Protocol Pathways to Care-Perinatal DBT:

Title: Pathways to Care-Understanding the impact of an Indigenous Elder co-lead in perinatal dialectical behaviour therapy (DBT) skills sessions in pregnant persons with complex care needs.

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Funding group: Innovator Fund: Children's Hospital Research Foundation

Sites: Interprofessional Psychosocial Perinatal Care clinic in the Ambulatory Care Clinic at the Women's Hospital at Health Sciences Centre in Winnipeg

Ethics/Impact:
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Background and Rationale

Maternity care has been hard-hit by increasingly complex medical and social comorbidities in pregnancy over the past decade,[1] exacerbated by increased substance use in pregnancy, a widening gap in socioeconomic inequities, and the deep impact made by the COVID-19 pandemic on vulnerable populations.[2] We have seen an increase in maternal mortality, and while advancing maternal age is a major risk factor, socioeconomic disadvantage is equally deleterious.[3] Traditional single-care-provider models have not adapted to address the complex care needs of the 21st century[4] with current research being dominated by provider perspectives rather than patient perspectives and experiences.[5] This gap in the literature is troubling as the patient voice is essential to the ethical design of more responsible care strategies. As a former Canadian Child Health Clinician Scientist Program (CCHCSP) Career Development Award recipient and first Canadian Clinician Midwife, I focused on the development of an innovative interprofessional model of maternity care to improve perinatal outcomes in pregnant persons with complex care needs. As a result of the CCHCSP training and support, I successfully co-developed an interprofessional team of maternity care providers, who have a unique approach to address the complex care that persons need during pregnancy, birth, and postpartum. This *Interprofessional Psychosocial Perinatal Care Clinic* (IPPCC) team features obstetrics, midwifery, psychiatry, and opioid agonist therapy access within a dedicated team of shared-care providers who offer clinic, virtual, and home/shelter based-care to pregnant persons at high psychosocial risk. We have aligned our care approach with the World Health Organization's international guiding principles for the management of substance use in pregnancy, which include prioritized prevention, access to prevention and treatment services, respect autonomy, comprehensive care, and safeguard against stigma.[6] Our team seeks to advance the interprofessional care approach and research by trialing Dialectical Behaviour Therapy (DBT) skills, based on Dr. Marsha Lanhan DBT skills group outlines[7], and then to inform content by Indigenous knowledge from the Elder on our team. Therefore, the primary goal for this project is to conduct interviews (pre/post DBT skills session) with patients who agree to participate in Perinatal DBT skills sessions with an interprofessional team which will guide our care approach with equity-deserving populations and future clinical research priorities.

Many persons who are Indigenous, newcomers, underhoused, suffering substance use disorders and those who experience mental health conditions have significant barriers in accessing health care.[8-10] Most notably persons may not seek care due to stigma, systemic marginalization, structural racism, concern for criminal consequences, and fear of child apprehension.[10] To understand more about substance use in pregnancy and patient-centred care approaches, we conducted a scoping review and found no published evidence of an interprofessional maternity care model that was informed by the voice of pregnant persons who use substances.[11] Furthermore, we did not find any evidence of best practice guidelines that were comprehensive and actionable; most guidelines cited broad, generic clinical recommendations.[11] Our proposal aims to fill these knowledge gaps and centre the patient's voice in our clinical model.

Dialectical Behaviour Therapy skills interventions have been shown to improve depression, anxiety, anger control, and emotional regulation[7,12-13] We plan to modify DBT based on feedback from the Elder's experience co-leadership in the sessions, and the patient's experience The team members from the interprofessional team who will guide the sessions are, Psychiatry-lead, Social Work, and Elder.

Hypothesis and Outcomes

There are 2 outcomes of interest related to our work with our patients: 1) Evaluate the impact of the perinatal DBT skills sessions in patients with complex care needs 2) Adapt DBT to ensure cultural safety throughout the process. Ultimately these outcomes will inform our research priorities and care approach. We expect the care outcomes to align with constructs reflected in our team's *Interprofessional Psychosocial Perinatal Care Framework* juxtaposed with the *Valuing All Voices Framework* (Appendix A).

