RESPONSIBILITY & JUSTICE:

INCREASING ACCESS TO PRENATAL CARE

RESPONSIBILITY AND JUSTICE: CONSIDERATIONS FOR INCREASING ACCESS TO PRENATAL CARE. AN INTERPRETIVE DESCRIPTIVE STUDY OF HEALTH AND SERVICE PROVIDERS UNDERSTANDINGS OF INADEQUATE PRENATAL CARE IN HAMILTON.

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TITLE: Responsibility and Justice: Considerations for Increasing Access to Prenatal Care. An Interpretive Descriptive Study of Health and Service Providers Understandings of Inadequate Prenatal Care in Hamilton.

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LAY ABSTRACT

Prenatal care (PNC) can help to reduce complications of pregnancy and birth and connect expecting families with other support services. Even though health care is free in Canada, people who are marginalized struggle to access enough PNC. We know the complexities of people's lives and their negative experiences with the health care system prevent them from getting PNC. We know little about what PNC for people who don't access it is like for the providers or why they can't make their care easier to access. Mindful of systems of power, the goal of this research is to explore how health and social service providers understand inadequate PNC (IPNC), to inform accessible PNC models. Participants proposed an interdisciplinary outreach PNC model responsive to needs of the community. The Social Determinants of Health were an important part of how participants understood IPNC which shaped the way that they proposed to address it.

ABSTRACT

Prenatal care (PNC) is an essential health service that can reduce adverse health and social outcomes through prevention, detection and treatment of abnormalities of pregnancy. It offers an opportunity to mitigate the impact of the Social Determinants of Health (SDoH) on individual patients through advocacy and referral to social services. Despite a publicly funded health care system in Canada, disparities in access to PNC persist. Much is known about the barriers to PNC and client experiences of inadequate PNC (IPNC). Very little is known about care provider perspectives of IPNC, what should be done about it and are the barriers to doing it. The goal of this project was to address this gap in knowledge to inform the development of novel care delivery models that could reduce disparities in access to PNC in Hamilton. Using a Critical Theory lens, I conducted an interpretive descriptive study using individual interviews and focus groups with health and social service providers in Hamilton to explore their understandings of IPNC. Participants viewed IPNC as a small but important phenomenon disproportionately impacting people who are marginalized. The experience of IPNC is chaotic, worrisome and joyful for providers. An interdisciplinary, midwifery-led outreach PNC model would better meet the needs of the client population and providers alike. A Community Centred Care model of PNC embodies and enhances participant suggestions for addressing IPNC. Access to abortion, postpartum care and newborn apprehension require special attention. Peer participation and the impacts of patriarchy and racism must be addressed in the development of future PNC models. The ways in which participants described and proposed intervening in IPNC revealed an individualized understanding of the SDoH that is paralleled in existing research on IPNC. This conceptualization of the problem obscures the root causes of disparities in access and warrants future consideration.

Keywords: inadequate prenatal care, barriers to care, facilitators to care, marginalized, health service accessibility, newborn apprehension, community centred care, social determinants of health, qualitative methods, critical theory

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Finally, I would like to thank all of the clients over the years who have inspired this project. As a well-resourced single mother, I have always marveled at the scrappy and ingenious ways people keep going under such duress.

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LIST OF ABBREVIATIONS

APNCU	Adequacy of Prenatal Care Utilization
CAS	Children's Aid Society
CSDH	Commission on Social Determinants of Health
EMCM	Expanded Midwifery Care Model
FP	Family Physician
GA	Gestational Age
HMOT	Hamilton Midwifery Outreach Team
IPNC	Inadequate Prenatal Care
LBW	Low Birthweight
LGBTQ	Lesbian, Gay, Bisexual, Transgender, Queer
MW	Midwife
MUMC	McMaster University Medical Centre
NP	Nurse Practitioner
OB	Obstetrician
ODSP	Ontario Disability Benefit Program
OW	Ontario Works
PIIPC	Partners in Inner-City Integrated Prenatal Care
PNC	Prenatal Care
PTB	Preterm Birth
PWUD	People who use drugs
SHN MCT	Shelter Health Network Maternity Care Team
SGA	Small for Gestational Age
SES	Socio-economic Status

SDoH	Social Determinants of Health
SJHH	St. Joseph’s Healthcare Hamilton
R-GINDEX	Revised Graduated Prenatal Care
WHO	World Health Organization

LIST OF APPENDICES

DECLARATION OF ACADEMIC ACHIEVEMENT

I, Lisa Nussey, am the primary author and was solely responsible for all data collection for this study. The study design, data analysis and writing of the manuscript were done with support and input from my committee, Dr. Liz Darling, Dr. Beth Murray-Davis and Dr. Naomi Thulien.

Chapter 1. Introduction

In 2012, I was invited by the now defunct front line social services education project, Core Collaborative Learning, to speak to shelter workers about midwifery care and what the service might offer pregnant people[1] experiencing homelessness. Arrangements were made, the invitation to social service workers and managers went out and no one came, not a single person. We knew anecdotally that pregnant people were accessing the shelter system and not getting prenatal care (PNC), so the radio silence on the invitation was a bit puzzling. We re-worked the invitation, and instead asked these same front-line workers and managers to come to a discussion on how to better meet the care needs of pregnant people experiencing homelessness. That invitation received an overwhelming response, with close to 30 people attending the meeting. The very generative conversation provided us with excellent ideas of what might be needed to better serve pregnant people experiencing homelessness. It ultimately resulted in the formation of the Shelter Health Network Maternity Care Team (SHN MCT). The SHN MCT, now renamed the Hamilton Midwifery Outreach Team (HMOT), continues to provide ad hoc, on call PNC to people accessing the shelter system and adjacent services to this day.

The experience of the differential response to the offer to "educate" service providers on midwifery care versus engage them on what they saw to be the problems, needs and solutions for their pregnant clients[2] trying to access care, was formative for me. It is an ethic that now guides all of my work in health care and health research - to take my lead from those who live it. It is in that spirit that the research project described herein was taken up.

Since its 2013 inception, the HMOT has been well subscribed and incapable of meeting the demand or of offering a full complement of services because it remains a volunteer-based program. The establishment of this research project comes out of our experience building and providing care within the HMOT. Through our clinical work we first identified the need to better understand the phenomenon of inadequate prenatal care (IPNC) and to find a way to bring people together to provide much needed improved access.

In this chapter I will set the stage for my master's thesis on access to PNC care by describing the local context and rationale for the study. I begin by describing the purpose and standards of PNC in Canada. I then define IPNC as it is understood in the literature and operationalized in this study. Additionally, I have defined a few key terms and concepts that are central to understanding the phenomenon of IPNC as I have framed it in this work and as they are reflected in the literature. Then I discuss the study setting, with a particular focus on socio-demographic characteristics and pregnancy care settings. This study is then situated in the larger research program of which it is a part. Briefly, but importantly, I will review the impact of the COVID-19 pandemic on both this study and the health and social service landscape in Hamilton. I close the chapter by laying out the purpose statement and articulating the research question which anchor this work.

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[1] I have endeavoured to use gender inclusive language throughout this work. Where I use the term woman only, it is as a direct quotation or in reference to the language used in the source material

[2] I use the terms client and patient interchangeably throughout this paper

1.0 Prenatal care

1.1 Purpose and standard of PNC

PNC is designed to improve maternal and newborn outcomes by providing health teaching and by identifying and treating medical conditions to mitigate complications in pregnancy. (1) Given that pregnancy is often a time when people are motivated to engage in health promotion and behavioural modification activities, PNC can also help connect families with community resources that may be of benefit, including parenting and early childhood education resources and mental health and addiction counselling. (2,3)

The World Health Organization recommends at least eight prenatal visits for a positive pregnancy experience (World Health Organization, 2016). While Public Health Canada remarks that there are no Canadian guidelines or consensus in the literature to define the ideal number of prenatal visits during a pregnancy. (1) Despite a publicly funded health care system, inequities in access to PNC exist in Canada and a segment of the population struggles to access regular, quality PNC.(4)

1.2 Inadequate prenatal care

Two indices to measure the adequacy of PNC have been taken up in the literature: the Adequacy of Prenatal Care Utilization (APNCU) index and the Revised Graduated Prenatal Care (R-GINDEX). These indices have been developed to describe IPNC based on gestational age at prenatal first visit, and the total number of visits as a proportion of the number recommended by the American Association of Obstetricians and Gynecologist (which are slightly more than Canadian convention).(5,6)

The APNCU index is calculated by combining the month of PNC initiation and the number of prenatal visits thereafter until delivery. IPNC is defined as initiation of care after 4 months or getting less than half the expected number of visits. Care description is also further parsed out into categories of intermediate, adequate, and intensive care based on these same criteria. (6)

The R-GINDEX adds a layer of measurement by prorating the number of visits to the gestational age (GA) at delivery. Like the APNCU index, it also uses the GA at onset of care and total number of PNC visits. The R-GINDEX stratifies care utilization into 6 categories: no care, inadequate, intermediate, adequate, intensive, and missing. (5)

In her 2008 study comparing PNC utilization patterns and associated outcomes, Maureen Heaman concludes that the described indices are not interchangeable and confer different rates of IPNC and degree of association with preterm birth (PTB), low birthweight (LBW) and small for gestational age (SGA). They further encourage future research on what aspects of PNC, not just the number of visits, impact these and other outcomes. (5)

In the quantitative portion of this research program, described below, we used a very restrictive definition of IPNC, based on the World Health Organization (WHO) guidelines at the time of the study design, of four or less PNC visits. However, for practical purposes (IPNC is not systematically tracked or trackable in Hamilton) in this study interviewing health and social service providers I have operationalized the definition of IPNC as provider perceived inadequacy, significant enough to impact care provision, clinical and social outcomes and/or to justify intervention.

2.0 Important terms and concepts

2.1 Marginalized

Throughout this work I make use of the term marginalized or pushed to the margins. I take those terms to (not exhaustively) mean the groups of people who struggle to access a system of care that does not centre their needs: people of low SES, people with disabilities, LGBTQ+ people, people experiencing homelessness, those who use drugs, engage in the sex trade, or are imprisoned. In short, by marginalized I mean those who are not centred in the existing structures of power. Here, defining the centre becomes equally important to defining who does not constitute it. In my view the "centre" should not be taken for granted, normalized or de facto accepted as that to which people should aspire.

