protocols, monitoring key performance indicators, and continuous quality improvement are underlying success factors".[29] Participation in the MMSF Collaborative added the patient safety lens that helped the CIT to exceed the national target for PD catheter placement and function in alignment with optimal guidelines for PD access and care.

5.5 Limitations

The MMSF was a local initiative to enhance patient safety and process improvement, in combination with targeted strategic efforts to improve PD catheter success rates and transition to IR supported insertion and may not be generalizable to other programs. This local initiative needs to continue to utilize MMSF to drive improvements and break down silos, but ongoing commitment and training are unknown. A broader limitation is the variation and lack of consensus internationally in what experts and clinicians consider an acceptable rate of PD catheter non-function (a PD catheter never being able to be used for PD) and benchmark targets.[30]

5.6 Conclusion

A rounded, accurate real time view of safety drives clinical process improvement. The MMSF assisted the CIT in the practical application/evaluation of PD quality and safety management. Mapping the five dimensions of the MMSF against this program's PD insertion procedures and patient care enhanced focused improvement of PD catheter function rate and patient and family experiences. The MMSF provided a unique opportunity to improve safety, and the structure and constant feedback loop, employing standardized PD catheter failure definitions, embedding clinical quality improvement into daily practice, and interdisciplinary quarterly reviews to track and evaluate progress are key to success. With the PD insertion technique stabilized, improvement efforts are shifting to address sub-optimal PD function and enabling patients to remain on PD in their homes in a safe care environment is critical.

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5.8 Summary

The MMSF improvements made over time encompassed policy change for PD catheter insertion (primary method IR), integration of clinical outcome assessments as part of KH program practice (PD database and standard PD catheter failure definitions), and ongoing clinical quality improvement. These changes would not have occurred without the MMSF Collaborative opportunity, training, and involvement of the CIT (ward to board perspective). The shift in focus on patient safety and critical thinking, was significant, and represented a change in KH program culture.

The "So What" factor for the MMSF research showed a clinically significant decrease in PD catheter dysfunction rate from 40.3% to 8.8%. This achievement required training in MMSF, a dedicated CIT and a robust database to drive improvements over time.

Focusing on failures was not an easy path, but it led to achieving a PD catheter dysfunction rate of 8.8% that was less than the national target of 10%. The definitions of primary and secondary PD catheter dysfunction held the CIT to criteria that other KH programs saw as too restrictive, including those participating in PD registries. The ability of the CIT to adapt clinical practice over time allowed for process improvements to test and improve real time scenarios. Although there are several well-established PD registries, the degree of variation in definition of PD catheter failure was a significant challenge (see Table 5.1 A/B, page 64).

The MMSF research question was:

- Will the implementation of MMSF improve PD catheter dysfunction and patient experience?

The results demonstrated a significant improvement in PD catheter dysfunction from 40.3% in 2016 to 8.8% in 2020, and in patient experience through active participation in clinical redesign and an active voice in improving the KH model of care. The CIT was able to implement over 72 process improvements from 2018 to 2020, to reduce the PD catheter dysfunction, and to improve patient care. Process improvements were selected and implemented by the CIT, to complement

mapping patient and family care over time. Without the training and focus provided by the Collaborative, this clinically significant result would not have been achieved.

KH and IR Operational Objectives:

- To improve quality, safety and access to care for patients and families through the implementation of the MMSF – significant decrease in PD catheter dysfunction rate, improvement in outcomes tracked through MMSF dashboard metrics;
- To facilitate more effective use of financial resources by redirecting existing surgical procedures for PD catheter insertion to IR – shift to 90% IR PD catheter insertion rate;
- To integrate research and PD program operational initiatives – the PD catheter database serves both program and patient outcome tracking, resulted in peer-reviewed conference presentations and publications, and new research opportunities for Nephrology residents;
- To improve patient and family home based PD care – PD patient and family journeys were mapped, and clinical practice redesign improvements were tailored to better meet their needs and preferences.

CHAPTER 6: Discussion and Conclusion

6.1 Discussion

From 2016 to 2020, I was humbled by the dedication of our Saskatoon Kidney Health and First Nations and Métis patient and family partners, and the CIT. The results achieved through *Nîsohkamâtowak* truly exemplified the meaning in Cree, '*helping each other*'. The learnings from *Nîsohkamâtowak* complemented our team's participation in the MMSF. Mapping the First Nations and Métis patient and family journey gave heartfelt insights into the challenges of living with ESKD, managing care and safety in the home, and ensuring the PD model of care is patient and family centric. From a healthcare system perspective, transitioning to a primary IR insertion pathway and a specific focus on improving PD catheter failure rate to 8.8% (below the national target of 10%) showed significant stability in procedural technique and patient outcomes.