Project Design, Framework, and Specific Aims

Project Design: Our project design involves the development of Perinatal DBT. We will follow patient-engagement strategies as delineated by the Centre for Healthcare Innovation. Specifically, we will adopt the *Valuing All Voices Framework* to guide our work with the vulnerable population we serve.[14] This framework encompasses five key concepts with definitions that will guide our work: 1) Education and Communication, 2) Understanding and Acceptance, 3) Trust, 4) Relationship Building, and 5) Self-Awareness. In 2021, our interprofessional clinical team created a framework to guide our clinical care approach. Our framework is based on an integrated psychosocial perinatal care model that we practice and delineates three domains: Social, psychological, and perinatal. Each domain intersects and describes aspects of interprofessional engagement to consider when tailoring care for each person with complex needs. Birth experience is at the centre of these domains. Examples of our IPPC model that we offer are reflected in the intersecting domains and are as follows but not limited to social supports, housing, food safety, meaningful employment, neurodiversity health, gender identity, trauma informed care and support, addictions treatment, coping skills, cultural supports, self-care, parenting tools, grief counselling, perinatal psychiatric care, emancipation from domestic violence, and others (Appendix A). Finally, in adopting and considering the *Valuing all Voices Framework*, we will evolve our approach to patient-informed care, and it will support and guide us to use a health equity and a social justice lens to guide our patient-engaged approach.

The purpose of this study is to understand if an adaptation of the standard DBT is culturally safe. We have engaged and invited an Indigenous Elder to co-lead and inform the adaptation of DBT.

Specific Aim 1: To evaluate patient feedback from evidence informed adapted DBT in the context of complex care patients.

Specific Aim 2: To understand patient perspectives of the DBT skills sessions with the participation of an Elder.

Experimental Methods of Engagement

With patient engaged research, various participatory approaches and engagement methods can be considered at different stages in the research process. We are utilizing an evidenced informed method of DBT skills and adapting it to include leadership from an Indigenous Elder. This process will be reciprocal, and flexible regarding the protocol to ensure a culturally safe environment. We will utilize the Methods for Patient and

Public Engagement Guide to map our research stage, level, and method of engagement.[15] These stages include preparing for execution, data collection, data analysis, dissemination, implementation, and evaluation. Within each of these stages there are various engagement levels (consult, collaborate and partner representative) and then various methods of engagement (appreciative inquiry, discussion groups, interviews, etc.). With this stepwise approach, we will identify outcomes-measures that are meaningful to the population served while maintaining study rigour.

Population: Complex care persons with lived experience of psychosocial comorbidities in pregnancy experience systemic barriers to accessing comprehensive maternity care. Patients will have engaged in care in the *Interprofessional Psychosocial Perinatal Care* clinic from October 2023-June 2024 (9 months). We anticipate 6 to 8 persons per cycle, up to a maximum of 15 persons per cycle. We anticipate running 6 cycles over 9 months. We hope to interviews approximately 40-50 patients during this 9-month period. This clinic has a minority Caucasian population, with most patients living on social assistance or with homelessness, and an overrepresentation of criminal justice and/or child protection agency involvement, with approximately 75% of patients identify as Indigenous (First Nations), Métis, and/or Inuit. Our research team has significant experience in collaborating respectfully with and servicing Indigenous patients and communities. The Elder will be the Indigenous lead and understanding as we undertake this project in a good way with the patients.

Recruitment: Using the Patient Recruitment Script postcard we will seek permission to contact persons to participate in interviews related to the DBT skills sessions. The psychosocial obstetrician and the perinatal psychiatrist will engage potential patients to identify if they might have an interest in participating in a pre and post session interviews. *Inclusion criteria*: Patients who have their own agency and decision-making power over their health care. Patients may be antepartum or postpartum at the time of patient invitation. We will not engage minors, nor will we engage a patient who is psychologically or physically unstable. Our patient population in this clinic is very diverse and includes Black, Indigenous, and People of Color (BIPOC). *Exclusion criteria*: Patients who are minors or who are psychologically or physically unstable. Our team of clinicians will screen patients prior to any initiation of engagement with these inclusion criteria as our guide, and a Pledge of Confidentiality will be obtained.