Because my work is rooted in a critical theory perspective (discussed more in chapter three) which seeks to understand systems of power, their impact on communities and individuals and the ideological justifications or explanations for these same systems that grow up around them, I view the centre as that which is valued by and of value to the perpetuation and expansion of a capitalist system. (7) The centre is thus able bodied, white men of property, for whom the capitalist system was built and whom it continues to serve. (8,9) Importantly then, I take marginalized here to be an active process imposed upon a person or group of people by systems of power, (i.e. not an individual attribute, inherent or acquired), which puts people at higher risk of adverse health and social outcomes. (10)

2.2 Stigma

The Canadian Association of People who use Drugs define stigma as "the experience of being "deeply discredited" or marked due to one's "undesired differentness." To be stigmatized is to be held in contempt, shunned or rendered socially invisible." (11, webpage) In 2019 Public Health Canada released a report on the negative impacts of stigma on health outcomes and suggestions on how to counter stigma in our own practice and organizations. Public Health Canada conceptualizes stigma as othering that dehumanizes those outside the defined (often by the organizations providing the care) norm and defines discrimination as the enactment of stigma. These stigmatizing attitudes and discriminatory practices are known to lead to health system aversion on the part of the people impacted by it. This is in addition to the ill health burden born through chronic stress, material deprivation and the increased risk of injury due to assault experienced by those decentered in Canadian society. (12) Here again our concept of the centre and the margins, is important. Those who are stigmatized in the healthcare and social services systems, as in society at large, are those who are broadly speaking, economically and socially marginalized. (12)

2.3 Social Determinants of Health (SDoH)

According to the World Health Organization (WHO) the SDoH:

> *are the non-medical factors that influence health outcomes. They are the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems.* (13, webpage)

The WHO lists some of the SDoH which can determine health as: "income and social protection, education, unemployment and job insecurity, working life conditions, food insecurity, housing, basic amenities and the environment, early childhood development, social inclusion and non-discrimination, structural conflict, and access to affordable health services of decent quality." (13) In its summation of the importance of SDoH to health, the WHO goes on to describe addressing them as more fundamental to health equity than health care or lifestyle choice based interventions. (13)

In 2004, the WHO convened the Commission on the Social Determinants of Health (CSDH) to mobilize knowledge on SDoH into action. The CSDH's 2010 conceptual framework relies on an analysis and redistribution of power to guide assessment of and action on the SDoH. The CSDH emphasizes the importance of the socio-economic and political context (the Structural Determinants of Health Inequities) that gives rise to the SDoH and health inequities. The framework thus directs that interventions and policies aimed at reducing health inequities must necessarily intervene in the policies that address the socio-economic and political backdrop of people's lives. (14)

3.0 Study setting

3.1 Socio-demographics of Hamilton

With a population of 747 545 people, Hamilton is the third largest city in Ontario, Canada. (15) Hamilton has a long and storied history of social and labour movement organizing. (16) In recent decades the manufacturing sector in Hamilton has been dismantled and the new economic engine in the city is health and social services. (17) The city is also home to a vibrant arts community, that has been met with mixed reaction for its role in gentrifying the downtown core. (18) The destruction of the manufacturing sector has not been without cost to the community, and poverty and income disparity are significant players in Hamilton's social and economic context. Here I try to paint a picture of the wider socio-demographics of the city as a way of contextualizing the need for program development that propels this research project.

The most recent census data reports that Hamilton's poverty rate, according to the low-income cut off, is 16.7%; this is 3 and 4% above the provincial and national averages respectively. (19) Recently, Hamilton earned the distinction of being the fifth least affordable place to live in North America, as measured by the ratio to of average income to average house price. (20) On average, a one bedroom rental in Hamilton is $1559. (21) This is more than double the current rates of income support in Ontario: Ontario Works rates are $733/month for a single person and $1136 for a couple, with an included shelter portion of $390 and $780, respectively. (22) Ontario Disability Benefit Program rates are slightly higher at $1169/month for a single and $1750 for a couple, with $497 and $781 respectively of that suggested to cover shelter. (22) Importantly and anecdotally, almost all the people served by the HMOT are supported by either OW or ODSP.

The waitlist for housing geared to income in Hamilton is more than 6000 people long. (23) The City's more than 455 shelter beds are often full or over capacity, especially in the women's sector. (24) The 2016 Hamilton Point in Time Count found that 28% of people experiencing homelessness identified as Indigenous. It is estimated that 3% of Hamilton's total population is Indigenous. (23) While women and gender-diverse people are poorly accounted for in statistics on homelessness, it is well established that their routes of entry are gendered; propelled by violence, child welfare, sexual and physical abuse, and the consequent disruptions to mental and physical health. (25)

The Woman Abuse Working Group in Hamilton, a coalition of social service agencies working in domestic violence, recently produced a snapshot of 2020, they reported: (26)

-860 women and children in shelter in the city
-85 women in shelter self-identified as Indigenous
-1971 women were turned away from shelter due to shortage of beds
-6-month waitlist for domestic violence/sexual violence counselling
-6922 domestic violence related police reports
-1367 domestic violence related charges (86% male)
-52 incidents of police reported human trafficking
-7676 shelter crisis/helpline calls
-1276 sexual violence crisis helpline calls

In 2018 Women's Housing Planning Collaborative [In]visible Project investigated the experiences of 75 women and gender-diverse people experiencing “chronic homelessness” in Hamilton. (27) They found:

-85% were homeless for four or more years.
-65% struggled with addiction and substance use.
-78% struggled with their mental health and well-being.
-95% experienced some instance of trauma or gender-based violence.
-72% were mothers, the majority had lost custody to child-welfare agencies

This housing crisis intersects squarely with the drug policy crisis to produce increasingly beleaguering and fatal results. (28,29) Since January 1, 2021, Hamilton Paramedic Services responded to 816 incidents related to suspected opioid overdoses. In 2020 the total number of paramedic responses was 565.(30) From January to June of 2021 85 people are confirmed dead from opioid overdose. The total number of opioid related deaths in 2020 was 124. (30)

An important report was released by Public Health Ontario in May of 2021 entitled *Changing Circumstances Surrounding Opioid-Related Deaths in Ontario during the COVID-19 Pandemic*. (29) It reported that the opioid overdose rate had almost doubled during the pandemic in comparison to the previous year. The report also remarked that the Opioid related deaths among women ages 25-44 were on the rise, as were the rates among people experiencing homelessness. (29) A November 2020 version of the same report also showed that there was an increase in the proportion of opioid related deaths in materially deprived and/or ethnically diverse neighborhoods. (28) While these reports were based on provincial data and rates, it is worth noting that the city Hamilton consistently reports adverse drug related outcomes higher than the provincial averages. (30)

Overall, Hamilton is a vibrant, gritty city with significant social and economic difficulties and disparities. This is the backdrop against which PNC services are provided. The models of PNC service delivery are described in the section that follows.

3.2 Pregnancy care settings in Hamilton

Hamilton has two obstetric units, one level 2 and one level 3 centre, St. Joseph's Healthcare Hamilton (SJHH) and McMaster University Medical Centre (MUMC) respectively. Combined they deliver about 7000 births a year. There are three types of PNC in the city: obstetrical (OB) care, family physician (FP) and nurse practitioner (NP) care, and midwifery care. While there is a modest amount of inter-professional collaboration, primarily through consultation, the three groups work mostly in silos.

3.21 Midwives

There are four large midwifery practices in Hamilton, who provide primary PNC, intra- and post-partum and newborn care in keeping with the standard midwifery model of care in Ontario. Midwifery care is self-referred. Midwives generally provide care from 8-10 weeks of pregnancy through six weeks post-partum in a continuity of care service model. Midwives also care for the newborn until 6 weeks of life. They are funded per course of care, receiving an experience-based fee for the entirety of the client's care when the client is discharged at six weeks postpartum. A small group of midwives in Hamilton also work in a collaborative Expanded Midwifery Care Model (EMCM) at the Crown Point Midwifery Program, providing reproductive care (including menopausal care and medical terminations) to non-midwifery clients and referral based newborn care to patients without a family doctor.

3.22 Family physicians and nurse practitioners

The Maternity Centre of Hamilton is a group of FPs and NPs providing prenatal and intra-partum care in a shared care model. The clinic is housed in the David Braley Health Sciences Centre in downtown Hamilton and is a self-refer service. Maternity Centre FPs with active family practices in the city pool their time to provide PNC to people from all over Hamilton. Providers also rotate through 12-24 hours hospital call shifts, during which they care for any Maternity Centre patients who present to hospital either for labour or assessment. The clinic is co-led by an NP (who does not provide hospital-based care) and a FP (who does provide hospital-based care). The Maternity Centre is a part of the McMaster Family Health team and is co-located with McMaster Family Practice. They share their allied health services including a social worker, a dietician and systems navigator. They are also host to the Program for Substance Use in Pregnancy (PROSPR) program, which provides concurrent prenatal and substance use care. The Maternity Centre offers post-partum care up to 6 weeks and although they do not routinely provide newborn care, they will do so for babies who have no family doctor access. They are paid via a longstanding ministry contract and fee for service billings.

3.23 Obstetricians

OBs provide primary maternity care in Hamilton for low and high-risk pregnancies. Providers who deliver at SJHH are entirely hospital based; their prenatal and gynecology clinics are in the hospital itself. Doctors delivering a MUMC provide care in both hospital and community-based clinics. There is also a high-risk maternal-fetal medicine clinic at MUMC, which is a regional centre for high-risk obstetrics. Entry into obstetric care in Hamilton requires a physician or midwife referral. Generally, community-based family physicians provide some PNC to their own low risk patients and refer to OB for shared care between 12 and 28 weeks. At 36 weeks, the OBs assume full care of the FP patients. Midwives and FPs also refer patients for consults and transfers of care for conditions and complications of pregnancy out of their respective scopes of care. Obstetricians are funded in the fee for service model that is characteristic of how physicians are remunerated in Ontario.

3.24 Newborn care providers

Newborn care is provided by midwives to their clients up to six weeks of age, at which point they are discharged into the care of their FP. The babies born to OB and FP patients are cared for by newborn care rota staff FPs in hospital. Newborn care is provided in the community by the family's assigned primary care provider. The hospitals have support clinics for assessing the wellbeing of babies with no community primary care provider. Efforts are made by hospital-based systems to secure a primary care provider for the family. SJHH and MUMC also have level 2 and 3 nurseries respectively which care for newborns out of the scope of midwifery or FP care. Pediatricians in the city work primarily in consultant roles and do not provide primary well baby pediatric care. FDSFSDFSDFS

3.25 Pregnancy and parenting related social services

There are many ancillary supports and services to the maternity care system in Hamilton.

- Healthy Babies, Healthy Children, a Hamilton Public Health program which is available to all pregnant people and new parents and provides in home and office-based health education and some system navigation supports.
- The Nurse Family Partnership Program is an intensive program of support for young pregnant people which follows families into the second year of the child's life.
- Two parenting homes for young mothers exist in Hamilton: Grace Haven and St Martins Manor. These facilities run by the Salvation Army and Catholic Family Services,

respectively, offer residential and day programing to support young pregnant or parenting people.

- The Healthy Birth Weights Coalition was formed in response to the 2011 Code Red report that showed high rates of low birth weight and adolescent pregnancies in Hamilton's priority neighborhoods. (31) The coalition produced the Hamilton Pregnancy Care Pathway, an interactive systems navigation site to help young pregnant people and/or their care providers understand and access available services in the community. (32)
- There is also a large and mostly uncoordinated social services landscape in Hamilton which provides support in accessing food, shelter, legal and health services in the city. These services variously prioritize services to pregnant people and are largely oversubscribed.
- There are two small city centre programs which sometimes serve as routes of entry to the maternity care system described above, like the Shelter Health Network and Hamilton Social Medicine Response Team. Both are community-based programs aimed at providing health care to people who are homeless or precariously housed, many of whom suffer from mental health conditions and/or the consequences of the drug policy crisis.