Pre-dialysis education is critical to support patient choice and decision-making, throughout the stages of kidney disease. Significant variation in provincial Kidney Health program design and operations exist in Saskatchewan, and across provinces and territories. Current education models need to better tailor pre-dialysis education, standardize care pathways, and promote patient and family choice for PD and HHD. Differences in patient population, staffing model, Kidney Health program delivery, geographic location, good roads/highways for travel, ethnicity and access to healthcare services requires further investigation. Information technology, integrated electronic medical record systems, and ability for remote monitoring of dialysis regimes need further development and investment. The SHA is undergoing a significant provincial transformation, which has the potential for positive impact on Kidney Health care coordination across health services, and most important the patient and family care. Table 6-1 shows a pre-dialysis education approach from prevention through to long term care and support. Stabilizing PD insertion and improving success rates was a critical step for a *Home First* model of care.

Table 6-1. Pre-Dialysis Education Approach

Find the Condition Early	**Best Care and Support in the Early CKD stages**	**Best Long Term Care and Support**
At Risk CKD/ESKD Prevention	Diagnosed Disease Stages of CKD	Complex/Comorbid Disease Home Dialysis
- partnerships with local general practice, health services, tribal councils, community health centres - active screening and referral pathways - care coordination - healthy lifestyle - disease prevention and awareness	- *Home First* approach - CKD pathway - CKD education - home dialysis assessment - care coordination - healthy lifestyle with kidney failure - confirmation regarding patient modality choice - CKD management and education, with a focus on preventing disease progression	- home dialysis training - support at home - link to social support - plan for respite - assisted PD and HHD - modality transition - conservative and palliative care - healthy lifestyle with kidney failure

Thoughtful inclusion of Kidney Health partners directly or indirectly impacted by clinical practice redesign improvement opportunities needs to be considered early on in planning phases. Engagement of First Nations and Métis partners, respecting protocol, local councils, and communities will require engagement. The generalizability of results may be limited by provincial context in terms of funding model, physician practice and billing patterns, and unique patient population characteristics. This research represents KH patient care in Saskatoon, and rural and northern communities. The findings may be unique to the First Nations and Métis communities and people that shared their stories.

The *Nîsohkamâtowak* patient and family stories were captured in video format which are hosted on the St. Paul's Hospital Foundation website. These stories have served to highlight and educate others on traditions, culture, and spirituality in a safe, open atmosphere that promotes equal opportunity for all to share and learn, where healthcare professionals listen versus teaching and talking.

The short story telling videos can be viewed at:
https://www.stpaulshospital.org/foundation/donate/nisohkamatowak.php?page=270

- Video 1: *Nîsohkamâtowak*
- Video2: Chronic Kidney Disease Education
- Video 3: *Nîsohkamâtowak* Process
- Video 4: Challenges

The *Nîsohkamâtowak* results achieved to date show the positive impact of community engagement and incorporation of the *Calls to Action 19, 20, 22, 23* into Kidney Health planning, building healthcare team cultural competencies, and learning about the importance of respecting culture and traditional protocol.

The common themes expressed by *Nîsohkamâtowak* participants included:

- The need for communication and culturally appropriate understanding and acceptance;
- Incorporation of western and traditional ways - medicines, foods, prayers and customs;
- Patients want to guide their own care;

- ‘Up to date’ and timely education;
- Peer support and workshops in their communities.
- Education - improved kidney health education, information delivery and print resources;
- Wellness – improved support for healthy diet and exercise; and
- Cultural Competency – better understanding by health providers, translation of education materials into indigenous languages, and as part of patient visits.

Future considerations include: community screening done by culturally competent health care professionals with community support by existing diabetes & support people in the community, the need to include more caregivers in the process, training related to understanding the effects of colonization on communities for health care professionals, and more work done with youth in terms of education and awareness of diabetes and kidney failure. These considerations are worth further exploration and align well with advancing *Truth and Reconciliation* and the *Calls to Action*, in partnership with patients, families, local communities and Kidney Health staff.

To better understand current state for PD catheter dysfunction, one of the most difficult components of this initiative was to establish operational definitions for primary and secondary PD catheter dysfunction rates, and inconsistencies in the literature (see Table 5-1A/B, page 59). Definitions vary in terms of clinical outcome, timeframe (30 days to 12 months patency), and complication types making it difficult to compare results. The research question was based on defining PD catheter complications in a manner that was practical and reflected the following components: reliability, success, PD dysfunction (primary and secondary failure), and sub-optimal outcomes. The goal was to measure and monitor what matters most to the patient and operational staff and reflects excellence in patient care. Through focused efforts, PD catheter dysfunction rates were reduced from 40.3% in 2016 to 8.8% in 2020 which is less than the national target of 10%.