Timeline: October 2023-June 2024 (9 months). There are 6 sessions that will rotate on a weekly basis throughout the 9 months. The 6 sessions make up one cycle. The DBT skills sessions will be run the first three Thursdays of every month.

Setting: *Interprofessional Psychosocial Perinatal Care* clinic (Green Leaf) in the Ambulatory Care Clinic at Health Sciences Centre, Women's Hospital.

Interprofessional Psychosocial Perinatal Care (IPPC) team composition: Psychosocial Obstetrician with expertise in substance use and mental health issues during pregnancy; Midwife clinician scientist, Perinatal Psychiatrist with capacity for mobile care; Indigenous Elder, and Social Work with hospital-based and out-patient capacities. These individuals comprise the dedicated team of shared-care providers who offer in-patient, clinic, virtual, and home/shelter-based care to pregnant persons at high psychosocial risk with complex care needs and liaise with care-partners such as Infectious Disease, Cardiology and Outreach Nursing on a case-by-case basis. Community programs such as Nine Circles, Klinic Mobile Withdrawal, the Mothering Project and Ka Ni Kanichihk provide reciprocal referral pathways. Only the Psychosocial Obstetrician and the midwife clinician scientist, however, will be involved in the recruitment via the patient engaged activities we have delineated in our project, as they have the primary relationship with all IPPCC patients.

Data Collection: Pre and post session Interviews and Appreciative Inquiry (see data analysis stage) will be the two methods of engagement. The purpose of the qualitative pre and post session interviews is to glean an understanding of what the patients understanding of the benefit of DBT and their needs and then to understand how DBT impacted health and well-being at the end of the DBT skills session. Our team will use a semi-structured interview guide for the pre-interviews and develop the post interview guide towards the end of the nine months. The post interview guide will be informed by what we learn and feedback from the Elder throughout this process and from the pre-interview data. Our IPPC team supports 35 to 40 patients during any given month, with deliveries balanced by new intakes. Our end goal is to have 8 to 10 patients participate in DBT skills sessions, with a maximum of 15 per cycle.

During our pre and post interviews we will gather qualitative data to articulate patient care priorities and to understand the impact of the DBT skills sessions. We anticipate each interview to be approximately one hour in a neutral space provided at HSC. Because these patients are under our care, we will provide continual support throughout the process in terms of mental health supports and other supports.

We will also use Appreciative Inquiry to guide our reflection in our team outside of our patient engagement processes. Therefore, another point of data collection for this project will entail an IPPC team meeting at 6 months and 12 months to reflect on our understanding, interpretation, and analysis from our engagement with patients. We will have an Appreciative Inquiry facilitator lead our team meetings to ensure reflexive practice amongst our IPPC team throughout the time of this project.

Data Analysis

As we engage patients to gain an understanding of patient experience and impact of DBT skills sessions, we will use a *collaborative* Appreciative Inquiry approach in these dialogues (i.e., interviews). Appreciative inquiry (AI)[16] is a strengths-based approach that identifies optimal care experiences to define care strategies that are successful from a patient perspective; it begins with “what works” rather than staying mired in “what doesn’t.” Additionally, AI identifies patient strengths to provide a conceptual scaffold upon which to build a care model grounded in lived experience and will use this approach to analyze the client interviews. This method of engagement will guide our interprofessional clinical team to ensure we employ reflexive practice, explore patient expectations, and respect and hear the patient’s voice in research design and development to improve their care experiences. This design partnership supports positive change among the clinical team members and facilitate true interprofessional work, and ultimately ensure the patient is at the centre of our care delivery and team.