4.0 Study context

4.1 interdisciplinary mixed methods research program

My thesis research project is part of a larger mixed methods interdisciplinary research program devoted to better understanding the issue of IPNC in Hamilton. As described above, it was born out of community-based work with the Shelter Health Network (a network of care providers providing low barrier health care to patients in the shelter system in Hamilton) which resulted in the formation of a mobile unit of volunteer midwives providing ad hoc on-call PNC to pregnant people with no care provider who are accessing the shelter system in Hamilton. People experiencing homelessness are over-represented among people who receive IPNC, but they do not represent the entirety of the phenomenon. (33) Having initially raised the question of increasing access to care for people experiencing homelessness, the focus of the work organically broadened to encompass the question of IPNC more generally.

The interdisciplinary team that conceived of and drove the early phases of this mixed methods study is comprised of midwives, obstetricians, a family physician, pediatricians, and two social workers. The research program consists of a retrospective chart review comparing patient characteristics and maternal and newborn outcomes of people with IPNC to a control group, matched for age and parity who received adequate PNC. (34) An unpublished study of a patient experiences, barriers, and facilitators to PNC was also conducted as background to this work. This thesis investigating care provider experiences of the phenomenon rounds out a thoroughgoing investigation of the issue of IPNC as it presents itself in Hamilton.

4.2 The COVID-19 pandemic and the shifting landscape in Hamilton

I undertook these interviews before the March 2020 onset of the COVID 19 pandemic in Canada. The shutdowns to curb the spread of the multiple waves of the virus have impacted this work in many ways. First, my clinical and organizing work hit a fever pitch of intensity like I have never in my life experienced. In the name of public health, almost all the health and social services for people experiencing homelessness shuttered their doors, leaving many to fend for themselves with little to no resources. For those of us who couldn't abide this, it meant a grinding pace of being on the front lines, advocating to those in power and organizing communities to respond to the desperate needs, for months on end. At the same time, my children, like everyone else's, were meant to be homeschooled while they coped (often poorly) with the abrupt social dislocation and isolation. All of this meant that work on my thesis was put on hold until such time as "things calmed down" and I could pick it up again – some 15 months later.

The world kept moving while this work was on pause and the clinical and social services landscapes as it relates to IPNC in Hamilton were no exception. Here I outline some of the developments and collaborations that have taken place since the interviews took place in 2019-early 2020. These are provided as context to the results and discussion sections of this thesis, which cannot completely reflect the current landscape, given that they predate it.

- In response to a growing recognition of the major gaps in housing and reproductive care for women and gender non-conforming people experiencing homelessness in Hamilton, the Mobilizing Resources for People Experiencing Pregnancy and Homelessness initiative was created. This is a partnership between community agencies, health care and McMaster University's Community Research Platform. The formation of the initiative represents a City-wide acknowledgement of the need for better care and service coordination. It has issued a call to action focused on prioritized access to shelter and housing for pregnant people experiencing homelessness as well as better care and service coordination. Importantly, it's first recommendation is a commitment to truth and reconciliation and a call to redress the over-representation of Indigenous children in the child welfare system. (35)
- The reorganization of Ontario's healthcare system into Ontario Health Team's (OHT) was well underway prior to the onset of the COVID 19 pandemic. (36) Hamilton's OHT, the Greater Hamilton Health Network (GHHN), has adopted women's homelessness as one of its year 1 priority focuses. This will mean targeted resources and collaborations to address women's homelessness broadly, which will necessarily include reproductive health. (37)
- The inpatient addiction medicine service at St. Joseph's Healthcare Hamilton and Hamilton Health Sciences have created a Collaborative Care Pathway for Pregnant Women Requiring Inpatient Stabilization of Substance Use Disorder. This service and pathway provide access to best practice for pregnant people using substances in

pregnancy, admitting them to hospital for rapid titration of opioid replacement therapy. The HMOT has been a part of creating that pathway.

- This work, in its unpublished and unfinished format, has informed two submissions to the Ministry of Health's Expanded Midwifery Care Model (EMCM) funding program. The existing Crown Point EMCM in Hamilton has partnered with the HMOT in hopes of becoming the future home for a robust, funded outreach midwifery program. As we await the response of the last round of applications (for which we submitted a very scaled back proposal of one full time midwife, instead of 4.5) we are also beginning to explore ways of funding the program with other grants and partnerships.
- After the rejection of the first ECMC application in the spring of 2021, we began thinking of ways to use existing resources to expand the services of the HMOT. This has resulted in the establishment of a drop-in clinic at Carol Ann's Place, an emergency overflow nighttime drop-in which provides service to many women and gender non-conforming people experiencing homelessness.

5.0 Purpose statement and research question

Given the benefits of PNC and the known disparities in access (described in chapter 2), it is sensible for maternity care providers and policy makers to create ways to increase access to PNC for people and populations whose needs are not met by the current model. There are several important sources of information and perspectives that could inform the development of such programming. One such source is the people providing the healthcare and social services to those who struggle to access it.

To that end, the purpose of this interpretive descriptive study was to understand how healthcare and service providers experience IPNC. I wished to gain insight into how they view the phenomenon and what, if anything, they viewed as the short and long-term solutions to the problem. I sought to better understand what are the existing barriers to providing more accessible care and what preoccupies providers that motivates to or prevents them from putting energies into increasing access? I was also interested in how care providers view the people they care for as it relates to IPNC, i.e., those who generally live in intense poverty, have lower education levels, higher rates of substance use and mental health concerns – in other words, a highly marginalized and stigmatized population. How do their views about their patients translate into the kind of care they provide or could deliver? Ultimately, my inquiry was interested in identifying what would be necessary to increase access to PNC and what are the material, intellectual, and disciplinary blocks to doing so.

The research question is thus:

> *How do healthcare and social service providers understand the problem of IPNC in Hamilton?*

The goal of the research project is to inform the development of novel care delivery models that increase access to PNC for people who struggle to access it. This is an important goal because increasing access to care is a way, though not the only way, to improve clinical and social outcomes for an important population of people up against overwhelming odds.

Summary

The impetus for this research program springs from the identification of a need for better care delivery models for people experiencing homelessness, who use drugs and/or struggle with mental health. The identification of that need was born out of the work I and others have done building and providing care through the HMOT and the recognition that a volunteer, ad hoc program cannot meet the needs we are seeing in practice. The study is part of a larger mixed methods program aimed at informing the development of more a more suitable care model.

Hamilton has a care and service landscape which is comprised of three largely independent maternity care provision models: midwifery, FP/NP, and OB. This care is provided against a backdrop of relatively high rates of poverty, homelessness and addiction. The COVID 19 pandemic has propelled some more widespread recognition in the health and social service sectors of the need for better service coordination for pregnant people struggling to access care for reasons of homelessness, poverty, addiction and mental health. However, there is currently no dedicated programming to meet the needs of this group of people during the pregnancy, intra-partum and post-partum periods.

In the chapters that follow, I endeavour to systematically ask and answer my research question with the aim of informing the development of such programming. I begin in chapter two with a summary of the relevant literature on IPNC. In chapter three I describe my methods and methodology and the rationale for each. In chapter four I provide the results of my data collection organized around four major themes relating to access to PNC. In chapter five I provide an analysis of the data, some commentary on what is missing from the data and some suggestions for future practice, research, and education. Finally, I conclude in chapter six with some reflections on what this project and the broader work on IPNC meant to me personally, as well as how I think it has influenced the landscape of IPNC in Hamilton and what it might all mean for my future work.

Chapter 2. Review of the relevant literature

In this chapter I will provide an overview of the literature that was relevant to the design and analysis of this study. Throughout, I have endeavored to reflect critically on the questions asked and answered in the literature, particularly as it relates to provider experiences of IPNC and proposed interventions. I have organized this chapter under five broad headings: (1.0) *Historical overview, (2.0) Characteristics and outcomes related to IPNC, (3.0) Barriers and facilitators to PNC, (4.0) Provider perceptions and understandings IPNC,* and *(5.0) Interventions aimed at increasing access to PNC.* Sections 1.0, 2.0, and 3.0 provide an overview of what is known and unknown about the phenomenon of IPNC as background to the study. In sections 4.0 and 5.0 I have provided a more detailed review of the literature as it relates specifically to the line of inquiry taken up in this work.

To retrieve the reviewed literature, I conducted searches in McMaster University Health Sciences databases- CINAHL, PubMed and OVID, as well as Google Scholar using the keywords “prenatal care”, “inadequate prenatal care”, “access to prenatal care”, “prenatal care utilization”, “poverty”, “low-income”, “low socioeconomic status”, “marginalized”, “pregnancy outcomes”, “characteristics”, “health care delivery methods”, “barriers”, “facilitators” “social determinants of health”. I then reviewed the titles and the abstracts to select relevant studies for review. I also scanned the reference lists of the retrieved articles for studies that may have been missed by my search strategy. I conducted the review of the literature described below in two distinct stages, once at the outset of the design and implementation phase of the work and again during the final stages of the analysis and writing. For this reason, literature published after my data collection in 2019, is described herein.

I have focused my review of the relevant literature primarily on the Canadian studies because of its applicability to my research. I have selectively made use of international studies when they add to or trouble what is known from the Canadian literature in a way that I think is transferable to a Canadian context.

1.0 Historical overview

For almost a century the international medical literature has pointed to the relationship between IPNC and adverse maternal and newborn outcomes. (38) The earliest Canadian references in the literature on the importance of PNC focus on the relationship between PNC and maternal mortality. A 1963 Canadian Medical Association Journal report on the Maternal Mortality Study in Nova Scotia found that in 35% of cases IPNC, *family at fault* was a preventable factor in maternal death. This same study found that in 3% of the cases IPNC, *physician at fault* was a preventable factor in the 38 maternal deaths examined between 1958 and 1962. (39)

A 1966 mortality case review published in the Canadian Medical Association Journal entitled “Inadequate Prenatal Care and Toxemia of Pregnancy” concludes that a spate of physician errors culminated in the death of 31-year-old woman and her two-week-old baby. The report, as the title indicates, also found that “the patient did not seek early and adequate prenatal care and was extremely uncooperative during the course of her pregnancy”. (40, p. 411) On the subject of PNC, the author concludes that when a patient does not seek maternity care, “the physician has an obligation to attempt to stimulate the patient to obtain such care [by] telephone contacts with the patient or home visits by the attending physician, regional medical officer, or public health nurse.” (40, p. 411)

The systematic evaluation of the impact of PNC on obstetric outcomes began to proliferate in the 1980’s, particularly in the US. (41–45) While it struggled to account for the impacts of socio-economic status on utilization and outcomes, all this literature tenuously pointed to an improvement in neonatal outcomes as PNC utilization increased.