During the course of my PhD studies, I also presented at several international research conferences highlighted below:

- 2020 - International Forum for Healthcare Quality and Safety - Improving Peritoneal Dialysis Catheter Success Design for Measuring and Monitoring Patient Safety – Glasgow, Scotland – In Person
- 2019 - Peritoneal Dialysis International - Improving Peritoneal Dialysis Catheter Success: Lessons Learned from the Clinical Improvement Team, and Linking Patient Safety to Programs and Patients – Virtual Conference
- 2019 - Sante Awards: Improving Peritoneal Dialysis Catheter Success: Lessons Learned from the Clinical Improvement Team – Regina, Saskatchewan

The CIT continues to focus on sub-optimal outcomes for further improvement. This study represents the experience of a single interdisciplinary program and may not be generalizable to other programs. The MMSF focus and training was a significant contributor to the success of this study. Comprehensive peritoneal dialysis programs include clinical quality improvement and implementation of best practices, but there is limited published literature that employs a patient safety framework to drive success in PD. The MMSF Collaborative provided the unique lens to apply and analyze patient safety principles over time to improve PD catheter success and patient outcomes.

The MMFS continues to expand thinking and action regarding PD care:

- Past Harm: *Has patient care been safe in the past*? We need to assess rates of past harm to patients, both physical and psychological – identified need to establish definitions and outcomes to track over time, and prospectively prevent PD catheter complications
- Reliability: *Are our clinical systems and processes reliable*? This explores the reliability of safe critical processes and systems but also the capacity of the available staff to follow safety procedures – identified need to standardize PD insertion referral criteria, procedures, and model of care
- Sensitivity to Operations: *Is care safe today*? This is the information and capacity to continuously monitor safety on an hourly or daily basis given any changes of staff and resources – identified need to start with team huddle to determine safety of procedure, exit site patient teaching, and staffing model

- Anticipation and Preparedness: *Will care be safe in the future*? The ability to anticipate and be prepared for problems and threats to safety – identified need for daily huddles, monthly and quarterly reviews, and clinic feedback loop for improvement cycle planning
- Integration and Learning: *Are we responding and improving*? The capacity of the organization to detect, analyze, integrate, respond, and improve from safety information - identified need to interdisciplinary team meetings, ongoing process mapping, and report out to Senior leadership

From the MMSF, both *Nisohkamatowak* and the PD catheter dysfunction results show that we were able to integrate, learn and improve safety in a culturally sensitive manner and accelerate clinical improvement. The "So what" factor definitely required passion, persistence, planning, and patience.

Mapping the five dimensions of the MMSF against PD insertion procedures and patient care enhanced focused improvement of PD catheter function rate and patient and family experiences. The MMSF provided a unique opportunity analyze and to improve safety, and the structure and constant feedback loop, employing standardized PD catheter failure definitions, embedding clinical quality improvement into daily practice, and interdisciplinary quarterly reviews to track and evaluate progress are key to success. With the PD insertion technique stabilized, improvement efforts are shifting to address sub-optimal PD function. Enabling patients to remain on PD in their homes in a safe care environment is critical.

Of note, the SHA CIT team received an award of excellence for patient and family engagement from the Canadian Patient Safety Institute and a Health Standards Organization Leading Practice Award in 2018 for the MMSF work:

https://healthstandards.org/fr/leading-practice/mise-en-place-du-collectif-de-securite-des-usagers-du-cadre-de-travail-vincent-pour-accroitre-la-participation-des-usagers-et-de-leur-famille-programme-de-therapies-domicile-du-service-de-sante-ren/

The PD catheter database has served to advance research and operational initiatives. A standardized data set, definitions, and ongoing data collection continues to enable a better match

of research and operational program outcomes, including determination of baseline patient clinical characteristics that lead to technique failure (retrospective chart review from 2016 to 2020, three years post PD initiation). Maintaining the PD catheter database since COVID 19 has been a challenge with human resources. Future research opportunities include analysis of technique survival as a core outcome captured in the PD database. Saskatoon and northern Saskatchewan have a diverse and unique population, and differences in baseline characteristics and risk factors for technique failure of PD patients need to be assessed (expansion of data collection to include chart review).