In analyzing the data from the pre and post interviews, we will complete a content analysis from the recorded interviews. We will all code the data and come together to cross-check and validate our interpretations of this experience via the Appreciative Inquiry process at one of our clinical team meetings without patients involved. This will ensure we have an opportunity as a clinical team to reflect on process. Our patients will have the opportunity to review the transcribed interviews and the analysis by the team to ensure accuracy of their perspectives.

All our analyses from this project will be an iterative process as we go back and forth to both the IPPC the Valuing All Voices Frameworks (Appendix A) to analyze and validate our findings in relation to the constructs reflected in each. We will adapt DBT based on the feedback and insight from the patients.

Safety and Risk

We anticipate low potential risks and discomforts in this project. Patients will be asked about their experiences surrounding DBT skills sessions offered by the Interprofessional Psychosocial Perinatal Care team which could bring up past trauma and discomfort. The care team will support patients who participate in DBT skills sessions and will offer the services of the clinic's perinatal psychiatrist if the patient chooses. An Indigenous Elder will be available to speak with patient if they choose. Because these patients are under our care, we will provide continual support throughout the process in terms of mental health supports and other supports. The PI or Dr. Watson will follow up with the affected patient at an appropriate time.

Dr. Thiessen, Dr. Watson, and Dr. Ashdown will meet every month to discuss the progress and safety of the project. All adverse events and unanticipated problems will be resolved immediately after the event and Shared Health Impact will be notified.

Privacy

The Patient names and other identifying information will only be captured on the Patient Recruitment postcard and the Pledge of Confidentiality. These documents will be uploaded to a secure server at the University of Manitoba (UM) by the research coordinator (RC) and only the PI and RC will have access to the folder. The hard copies of the documents will be stored in a locked filing cabinet in the PI's locked office at the University of employment, which only the PI has access to that filing cabinet. The audio-recording will not contain identifying information but rather the patient's assigned code.

Dr. Thiessen's work computer is password protected and the passwords are only known by the individual's whose computer it belongs to. Any confidential information that needs to be printed and stored will be placed in a locked cabinet in the RC's office, which is accessed through a locked door.

The audio-recordings and digital files will be deleted from the UM server and DataVerse. All physical data will be confidentially shredded and discarded.

The data will be stored for 7 years.

Outcomes and Knowledge Translation

Anticipated outcomes: We anticipate we will garner new knowledge from the patient pre/post interviews. And from this we can adapt DBT to ensure it is culturally safe. We are planning research priorities and future grant development and will include this process.

Knowledge Translation: Our team keeps health equity as the focal point of every study. To understand the effects of interventions on health equity for the populations we serve, an iterative process of analysis, synthesis, and ethical knowledge dissemination and application will be executed alongside decision makers and patients involved. We hope to discuss this experience and findings at obstetrical rounds and national forums. Our KT plan will also be informed with engagement of our Indigenous research team members. Additionally, we would publish in peer reviewed journals.

Anticipated Barriers: We anticipate logistical barriers with the patients, which can include transportation, childcare, and transient housing. There are also systemic barriers such as power inequities, lack of trust in the health care system, and the colonization that is represented in institutional environments. *Mitigation*: We will support travel and honorariums for each of the patients who are involved. We will provide the following with the support of this grant to encourage patient attendance at meetings: 1) Taxi slips there and back, and 2) snack food and drinks (and let them know ahead of time this is provided). We will collaborate with our patients to ensure meeting spaces feel safe and times are convenient. Practicalities like childcare and COVID-19 protocols will be addressed. The Indigenous Elder will give guidance throughout this project to ensure our care approaches reflect the priorities of Truth and Reconciliation, coming to this work from a place of humility and willingness to learn.