The engine of Canadian knowledge production on the phenomenon of IPNC is Winnipeg, Manitoba. In 1994, Mustard and Roos published the first large scale Canadian study of the characteristics and outcomes associated with IPNC. Through the use of administrative data, they analyzed the relationship between maternal socio-economic status, PNC utilization and birthweight of 12,646 women delivering between July 1, 1987 and December 31st, 1988. Mustard and Roos found an overwhelming association between poverty and inadequate access to PNC. They were however skeptical about PNC’s mitigating effects on birthweight, reporting that in both complicated and uncomplicated pregnancies, the effect of APNC on birthweight was negligible. Their discussion points to a few plausible explanations for this finding, but ultimately, they recommended that RCTs are necessary to push through the ambivalence in the literature on the impacts of PNC on birth weight. (46) No RCTs on IPNC were identified in my review of the literature.

Twenty years later, also in Winnipeg, Manitoba, Maureen Heaman et al. undertook a massive program of research into the phenomenon of IPNC which culminated with the implementation and evaluation of a multi-disciplinary intervention to increase uptake of PNC: Partners in Inner-City Integrated Prenatal Care (PIIPC) Project. (47) The research related to IPNC and the PIIPC Project has produced more than a dozen studies spanning from 2005-2020. (5,47,56,57,48–55) Her team’s work is the most comprehensive source on the question of IPNC in the context of a publicly funded Canadian health care system. Her studies are cited repeatedly in this review, and they shape the current discourse and standard in Canada.

2.0 Prevalence of IPNC and related characteristics and outcomes

2.1 Prevalence of IPNC

Using responses from the Canadian Maternity Experiences Survey, Debessai et al. estimate that about 4.1% of pregnant people in Canada receive IPNC as determined by the APNCUI. (58) This information is based on a nationwide Public Health of Canada survey of 6421 people who had singleton births in 2006. Importantly, data collection explicitly excluded First Nations people living on reserve. Data was collected through the use of a 45 minute telephone survey, and was conducted in several languages and at various times of the day and week. (58) In addition to the deliberate exclusion of people living on reserve, one can easily imagine the selection bias that took place in conducting this important survey.

Our Hamilton-based retrospective matched cohort study compared parturients and their neonates born at St. Joseph’s Health Care Hamilton in 2016 with IPNC ($\leq$ 4 antenatal visits, or first visit in 3rd trimester) to those born with APNC (≥5 prenatal visits and initial visit prior to third trimester). We found an IPNC rate of 2.1% using this very restrictive definition of IPNC. (34) It is important to note that this small group represented an extremity of IPNC; the rate of IPNC in Hamilton based on existing Canadian standards and WHO recommendations is doubtless much higher.

2.2 Characteristics of people accessing IPNC

Internationally and in Canada, the literature points to a number of factors associated with IPNC including: low income, young maternal age, low maternal education and income, Aboriginal status, racialization, or recent immigrant status, exposure to interpersonal violence, single parenthood, homelessness, and multiparity (34,51,54,58–63)). Importantly, our local investigation also found that people accessing IPNC were less likely to have an assigned primary care or OB care provider. (34)

Racial disparities in access are more thoroughly researched in the US than in Canada, where studies consistently show Black, Indigenous and Hispanic women are less likely to access PNC. (64) Nonetheless, Canadian literature also points to disparities. In the first of her series of publications out of Manitoba, Heaman demonstrated that Indigenous women were less likely to access adequate PNC than their non-Indigenous counterparts. (48) An important 2016 study in British Columbia demonstrated that rates of IPNC (defined as ≤ 4 antenatal visits), were higher among nulliparous First Nations women than the rest of the population. This study also assessed quality of care by comparing rates of best practice interventions. Nulliparous First Nations women received lower quality PNC as indicated by rates of early ultrasound and indicated induction of labour for postdates or 24 hours of ruptured membranes. The authors highlighted that these differences in rates are concerning given the higher rates of perinatal mortality among First Nations as compared to non-First Nations people. (65)

2.3 Newborn and maternal outcomes associated with IPNC

An important consideration when interpreting the literature on the association between IPNC and increased rates of adverse maternal and newborn outcomes is the potential for interpreting correlation as causation. As early as 1994, Canadian researchers Mustard and Roos remarked that as the baseline health of the population increased, the effects of APNC, specifically as it relates to birthweight, become increasingly subtle. (46) The confounding nature of socio-economic status on the question of IPNC raised by Mustard and Roos persists to this day. There is ongoing debate and conflicting research findings about whether it is the lack of PNC or oppression and its concomitant stress and deprivation of resources that decrease the chances of healthy pregnancy and baby. (66–69)

To further complicate matters, there is no developed measure of adequacy of PNC outside a ratio of visits to GA. That is to say, we do not know which aspects of PNC are most contributory to a reduction in adverse maternal outcomes. Further, none of the adequacy indices account for the ways in which higher risk pregnancies might need an increased number of visits to be considered adequate. (64) The researcher, provider and program developer alike must keep in mind the multi-faceted complexity of the phenomenon of IPNC and the largely binary nature of outcome measures as we wade through the literature.

IPNC is associated with adverse newborn outcomes like PTB, LBW and apprehension by child services. (5,34,70) Heaman's work, described above, provides us with the largest Canadian study to date on IPNC. Her team evaluated the outcomes of 67,076 deliveries over a 5 year period in Manitoba to find that that IPNC is independently associated with stillbirth, PTB, LBW, SGA. (56) Additionally, they reported that people receiving IPNC had lower breast feeding rates, shorter inter-pregnancy intervals and increased rates of postnatal depression and anxiety (people receiving intensive PNC were also found to have higher rates of postnatal depression and anxiety).(56)

The associations with adverse outcomes have borne out in our Hamilton-based research as well. Our retrospective review at SJHH, found increased rates of PTB, SGA, NICU admissions and prolonged NICU stays among newborns of people who received IPNC. (34) This work built on a preliminary study done at HHS evaluating the outcomes of newborns born with no PNC, which similarly showed increased rates of placental abruption and non-reassuring fetal heart rates, along with increased NICU admission and foster care placement rates. (70) Our local chart review found that people receiving IPNC had significantly more placental abruption, general anesthetic use, and newborn apprehension.(34)

Newborn custody loss warrants special attention as it relates to its connection to IPNC. Custody loss, family separation, and apprehension here are taken to mean a state-sanctioned intervention to remove a child from its current family when a child or children are considered to be at significant risk of neglect or harm. (71) The mandate of child protection agencies, responsibilities of service and health care providers and what constitutes neglect or failure to protect are laid out in *Ontario's Family and Child Services Act*. (72) Recent evidence shows a bi-directional link between IPNC and Child Protective Services involvement. IPNC is linked with an increase likelihood of newborn custody loss (34,52,73), and newborn custody loss is associated with an increased likelihood of IPNC in a subsequent pregnancy. (74)

While the literature on the experiences of women who have children removed from their custody is scant, three important Canadian studies have been conducted on the matter. Collectively they confirm that women, when they are asked, repeatedly and consistently experience custody loss as unbearable grief that propels a downward spiral of isolation, poverty, homelessness and long term mental and physical health impacts.(71,75,76)

The literature on the characteristics and outcomes associated with IPNC described herein focuses primarily on Canada and occasionally the US. The great preponderance of the literature internationally however is in agreement with the summarized findings in this section: that there is something of a triangular *association* between IPNC, poor maternal and newborn outcomes, and material deprivation. (59,62,77–81)

Much of the literature around IPNC provides quantitative demonstrations of correlations with outcomes and characteristics of people who access insufficient care. Much of it is database driven and focused on characteristics like income, race, age and parity, and outcomes like PTB and LBW. The obvious next line of inquiry is why don't people access care and what can we do about it, either from within or from without the health care system? Recently, researchers have focused on the first part of that question, framed as barriers and facilitators to care.

3.0 Barriers and facilitators to PNC

The interplay between the patient characteristics and health system design is conceptualized in the literature as "barriers and facilitators to care" and serves as the basis for making recommendations for practice around increasing access to care for people pushed to the margins. Like much of the Canadian research on IPNC, the barriers and facilitators to PNC in a Canadian context have primarily been described by Maureen Heaman and her team in Manitoba.

Not surprisingly, given the correlation between low SES and IPNC, commonly described material barriers to care are inadequate finances, childcare and transportation. (53) Additionally, a host of psychosocial barriers including negative attitudes toward pregnancy and PNC, stress and competing priorities inhibit or prohibit access to PNC. (33,50) Clinical provider characteristics and settings have been described as barriers, including judgmental healthcare providers, inaccessible clinic times and locations and long wait times. (53)

Other Canadian work demonstrates that a fear of child protection services and medical exams, owing to a history of trauma, also prevent people from seeking care, (76) while a Canadian based scoping review found that stigmatization by health and social services providers is widely described as a barrier to care for people who use drugs (PWUD). (82)

Much of the US literature speaks to the barrier of being uninsured which makes extrapolation to the Canadian context difficult. (83–87) Literature out of the US which does not focus on insurance status points to a lack of social support and life skills as barriers to accessing PNC. (88) A study out of Texas points to the compounding nature of isolation and intellectual and developmental disabilities in preventing people from accessing PNC. (87)

McGeough et al. conducted a qualitative evidence synthesis of barriers and facilitators to PNC for women experiencing homelessness which included seven studies (4 from the US, one from Turkey, one from the UK and one from Iran). Their review concluded that the interplay between a fragmented, discriminatory health care system and the complexity of a life on the street make accessing PNC a challenge that individuals often just cannot overcome. (89) They synthesized the thematic presentation of the studies reviewed into two overarching themes: Person-Centred Care and Complexity of Survival. These map well onto the existing findings in the literature exploring the experiences of marginalized peoples more broadly in accessing PNC. (33,83–85,90)

Patient endorsed facilitators to PNC include flexible clinic hours, incentivized visits, mobile PNC units, support with transportation and childcare and non-judgmental relationships with care providers. (47,85) Additionally, a recent study out of the US, using a human centred design found that patient derived ways of overcoming barriers to care include telemedicine, peer support workers and co-location of services in high needs neighborhoods. (91)

The studies described above are largely derived from databases and patient interviews. A very small body of literature on IPNC focuses on the provider point of view.

4.0 Provider perceptions and understandings of barriers to PNC

Citing a lack of dialogue with HCPs on the question of IPNC, Heaman conducted a qualitative descriptive study to elicit "experiential knowledge of health care providers and administrators" in order to "illuminate the socio-political context of program and service delivery". (90, p. 2) She and her team interviewed 24 HCPs from a variety of disciplines, practicing in Winnipeg neighborhoods with high rates of IPNC. Four themes formed the core of their analysis with respect to barriers: caregiver qualities, health care system barriers, personal barriers, and program and service characteristics. These barriers to care map well onto those established in the existing literature on data base and patient interview-based research on barriers to care described above.