6.1.1 Limitations

This PhD represented an interventional research approach to research, in which *Nîsohkamâtowak* utilized a participatory evaluation framework and a community engagement approach to better understand the impact of *Truth and Reconciliation Calls to Action*, and the MMSF to quantitatively improve PD catheter function and clinical outcomes.

The approach to research was adaptive (interventional in principle), as each component evolved over time. In a more traditional research approach, a project starts with a defined hypothesis, protocol, data collection and analysis plan. There was intent in integrating research with operational initiatives which resulted in changes in focus, including less emphasis on increasing the penetration rate of home based therapies given the need to stabilize PD catheter insertion technique and patient outcomes, and build trust with First Nations and Métis patients and families.

Both *Nîsohkamâtowak* and MMSF involved the KH program, IR, Surgery, Nephrologists, patient and family partners, and First Nations and Métis communities. Although there was stability in staff from 2016-2019, change in leadership and COVID 19 led to attrition in those trained in MMSF and *Truth and Reconciliation* and cultural competencies. This made it difficult to sustain the gains in First Nations and Métis community engagement and in the PD catheter data collection and database maintenance.

The CIT was intentional in design so that clinical practice improvement was embedded as part of daily work. Without this commitment, it is difficult to continue to make real time process improvements, track metrics cascade across MMSF dimensions, results, and opportunities to share learnings.

Of note, with peer review of manuscripts, there was variation in the acceptance of program evaluation and quality improvement, without statistically significant clinical outcomes. There was also mixed feedback on PD catheter failure being a patient safety priority. This was a single program, with a single Interventional Radiologist, and a small sample size, but the CIT achieved significant clinical results and improved patient and family experience. The challenges of providing PD care across northern Saskatchewan may differ from other PD programs.

The "So what" factor was used in research/evaluation strategy, and is summarized as follows:

- "So what" – IR PD catheter dysfunction rate was reduced from 40.3% in 2016 to 8.8% in 2020 through the implementation of the MMSF, with less cost to the health system through more effective utilization of KH and IR resources; there was a shift from surgical insertion (56.5% in 2016) to IR (89.5% in 2020) for PD catheter placement; the clinical practice redesign focus is on improving sub-optimal patient outcomes
- "So what" - The *Calls to Action* were embedded to create a more culturally sensitive model of PD care, patients had better PD outcomes, and their traditions and values were respected; more efforts are needed to improve the update of PD for First Nations and Métis patients and communities
- "So what" - Other PD programs can tailor their PD model of care and include the MMSF principles and *Calls to Action* directly into programs/services, and adopt the definitions of PD catheter dysfunction and outcomes database; integration of research and KH operational initiatives enhances success and rigour for MMSF cascade of metrics is critical for performance, reporting and learning
- "So what" - The uptake of PD and penetration rate of PD as a home based modality needs to be addressed, to reach the SHA goal of 40% (30% PD, 10% HHD)
- "So what" is the chance that others will adopt and implement this intervention based on feasibility, reproducibility and cost? - The adoption of MMSF represented a significant

shift in patient safety culture, and required ongoing rigour for data collection, analysis, and clinical practice improvement and *Calls to Action* being embedded into the KH program. For other programs, this may be a significant challenge.

6.2 Conclusion

Nîsohkamâtowak was an important integral component of daily practice and service delivery program evaluation. The results achieved showed the positive impact of community engagement and incorporation of the *Calls to Action 19, 20, 22, 23* into kidney care program planning, building healthcare team cultural competencies, and learning about the importance of respecting culture and traditional protocol. The PD catheter IR insertion pathway research and program evaluation showed stabilization in PD catheter failure rate below national target of 10%, from 40.3% to 8.8%. PD catheter dysfunction rates (primary and secondary failure combined) were: 2016 25/62 (40.3%); 2017 19/71 (26.8%); 2018 11/50 (22.0%); 2019 12/54 (22.2%); and in 2020 5/57 (8.8%).

The MMSF collaborative resulted in a strong CIT approach to care, with a collective goal of imbedding patient safety at every point. Continuous quality improvement has led to patient driven quality of care and improved outcomes and care. A holistic approach involves staff, clinicians, and patients and families at all levels. Our First Nations and Métis patient partner served a member of the Kidney Health Patient Advisory Council, delivered education sessions on kidney health friendly lifestyles in the community, spoke to the need to further explore culturally sensitive models of care and to enhance PD uptake in vulnerable populations. He shared this quote: "*It is important that this work be brought out to the reserves, to let patients know that there is help, that people care about you and your safety. People like me can promote PD, and it's important that you listen to our stories, good and bad, to improve our lives and health*."