External readiness: Our team has experience working in Manitoba communities in dual roles as both researchers and clinical providers. We know from our clinical experiences and the literature that persons want to be self-directed in their health care particularly in pregnancy, persons desire choice and culturally safe care.[17] We also know many persons welcome opportunities to debrief and process the maternity care they have received whether it was a good or bad experience. Across all cultures new parents process their birth experience through storytelling as part of their transition into parenthood.[18] This study will not only create an opportunity for this type of sharing but will keep it at the heart of maternity care development.[19]

Significance of the Research

My innovative overall research program, *Pathways to Care,* aims to improve maternity care delivery for complex care persons by implementing innovative care models, that create seamless pathways to care. This project will advance intervention research with our clinical team that was established during the tenure of the CCHSP award. Our objective is uniquely grounded in patient-identified priorities, Indigenous wellness values, and collaborative care models; these interventions intersect and are the basis to my *Pathways to Care* research program. For this project as we accomplish our three outcomes, we will then work towards with future funding initiatives (see Future Research Directions section).

The patient perspective from this work will inform how we will define and measure outcomes in this patient population. We will budget in future grants funding to support ongoing resources for DBT skills sessions as a regular part of this care model. We expect this care model will support maternity care providers struggling to support complex populations with actionable strategies that align with patient goals. We expect to demonstrate the impact of an innovative interprofessional team to champion the care needs of marginalized pregnant persons without additional system resources. My overall research program addresses issues of equity and access at the root of the problem and includes disadvantaged voices at every level of my research. My work alongside patients, provincial and national policy makers, and Northern decision makers aligns with and impacts healthcare transformation priorities, such as integration, efficiencies, adaptability, equity, and quality.

Future Research Directions (including likely future sources of support)

At the end of this project, we will have the perinatal DBT skills integrated into our research initiatives in the *Interprofessional Psychosocial Perinatal Care Clinic*. We will engage patients from the outset to have them inform our process and direction for a larger CIHR grant. We hope the information generated from the patient voice will inform how to improve patient care processes and delivery in our clinics that serve diverse populations.

Forms/Information

- Pledge of Confidentiality
- Patient Recruitment postcard
- SOPs (Standard Operating Procedure)

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Appendix A: Frameworks

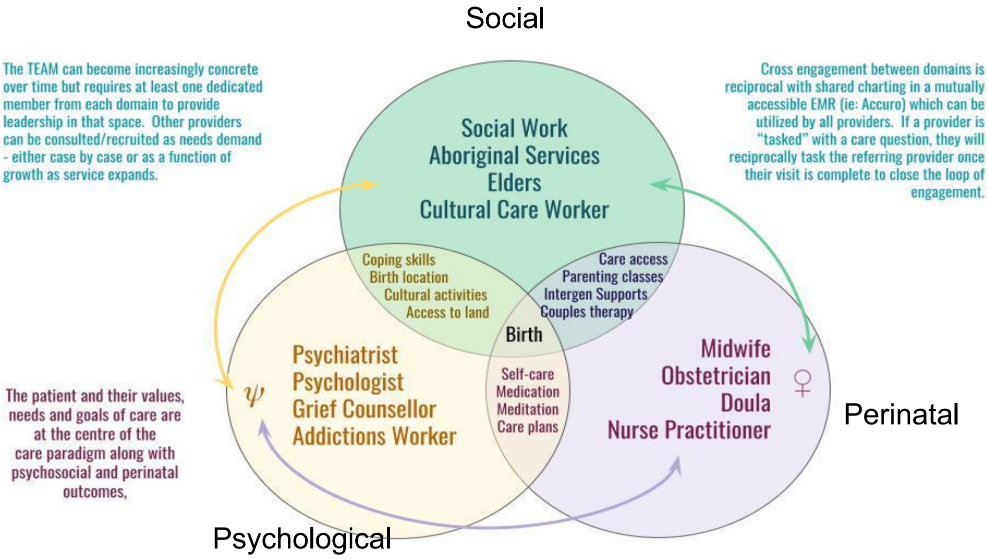

Figure1. Interprofessional Psychosocial Perinatal Care (IPPC) Framework.[20]

Figure 2.
Revised *Valuing All Voices Framework* image with input from study participants.[14]