Darling et al. (2020) conducted a qualitative descriptive study interviewing 13 Ontario midwives to explore the barriers midwives in Ontario faced in trying to provide accessible care to people of low SES. (92) They found that barriers existed at all levels of practice to providing accessible care. This included a personal level, in that the work to provide care to people of low SES can be emotionally demanding and time intensive; a demand for which there was no extra compensation by the Ontario Midwifery Program. (92) Inter- and intra-professional relationships made the work difficult if not impossible for some midwives to do. These barriers included specifically dissenting convictions about the suitability of people who are extremely marginalized for midwifery care, in that their social complexity was often intertwined with a degree of clinical complexity. Interprofessional struggles around providing accessible care often revolved again around suitability of the client population for midwifery care and around billings and distribution of caseload, especially in small communities. In addition, stigmatizing attitudes of midwifery and physician colleagues toward marginalized clients made collaborative practice to increase access to care difficult. (92) Finally, systems level barriers to providing care included inadequate education and mentoring opportunities to develop the requisite skill set to provide care to clients with complex needs, constraints around the midwifery scope of practice, and the incompatibility of midwifery course of care funding models which incentivize early acceptance of *uncomplicated* clients into care. (92) The funding models of the various care providers involved in reproductive care were also described as at odds with one another, disincentivizing or preventing true collaboration in many settings. (92)

A 2016 qualitative study out of the US explored barriers to providing accessible maternity care to women with physical disabilities. Mitra et al. interviewed 14 PNC providers in the US and found that a host of systemic and knowledge barriers induced them into providing suboptimal care for their disabled patients. They described a lack of provider expertise, exacerbated by a dearth of disability specific clinical research and governing body guidelines left providers feeling incompetent. Their offices were not equipped to provide quality care to people with disabilities. Finally, the remuneration system disincentivized providing quality care to patients with disabilities, who might need more time per appointment for which providers were not compensated. (93)

There are a handful of studies and syntheses looking at the experience of maternity care providers caring for migrants and refugees. Shorey et al. conducted a qualitative synthesis of 11 studies from Europe, Canada and Australia exploring a total of 295 maternity care providers' experiences of caring for migrant women. (94) Tobin et al. conducted a qualitative study interviewing 10 Irish midwives providing care to asylum seeking women in both a large urban setting and a small rural maternity hospital. (95) Taken together these two studies relate the difficulties providers face in caring for people when they don't speak the language of the client, that the increased workload created a barrier to providing accessible care, and that a lack of services and expertise inhibited delivery of high-quality care. (94,95)

In the Canadian context, Winn et al. conducted an interpretive descriptive study using a human rights framework on refugee care. They interviewed 10 PNC providers caring for pregnant women at a refugee clinic and a major hospital in Calgary, Alberta. (96) Their work highlights the difficulties providers face in supporting patients in a complicated and opaque health care system that struggles to accommodate the "extra" needs of many refugees. Additionally, providers expressed a lack of expertise around the needs of refugees and the systemic barriers they faced in accessing health care. (96)

In all instances of the literature on their experiences, providers reflected that health systems didn't accommodate, much less centre, the health needs of the people seeking or excluded from care. Interestingly, despite decades worth of literature on adverse outcomes associated with IPNC and the litany of known barriers to access for people who are marginalized, there is very little in the literature about what prevents providers from addressing these barriers. (94)

5.0 Interventions aimed at increasing access to PNC

I begin here with a short overview of some descriptive studies which look at existing or imagined practices for increasing access to PNC, without any evaluation component. I then look at the relevant literature which aims to evaluate the impact of efforts to increase access to care on both access and maternal and (mostly) newborn outcomes.

While I will not discuss the individual studies in detail, some of the existing literature extrapolates from its own or others' findings on the barriers to care to imagine effective interventions ranging from modification of existing practice to wholesale program development. Suggestions include adequate health insurance coverage (in the Canadian context, for newcomers and refugees) and coordination or co-location of disparate services. (88,97–99) Some authors advocate for improved communication skills among care providers, increased public education on the importance of PNC, and providing patients with information about ancillary services that can be accessed. (61,88)

The Heaman study on provider perceptions of barriers and facilitators to PNC described in section 4.0, also explored provider perceptions of strategies for improving access to PNC. Strategies and suggestions included providing client/patient-centred care, increased public education on the value of PNC, incentivized care and multidisciplinary, decentralized and drop in care models. (50)

In their efforts to develop criteria for the evaluation of “Her Way Home”, a novel community based integrated primary maternity care program in Victoria BC, Marcellus et al. problematized the very act of evaluating interventions aimed at increasing access to care for marginalized groups. (99) Participants in their study highlighted the ways in which the complex phenomenon of substance use in pregnancy and other forms of marginalization, cannot easily be evaluated in the binary terms that so often characterized health service research. (99) Whether it is quantifying the intangibles like building community and capacity or assessing the progressive nature of “recovery”, so many factors for “success” evade measurement with our existing health service research tools. (99) With this in mind, in the paragraphs that follow, I review the literature evaluating interventions aimed at increasing access to PNC for those who struggle to access it.

Darling et al. conducted a systematic review to evaluate the impact of targeted programming on rates of PTB, LBW and SGA. They reviewed 7 RCTs conducted in high income countries that took place in a variety of settings (hospital, community, community and hospital) with a range of health care providers, including physicians, nurse practitioners and midwives. They categorized the interventions broadly as group PNC, augmented PNC and combined group and augmented PNC. The authors found that there was insufficient evidence to conclude that the studied interventions decrease rates of PTB, or LBW or SGA. Darling et al. concluded that there is a need for high quality research to evaluate targeted interventions which broaden the range of outcomes evaluated. They cite mobile outreach models as having shown promise in the literature already. Their work points to the existing nature of evidence regarding impact of novel and targeted models for increasing access to PNC, which are largely case based, observational studies. (100)

Case and cohort studies comprise much of the research aimed at evaluating interventions designed to increase access to PNC. Broadly speaking, McRae et al.’s work comparing neonatal outcomes between women of low SES who had midwifery care to physician care in British Columbia, points to the value of the midwifery model for people of low SES. (101,102) In a large population based study of 57,872 women of low SES delivering in BC between 2005 and 2012, McRae et al. found that people of low SES have lower rates of PTB and SGA in midwifery care than physician care. (102) Specifically and relevant to this work, in a retrospective cohort study matching BC Perinatal Data Registry with Medical Services Plan billing data on 33,397 singleton pregnancies between 2008 and 2012, she also found that women with addiction and/or mental health concerns in midwifery care had lower rates of SGA and PTB when compared with obstetric (though not family physician) care. (101)

A 2007 retrospective cohort study out of California compared the adequacy of PNC, as measured by the RGINDEX, for 108 mobile van patients to 127 clinic-based patients in the same area. The researchers found that that patients who obtained care through mobile outreach in their community were more likely to initiate care in the first trimester, and had similar rates of APNC to the control group. (103) A similar 2010 study out of Florida compared adequacy of PNC between 182 mobile van patients and the same number of control group patients obtaining routine care, matched for age and parity. During the study period of August 2007 to September 2008, they found higher rates of uptake of PNC in the first trimester, and showed higher rates of

APNC in the mobile care group. Further, the mobile PNC van group had lower rates of LBW and PTB. (104)

A small number of case studies also describe efforts of individual clinics or communities to decrease the rates of IPNC. Shah et al. evaluated a quality improvement project undertaken at a large health clinic in Houston. The selected quality improvement measures were derived from feedback on patient surveys, focus groups and stakeholder input and consisted of provision of after-hours clinic appointments, system navigation support, presumption of patient insurance, simplified patient information materials, outreach, and community education. These relatively simple quality improvement measures increased the rate of PNC in the first trimester from 27% to 71.5% in just three months. The authors attribute a large part of this increase in early uptake to the clinic's streamlining of insurance eligibility, which they took as a given until proven otherwise. (105)

In 2020 Gold et al. described the inaugural two years of a faith-based free clinic in Detroit, created in response to disparities in reproductive health outcomes driven by poverty and racism. (106) The clinic had both fixed location and an outreach component which ran twice monthly for 4 hours. The clinic was nursing led, with family medicine oversight and offered free wrap around services. The clinic also ran a 24/7 triage line. The clinic reported on PNC rates and birth outcomes of close to 200 women enrolled in care in the first two years of the clinic's operation. They reported increased enrollment in PNC quarter over quarter and lower no-show rates than comparable standard urban clinics serving people living in poverty, and decreased PTB rate as compared to Detroit as a whole. The report concludes with a compelling invitation to others to take up the work in its own image, with the goal of increasing access to PNC, building better communities, improving maternal and newborn outcomes and decreasing racial disparities in health outcomes. (106)

As described in section 1.0, the PIIPC project in Winnipeg, Manitoba was a multi-pronged research and service delivery program. PIIPC's implemented a four-spoked approach to increasing access to PNC: facilitated access to PNC, drop-in clinics, mobile units, and social media campaigns. The PIIPC mixed methods program evaluation undertaken between 2012 and 2016 consisted of a retrospective chart review of 198 patients of the program, a survey of 101 participants, qualitative interviews with 24 patients and 30 care and service providers and a population-based component evaluating the impact of the PIIPC project on community wide IPNC rates. (47)

The evaluation report concludes that the PIIPC program resulted in increased and earlier access to PNC. Multiparous participants had reduced rates of apprehension when compared to their own previous pregnancies without the PIIPC (52% in previous pregnancy as compared to 30% in PIIPC project). The study showed "clinically significant", but not statistically significant reduction in PTB rates. The researchers suggest that the lack of statistical significance was due to the sample size. The team also found that the PIIPC program resulted in lower population-based rates of IPNC, in targeted neighborhoods.(47)

The qualitative component of the evaluation found that project client participants appreciated the coordinated and flexible approach to care, the incentives they received to attend care, and the non-judgmental approach of the care and service providers involved in the program. Patients also reported appreciation of the chance to be supported to initiate early and effective communication with child protective services. (47) Health and service providers interviewed found that the program led to better coordination, communication, and respect between providers. They also described improved service delivery and client outcomes as positive aspects of the program. (47)

While there is widespread acknowledgement of the barriers to accessing PNC having to do with the SDoH, few of the described interventions explicitly endeavoured to intervene in the same. While not speaking specifically to increasing uptake of PNC, a Manitoba evaluation of the impact of an unconditional (81$/month) income supplement for low-income families (below $32 000/year) on birth outcomes is instructive. (107) Using Manitoba's extensive and well-integrated health and social service databases, Brownell et al. correlated data points from the Healthy Baby Prenatal Benefit program data, newborn risk screen data, hospital discharge abstracts, data on receipt of income assistance and residence in social housing, physician visit records, prescription medication records, population registry data, and Canada census data. They compared three cohorts of mother-newborn pairs: low-income exposed to the income benefit (n=10, 031), low-income unexposed to the income benefit (10, 031) and not low-income and not exposed (n=55, 987). After controlling for the confounders that arose between the cohort of people who applied for the program and those who didn't, Brownell et al. found that mother-newborn pairs who received a government issued prenatal income supplement had decreased rates of LBW, PTB and SGA and higher rates of breastfeeding and LGA. Additionally, LOS for women with a vaginal delivery was shorter in the income supplement cohort. (107)

Summary

For more than half a century, researchers and practitioners have been considering the relationship between IPNC and maternal and newborn outcomes. The client characteristics and outcomes associated with IPNC are well established, though there is some nuance to be had around the question of correlation and causation. It is likely that PNC can best be understood as mitigating the impacts of population wide health, economic and social disparities on maternal and newborn outcomes.

The barriers to PNC are also relatively well understood and can be summarized as the incompatibility between patient lives and models of health service delivery. Most strategies and suggestions for increasing access to PNC flow from trying to adjust service delivery to addressing patient barriers. There is a modest amount of research evaluating the impact of adjusted, more patient-centred models of service delivery which shows improvements in access and outcomes.

Some of the literature on increasing access to PNC describes the perspective of the provider, but not very much. Additionally, there is very little research on why providers struggle to provide accessible care. That is to say: what is preventing health systems from implementing what is already known in the literature about how to make care more accessible? This a notably unasked question, whose answers could meaningfully be informed by the perspective of the providers who are caring for people who don't access enough PNC. Importantly, there is a dearth of literature on how care and service providers *understand* the phenomenon of IPNC or access to PNC.

This study endeavors to begin to fill in some of the academic gaps related to provider experiences and understanding of IPNC, with a primary aim of informing the development of programming to fill the well-identified clinical gap.

Chapter 3. Methodology and methods

I begin this chapter by situating my work in qualitative methodologies and critical theory broadly and Interpretive Descriptive (ID) method specifically. I also make explicit my own positionality vis a vis this research. I detail the way in which the study was conducted, describing sampling, recruitment, data collection and analysis strategies. I conclude the chapter by summarizing the ethical considerations undertaken before and throughout this work as well as strategies used to ensure trustworthiness and rigor. Throughout, I demonstrate congruence between my research question, my methodology and methods.

1.0 Methodology

1.1 Qualitative methodology

> *The goal of qualitative research is the development of concepts which help us to understand social phenomenon in natural (rather than experimental) settings, giving due emphasis to the meanings, experiences and views of all the participants.* (108, p. 43)

Qualitative methodologies offer a road map to gain nuanced insight into a phenomenon that is based in real life/naturalistic contexts. Qualitative methodologies provide both the structure and the flexibility needed to tap into existing and unquantifiable experience and expertise to co-produce knowledge needed to guide us beyond the numbers and into action. (109) Fascinated with meaning rather than measuring (which is the focus of quantitative methodologies), qualitative methodologies acknowledge and embrace the subjective nature of knowledge and truth. For qualitative researchers, reality in the world does not simply need to be apprehended or plucked out of an objective truth. Reality and knowledge are instead socially constructed. That is to say that meaning is collectively created and derived based on shared experiences and understandings. (110) Qualitative researchers gain access to this meaning through the co-construction of knowledge between researcher and participants. (110)

1.2 Interpretive descriptive method

In this qualitative study, I used the Interpretive Descriptive (ID) method named and described by Thorne. (111) ID as a method was created to meet the need for very practical qualitative research programs and findings in the health care setting. ID makes use of what is known and not known in the health field as the mandate for the study, its design, implementation, and use. The resolution of a disciplinary based health service problem is the method’s raison d’être and guiding logic. (111)

ID aims to answer a clinical question by exploring and synthesizing the common and disparate features and perspectives on a phenomenon in a way that “honors their inherent complexity”. (111, p. 70) While setting itself apart from its more theoretical social science ancestors, ID borrows selectively and accountably from grounded theory, phenomenology and case study methodologies. (112) At the same time, Thorne repeatedly admonishes adherents of her design to let go of the notion of ID as a stepwise guide to creating and implementing a research project. She instead describes the method as an ethic which compels researchers to be accountable for the steps that they take, the rationale for which is embedded in their own experiential knowledge of the clinical problem asking for solution. (113)

That is not to say that anything goes: ID is underpinned by tenets that constrain and confine disciplinary based decision making about the design of a particular study. Notably, ID studies are conducted in a naturalistic context - an uncontrived setting - and are attune to "the time and context within which human experiences are enacted". (111, p. 82) ID designs attend to the multiple and sometimes contradictory subjectivities between and within participants, drawing on that richness of experiential knowledge to inform practice insights. Finally, ID studies adhere to notions of knowledge as socially constructed. (111)

The moment I learned of ID as an approach to health service research, I knew it would be the right one for this study. First and foremost, the guiding logic of ID as a health services-based approach to research to solve a clinical problem makes it an obvious choice of methodology for this project. We have a well-defined phenomenon, IPNC in Hamilton, in need of a solution, increased access to quality care. ID's insistence on the production of disciplinary informed action that acknowledges methodological rigor without being constrained by a particular theoretical or methodological dictate, provides the flexibility needed for this study to move beyond describing and onto figuring out what to do. I am drawn to ID's offering of a reckoning, not a recipe.

For Thorne, it is the researcher's immersion and credibility in the discipline which gives the necessary logic and legitimacy to carry out the investigation. (114) Broadly, I am immersed in the discipline of pregnancy care, taken here to include many of the services orbiting the provision of prenatal and postpartum care, like newborn care and social services. Specifically, I approached this program of research with a midwifery disciplinary lens, which brings with it the central tenets of informed choice, choice of birthplace and continuity of care, nested in its fundamental principle of client-centred care. (115)

The interpretive turn in qualitative research, per Thorne, comes when we move from documenting into sense making. (111) In the case of my research, I was trying to understand how people make sense of their experience of IPNC, and how that enabled them to think about what is possible in terms of interventions. This approach allowed me to move from what people say to characterize the systemic constraints that they face and what they view as remedies into a foundation for understanding and action.

1.3 Critical theory

I approached this work with a critical theory (CT) lens to enhance the ID paradigm that I have chosen to frame this study. CT is preoccupied with understanding, describing and challenging manifestations of power. (7) Per Freeman and Vasconcelos "central to the critical theory argument is that systems like capitalism produce knowledge in such a way as to obscure their oppressive consequences." (7, p.8) CT posits that our ideas, drives and understandings of the world are rooted in the structural and organizational features of society, whether we are conscious of it or not.

Taken in relationship to health and health care, CT lends itself to an understanding that individual thoughts and behaviours cannot account for either individual or societal health inequities. Instead, CT moves us to consider health disparities as the *embodiment* of social and economic inequalities. (116) Muntaner et al. advise, "conceptualizing mechanisms of exploitation and domination as health determinants." (10, p.281) An examination of health inequities must therefore account for the ways in which neo-liberal economic systems disproportionately destabilize the lives of the "lower classes" and marginalized people, and the ways in which health care delivery is in fact organized around the needs of those in power. (10)

Beyond *examining* power, Freeman and Vasconcelos describe how CT is unapologetic of its desire to unearth the ways and kinds of knowledge produced in order to *transform* things into "what they ought to be". (7, p.7) CT is thus a suitable approach for this work in that my aim is not simply to interpret what is being said, but to change what is being done, with a view toward understanding and mitigating and changing power structures to the extent possible.

The use of CT allowed me to move from interpreting what participants say and do within a disciplinary framework to understanding their words in an ideological framework founded in my own explicit ontological understanding of the world. Enhancing an interpretivist approach with a critical lens is essential to advocating for both short- and long-term change that might not be imagined within the confines of what is circumscribed by a health profession discipline.

1.4 From where I stand: reflexivity statement

The principles of qualitative research do not ask us to have *a view from nowhere;* they admonish us to be transparent about where we stand and what that vantage point brings to the research and its findings. (117) For me this transparency, or reflexivity, is not about neutralizing my bias, or even exclusively about enhancing rigor as described by Bradbury-Jones. (118,119) Instead, I embrace the notion that reflexivity can be a way to move beyond neutralizing or accounting for the researcher as instrument, into harnessing its power for producing change. (120)

First, I am a single mother of three wonderful daughters. I am a white, middle class professional woman who has spent her career angling to increase access to care for people pushed to the margins of society. I am a community organizer who learned about the injustices of the world in my early 20s through the eyes of Indigenous and working-class people who became my comrades and friends. In the early 2000s, after moving from Fredericton to Hamilton to become a midwife, I was very active in the antiwar movement and again aligned myself with racialized, working class and poor people in the fight against imperialism. My current organizing revolves in and around harm reduction and advocacy with and for PWUD and/or are experiencing homelessness.

My experience working in community has thoroughly convinced me that people usually want to do right by their babies and want the best for themselves and their communities. I believe that pregnancy and parenthood, or the possibility thereof, offer profound opportunities for generative or destructive transformation. I believe that as health care providers we have an ethical and clinical responsibility to provide health care that meets the needs of patients/clients rather than the needs of providers.

I believe that health is political and that interventions into improving health therefore (whether stated or not) are and must be political. Layered throughout all of my midwifery practice, program development and research work is a longing for not just improved clinical access and outcomes, but justice.

2.0 Methods

2.1 Purposeful sampling

Purposeful sampling of participants was done based on my knowledge of the clinical and social service landscape in Hamilton and who would provide generative information on the phenomenon of IPNC from varying perspectives. Thorne encourages deliberate selection of participants who will be best "equipped to provide you with access to what is happening and why it is happening". (111, p.99) Specifically, the study sample included midwives, obstetricians, family physicians, nurses and nurse practitioners, pediatricians, social service workers (child protection and Ontario Works workers) and social workers.

As it relates to the phenomenon of IPNC in the city, I was interested in health or social service workers who either *chose* or had a mandate to work with people experiencing IPNC, for example street outreach doctors and midwives or child protective services. I was also interested in speaking with those providers who inadvertently cared for people with IPNC; namely those who worked on hospital wards either as nursing staff or on call physicians.

Within these groups I also sought to speak with people in leadership roles; department heads and managers (who may or may not have an interest in the phenomenon of IPNC). These were invited to participate because of their presumed understanding of health systems, policies, and their own workforce, and because of their potential as leaders to enact change.

2.2 Inclusion/exclusion criteria

The study's inclusion criteria were healthcare and social service providers currently or recently (within two years from the time of the interview) working in Hamilton with pregnant and post partum women and gender non-binary people, and newborns. All participants needed to speak English or French as those are the only languages that I speak fluently.

2.3 Recruitment strategies

Recruitment for the study was undertaken almost exclusively by personal communication between me and the desired study participants. In most instances, personal email was used to invite prospective participants and explain the study. Almost all the participants were known to me personally, but a small number of participants were identified through secondary contacts. (See appendix A for study email script.)

Additionally, participants were recruited through formal presentations about the study at clinical midwifery and obstetric department meetings. Participants were also sought through the Hamilton Healthy Babies Healthy Children program which, among many services, provides in-home nursing supports to new parents.

2.4 Sample size

Like all methodological decisions in ID, the sample size is not prescribed ahead of time, but based on the internal logic of the study. (111) In keeping with the scope of this thesis and the number of providers in the city conversant on the question of IPNC, I ended recruitment when I felt that I had spoken to enough participants to reflect the varied perspectives on IPNC. These perspectives included those who worked in the field day in and day out, those who didn't chose to care for people with IPNC but did so by virtue of being on-call when they presented to hospital, those who administered clinical programs that cared for people with IPNC, and both hospital and community-based providers. In addition to considering the different perspectives needing to be brought into the work, I was also mindful of when I felt that I had enough information to meaningfully answer the question.

2.5 Data collection: semi-structure interviews and focus groups

In keeping with my commitment to the co-creation of knowledge, data collection consisted of semi structured interviews and focus groups. These were used as a way of meaningfully engaging and acknowledging the expertise and experience of the participants, as well as my own in the field. (121) All interviews and focus groups were conducted by me between August 2019 and January 2020. They were audio recorded and professionally transcribed by a contracted third party.

I used one-on-one semi-structured interviews as my primary method of data collection. This modality was the best way for me to elicit the kind of nuanced information that I needed to best understand the views of the care and service providers whom I hope will take up the programming that comes of this research project. Further, the semi structure interview format allowed me to modify the interview either as it or the study progressed to address the emerging ideas or questions raised by previous participants. Finally, the individual interviews allowed me as a researcher to make use of my own intellectual and experiential expertise in the field. This allowed me to use my knowledge of the system's pitfalls and potential to guide and probe the conversation in ways that could not be done through the use of more structured data collection methods, like surveys for example.

Interviews lasted between 40 and 90 minutes and took place in the setting of the participants' choice, usually in their office. Informed consent was obtained prior to the commencement of all interviews.

Occasionally, I chose to use a focus group instead of an interview for data collection. In keeping with Thorne's suggestion that the group dynamic is the foundation of the focus group process, the modality was chosen when participants collectively had relatively little experience with or inadvertently provided care or services to people who struggle to access PNC. (111) The goal was to have participants synergize their limited experience and use it as fodder for discussion. (122) Focus groups were comprised of participants who knew each other and would be relatively comfortable sharing experiences and ideas together, minimizing the potential for power dynamics to silence a particular participant or point of view. In addition, one interdisciplinary focus group was used to pilot the interview guide with participants who were close to the research program.

All the focus groups were conducted in the setting of the participants choosing, namely at kitchen tables and in office spaces. Focus groups lasted between 60 and 90 minutes.

The interview guide for both the individual interviews and the focus groups was informed by the existing research on provider experiences of IPNC, barriers and facilitators, and interventions designed to increase access to care, as well as my own experience in the field, and an informal investigation of patient experiences of IPNC that I conducted in the early stages of this research program. The interviews and focus groups probed the provider experience of IPNC by starting with an invitation to share a specific example of a patient or interaction that related to the phenomenon. I then asked participants to described to me how those experiences made them feel. I tried to get at how providers understood the issues around access to care by asking them to describe their perceptions of patient barriers to care and what prevented them from providing more accessible care at an individual and systems level. I concluded the interviews and focus groups by asking participants to explore changes they thought could be made to care provision to increase access, what they saw as barriers to doing that and who they thought should take the lead on such initiative(s).

I informally adapted the interview guides prior to and during each interview or focus group to reflect or follow up on new or important ideas generated in previous data collection. Interview guides were also adapted to suit the disciplinary experience and expertise of each participant. For example, I asked different questions about the phenomenon of IPNC of the hospital-based pediatrician participants than I did of the community based social service workers. Multiple iterations of the interview guide can be found in appendices B-G.

2.6 Field notes

I maintained handwritten field notes throughout the interview phase of the study, capturing broad themes and new avenues for inquiry as they were generated. I used these notes to track my impressions and responses to the interviews and the study as it took shape and respond to the data as it was collected. (123) These impressions were incorporated into the data analysis and guided enhancements to the interview guide as the study progressed. These field notes were vital in consolidating impressions and turning them into findings. (111,123)

3.0 Data analysis

Data organization and analysis was assisted with the use of NVivo 12 software. As is the custom with QR, data collection and analysis were simultaneous and iterative. (124) Data analysis followed the pragmatic six steps of *thematic analysis* described by Braun and Clark:

data familiarization, generating initial coding, searching for themes, reviewing the themes, defining and naming the themes and producing the report. (125–127)

Throughout the steps described by Braun and Clark, I made use of Eakin and Gladstone's "value adding" approach to analysis. (128) Their approach describes features of an analysis that moves beyond the surface level interpretation that characterizes, in their view, the preponderance of qualitative health research today. Their value adding approach is aimed at "unleashing the interpretive imagination" in the service of creating new knowledge. (128, p.2)

3.1 Familiarization

Initial familiarity with the data came from conducting the interviews myself. I began my analysis of the interview data by conducting multiple readings of the transcripts. As I read and re-read the transcripts and became more familiar with my data, I constantly returned to my research question and study purpose and began making analytic memos and annotations on the transcripts (127). This stage was crucial to gaining a deeper sense of the data and helped generate my initial coding scheme. In this stage of the work I felt strongly what Eakin and Gladstone describe as the "creative presence" of the researcher. (128) I deliberately took stock of my reactions to the interviews and the data as I listened and read. Asking myself "why am I reacting this way?" and "whose side am I on?" allowed me to bring my experience and expertise and emotional response to the data. (128, p.5) This reflexiveness helped me move the data into codes that reflected my efforts to understand what it is about how providers experience the phenomenon that might be useful to break down some of the barriers to building more accessible services.

3.2 Generating initial coding

Codes are the labels given to units of analysis extracted from the data in relation to the research question. (127) Initial codes were created as the interviews were completed through inductive coding of the transcripts. I used a mixture of descriptive and interpretive codes at this stage. A descriptive code is one that simply described its literal content, transportation as a barrier to access, for example. While an interpretive or "generative code" labeled an idea or concept that was emerging as I worked my way through the transcripts, "Unaware of own barriers", represented this kind of interpretive code. It is here also that I really began "reading for the invisible", taking stock of what was not said at all and thinking through what that might mean. (128, p.7)

3.3 Searching for themes

Once I felt I had enough data, referring back to the research question, I began grouping smaller codes to create cursory or candidate themes. (125) These themes and codes were then used to code the incoming transcripts deductively. Data that did not fit the themes nascent in this middle phase of analysis was coded inductively to create new codes and subsequent themes. Throughout this stage, the relationship between candidate themes and how they would all "hang together" as a story about IPNC was considered. Additionally, here I began to deliberately take stock of the ways in which participants responses compared to one another. I also considered the internal logic of the responses of individual participants. For example, many could handily describe the barriers that patients faced in accessing PNC but struggled to describe things that they were or could be doing to increase access. This became a very important idea in discussing my findings.

Finally, candidate themes were organized into a sequential outline for writing with theme headings, salient codes and relevant quotes to represent each. This provided visible organization and structure to the data, which facilitated the work of reviewing the themes.

3.4 Reviewing themes

First, themes were checked against the data they contained to confirm or refute that they appropriately named their contents. This step resulted in the culling of some codes and the migration of others to new home themes. It also allowed for the collation of some themes whose boundaries blurred into one another. Throughout this process, supervisory and committee meetings were sites of lively and generative discussion challenging, articulating, refining and connecting these candidate themes. Finally, the themes and subthemes were checked against the entire data set, with a final re-read to ensure the thematic scaffolding captured and is captured in what people actually said.

“Analysis as contextualization”, whereby the “meaning of the data is understood to be produced by the context in which it is situated”, became very important at this stage of the analysis. (128, p.3) Specifically, I began to see patterns in responses that delineated generally along the lines of people who work primarily or deliberately with those who struggle to access PNC and those who worked in office and hospital-based settings where they saw all comers, caring for people with IPNC more by default than by choice.

3.5 Defining and naming themes

In this phased I worked to really bring the story together, first by finalizing the names of the themes and subthemes and defining them with as much precision and artistry as I could. I selected the best quotes around which to build each section of the findings.

3.6 Producing the report

While it is the “last” phase of analysis, it is certainly not one that is apart or distinct from the preceding steps. Eakin and Gladstone describe writing as analysis and emphasize the analytic process of turning ideas into words on the page. (128) For me, it was in the writing where I could see the coherence and incoherence of what I thought I was trying to say. In the writing stage, in keeping with the iterative process of QR data analysis, I re-visited and re-considered earlier phases of analysis, reorganized my codes, removed entire parts of the findings, and went right back to the original transcripts to re-consolidate my ideas. For example, the theme *conceptualizing the problem* was entirely reconstructed well into the writing phase, when the ideas about providing care as a responsibility just weren’t cohering well. In going back to the uncoded data at this stage, I was better able to interpret participant responses regarding their implied understandings of access in a way that held together in the broader argument I was co-constructing around access to PNC.

4.0 Ethics

4.1 HIREB

Ethics approval for this project was obtained through the Hamilton Integrated Research Ethics Board.

4.2 Consent

I obtained free, informed, and ongoing consent from each participant involved in the study. Before every interview or focus group, I explained and provided an information sheet, which outlined the objectives and purpose of the study, as well as the potential harms and benefits of participating and consent was provided to each participant (See Appendix H). I also informed participants that information would be kept confidential and would be anonymized to the best of my ability in any quotes used in presentations and publications. I reminded participants that they may feel uncomfortable answering certain questions and could choose to not answer any questions or to withdraw from the study at any time. They were offered the opportunity to be informed about the findings of the study upon its completion. Prior to commencing and recording the interview/focus group, the consent form was signed by the participants and witnessed by myself. Participants were offered a copy of the consent for their records.

4.3 Privacy

Participants were assigned a study ID which were used to deidentify the transcripts. At the outset of each focus group, I reminded participants to respect the privacy of their fellow participants and not to repeat what was said in the focus group to others. However, participants understood that due to the sharing nature of focus groups, complete confidentiality could not be ensured.

4.4 Data storage

Data was stored and protected by maintaining password protected electronic files, including the study participant linking key, audio interviews, and transcripts on a single, password protected computer on a secure network. Audio files were sent via secure network to a reputable transcription company, with whom the McMaster Midwifery Research Centre has a confidentiality agreement. Data was anonymized at the point of transcription. Data will be kept for ten years and then permanently destroyed by deletion of electronic files (audio recordings, transcripts, and participant linking key) and hard files (signed consents).

5.0 Trustworthiness and rigor

Trustworthiness and rigor describe not only the precautions taken to create meaningful, useful and credible research, but also ways for the reader to discern "mediocrity from excellence". (111, p.231) Thorne categorizes credibility under four principles: *epistemological integrity, representative credibility, interpretive authority, and analytic logic.*

5.1 Epistemological integrity

Epistemological integrity refers to the coherence between the assumptions about the nature of knowledge and the methods used to generate the study's new knowledge. In this study I have relied on data collection methods (interviews and focus groups) that are in keeping with the epistemological understanding of knowledge as co-created.

5.2 Representational credibility

Representational credibility indicates the ways in which a study's claims are consistent with the manner in which the phenomenon under study was sampled." (111, p. 234) That is to say, have I asked the right questions (epistemic integrity) of the right people? Further, representational credibility refers to the multiplicity of viewpoints that can be brought to bear on a question. In this work, I endeavoured to bring many perspectives within healthcare (midwives, obstetricians, family doctors, nurse practitioners and registered nurses) across a variety of settings (hospital, office, communities). I also brought in the voices of social service workers (hospital social workers, (Children's Aid Society) CAS and Ontario Works (OW) workers) who work with the target population from a differing vantage point. Additionally, across these categories (health vs social services) I sought representation from providers who care for this population by virtue of their position but don't actively seek out this work (e.g., on call OBs and hospital nurses), providers who actively choose to work with people on the margins (e.g., outreach health care providers), and providers who are mandated by law to engage with people (e.g., CAS workers). Finally, I sought to interview providers in leadership roles, with an eye toward their understanding of institutional barriers and facilitators to changes in practice that could increase access to care.

5.3 Analytic logic

Analytic logic refers to the ways in which the decision-making processes throughout the study are rendered accessible and, importantly, coherent. This accounting for decisions begins with the choice of methods and methodology and flows through to the interpretation of the data to the conclusions drawn therein. (111) In this chapter, I have rigorously accounted for the methodological decisions made in constructing and conducting the study. Throughout the chapters which follow, I have employed thick description and extensive use of participants words verbatim to ground and account for my reporting the data. In adherence with the principles of critical theory, I have contextualized participants words and interpreted their meaning with particular attention to questions of power and justice. I have articulated my findings and discussion in such a way as to make that clear to the reader. (129)

5.4 Interpretive authority

Interpretive authority essentially refers to the confidence the user of the research can have that the researcher's conclusion represent some form of "truth" and not just opinion. Here, I have explicitly tethered my analysis and conclusions to a critical theory perspective, within the confines of the ID method. As it relates to the ID method, my experience and role as a leader in the field positions me well/gives me the authority to understand in depth what participants are expressing as it relates to PNC, the population in question, the available services and the gaps in the system. From a critical theory perspective, I have interpreted the data from the point of view that inequality and oppression and the ideologies that give rise to both obscuring and sustaining the same are a function of systems of power, not the consequences of poor choices or bad genes. (130)

Most importantly, I am not simply interested in having a "correct" analysis. My interest in power is in confronting it in my clinical and organizing work. It is through elucidating the ways in which people see themselves, the world and their place in it, that I and my colleagues might strategize about intervening in it. To this end, I have interpreted the data with an eye toward shifting the power imbalances in the favour of those who want to provide the care but can't and those who want to access the care but can't. Said another way, I have located my work "in a transformative praxis that leads to the alleviation of suffering and the overcoming of oppression". (129, p. 315)

While a reader may not agree with my orientation to the world (that it should predominantly be understood in terms of power relations), they can follow my argument, appreciate the ways in which I have explained my interpretations of what people said (meaning making) and decide if it is compelling.

On a more logistical level, I have engaged with my supervisor and committee on a regular basis to check the intelligibility and coherence of my findings, as I developed them. I refined my coding and analysis based on those discussions. My committee has the requisite methodological, theoretical, and disciplinary expertise to provide this feedback as a trio of health researchers and care providers working with people living on the margins.

Summary

In this chapter I have accounted for the decisions I have taken in designing, implementing and producing the results of this study. I have outlined why ID with its solution focused, disciplinary based approach is best suited for this study, and further explained how the method is enhanced by CT's attention to examining and transforming relations of power. I have located myself as a health care provider interested in understanding power for purposes of bringing about change and intervening in what I consider to be an important problem of inequity in health access and outcomes. I have tried to demonstrate how the decisions I have made regarding methodology and methods have allowed me to meaningfully answer my research question: *How do health and social service providers in Hamilton understand IPNC during the antenatal, intrapartum postpartum and neonatal period?* As well, I hope I have satisfied the reader that my methodology and methods are a best fit for the purpose of the project: informing the development of programming to improve health access and outcomes for parents and newborns.

Chapter 4. Findings

This chapter opens with a description of the characteristics of the participants along with a brief discussion about missing representation. Then, the findings are presented based on the core themes of “describing the problem”, “experiencing the problem”, “conceptualizing the problem”, and “addressing the problem”.[3] Throughout this chapter, I utilize a CT lens to highlight what I find implied and missing in the data.

1.0 Participant information

I conducted 15 individual interviews and 4 focus groups, with between 2 and 6 participants each (described in Table 1 below). See Table 2 for demographic information on study participants.

Table 1 Participants by discipline and interview mode

Individual Interviews	**N**
Family Physicians	4
Obstetricians	2
Nurses (RNs, RPNs and NPs)	2
Midwives	1
Pediatricians	2
Social Service Workers (OW workers and CAS workers)	2
Focus Groups	
Midwives	5
Nurses (RNs, RPNs and NPs)	2
Social Service Workers (CAS workers, Hospital Social Workers)	5
Obstetricians	1
Pediatricians	1

Some providers worked deliberately with the population of people who struggle to access care, either by choice or by mandate. For example, the CAS workers I interviewed were mandated to provide service to protect vulnerable children. One participant was an Ontario Works case worker, working with clients experiencing homelessness. Several midwives volunteered for the HMOT, whose mandate it is to provide care to people without PNC accessing the shelter system in Hamilton. Some of the family doctors interviewed tailored their practice to decrease barriers or provide concomitant PNC and addiction medicine. Another set of providers I interviewed worked in a clinic-based, self-refer setting with a mandate to provide low barrier to care to pregnant people in Hamilton.

Other participants provided care to people with INPC less deliberately, and essentially, by default. These were primarily hospital-based providers working on shift, who saw all comers during their scheduled hours. For example, OBs on call are automatically assigned to patients

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[3] A reminder to the reader that the interviews were conducted before the COVID 19 pandemic, which propelled a number of new initiatives and collaborations, outlined in chapter 2.

who come through the door with no assigned care provider. Similarly, pediatricians on call and ward nursing staff provide care to the newborns of these same patients.

Importantly, there is missing representation from labour and delivery nurses. The impact of their absence is reviewed in the limitations section of the discussion. I do regret that their voices are missing from this work.

Table 2 Demographic information of participants

Profession	**N**
Family Doctor	4
Midwife	6
Nurse (RPN, RN, NP)	4
Obstetrician	3
Pediatrician	3
Social service Worker (OW workers, CAS workers, Hospital Social Workers)	7
Practice Setting(s)*	
Hospital	18
Clinic	2
Community	11
**Some providers worked in multiple settings*	
Years of Practice	
0-4	6
5-10	4
11-15	6
16-20	7
21-25	3
25+	1
Work	
Full time	24
Part time	2
Not currently working	1
Institutional Role	
Head of Service/Program Manager	7
Supervisor	1
Employee	10
Independent Practitioner	8

2.0 Themes

Describing the problem presents to the reader, just that, how the providers describe the problem, with a particular emphasis on why, despite being a numerically small phenomenon, it is an important one worth consideration and intervention. Additionally, under this theme I describe the ways providers speak about and understand the barriers that their clients face in accessing services. From there I move to the theme of *experiencing the problem;* an elucidation of how providers experience the phenomenon of IPNC, here emphasizing the emotional labour and experiences that are part of caring for people so pushed to the margins. In this section I also summarize what providers view as barriers to providing accessible care to the people whom they all agree need better access. Under the theme *conceptualizing the problem* I explore and analyze how providers speak of the problem of IPNC, and what it could reveal about their world views and how they see themselves in relation to the problem. Finally, under the theme *addressing the problem* I enumerate the existing strategies and ideas for practice that could improve access to PNC for people who so struggle to access it. The themes and subthemes are summarized in table 3 below.

Table 3 Thematic overview of findings

Themes	Subthemes
2.1 Describing the problem	2.11 Incidence is low, and importance is high 2.12 Complex lives 2.13 Logistical barriers 2.14 Stigma and fear leading to aversion
2.2 Experiencing the problem	2.21 Chaotic 2.22 Worrisome and frustrating 2.23 Joyful hard work 2.24 Challenges of the population 2.25 Low morale and high volume in a stigmatizing system 2.26 Constrained by funding models 2.27 Can't treat SDoH
2.3 Conceptualizing the problem	2.31 Getting care as a responsibility *of* the individual patient 2.32 Providing care as responsibility *to* the individual patient 2.33 Justice
2.4 Addressing the problem	2.41 Existing strategies for increasing access to PNC 2.411 No dedicated effort to increasing access 2.412 Flexible care with better accommodation to the existing system 2.413 Transformative power of trust 2.414 Still can't treat SDoH 2.42 Suggested strategies for increasing access to PNC 2.421 Shared commitment and leadership 2.422 Dedicated programming 2.423 Still won't be able to treat SDoH

2.1 Describing the problem

Under the theme *describing the problem* I have laid out how participants recount the problem of IPNC as it relates to the clients they see in practice. The subtheme *incidence is low, and importance is high* describes who providers view as struggling to access PNC and why they think providing them with better access to care is important. The subthemes *complex lives, logistical barriers,* and *stigma leading to aversion* describe provider perspectives on the barriers to care that their clients face in their own lives and the health care system that result in IPNC.

2.11 Incidence is low, and importance is high: "*this is the beginning of somebody's life*"

Participants described the population of people receiving IPNC primarily as "marginalized"; specifically, people deprived of housing, precariously housed or incarcerated, people living in poverty, PWUD, victims of violence and human trafficking, as well as those suffering from mental health conditions and intellectual disabilities. Additionally, participants spoke of newcomers as commonly accessing IPNC, but considered the barriers they faced as somewhat distinct from the non-newcomer demographics. Certainly, many newcomers were described as living in poverty; however, the barriers most commonly ascribed to this specific group were language barriers and a lack of opportunity and time to learn how to navigate the health care system in Hamilton.

Data on IPNC was not systemically tracked by any of the participants, their practices, or institutions; however, participants were able to describe their perception of the incidence of IPNC by reflecting on their last year of practice. All participants contended that, as an absolute number, the population of people accessing IPNC was small. Most were quick to add, however, that the small numbers belied the magnitude of the problem and its impacts on the health and wellbeing of the individuals involved and the society and health systems at large:

> *… but I mean this is the beginning of someone's life, right? It's like the start. So, it's an 80-year problem as opposed to our people who develop COPD at 75 – that's a much shorter-term health issue in terms of funding in dollars.* (Obstetrician)

For many, the identification of IPNC as a small but mighty problem pointed to the importance and potential for interventions to facilitate meaningful change in health and social status. Interviewees described the growing literature on the importance and impact of in utero events over the course of a lifetime and the endless cycle of child welfare interventions and family disruption that could be interrupted, in part, through robust and well targeted programming:

> *There are lots of other interventions that have looked at or are being studied to decrease the low birth weight, and preterm labour. It's an area that gets a lot of funding and a lot of attention, but Child Protective Services and child apprehension does not. And the lasting impacts of likely improvement in child growth and development, and family unit functioning, and all those kinds of things are probably pretty significant from*

> *[intervening in] that, then they are from changing a birth weight by 200 grams.* (Family Physician)

This doctor was speaking in broad terms of the relative inattention and untapped benefit of more robust PNC programs to intervene in the individual trauma and societal impact of apprehension. They also focused in on the particular trauma and injustice that has been and continues to be wrought on Indigenous peoples through the child welfare system. Here they wonder if and how we could do better:

> *The engrained kind of association for our Indigenous patients and our fellow Canadians of association of CAS with residential schools and that trauma, and how that impacts their perception of CAS involvement in their care today, even though residential schools don't exist. That living trauma of that experience. Are there ways that we could work and do things differently with people, where that particular organization is such a trigger point for trauma? There may be times where that is very important and useful, but is there a way to do it differently?*

Overall, there was no question among study participants that the phenomenon of IPNC was worthy of focused attention. It was worthy, not because of the huge number of people impacted but because of the huge impact genuine intervention could have on a small number of people directly and, by extension, on the health and social service systems and society more broadly.

2.12 Complex lives: *"…we sort of think the only things they had to do all day was look after their health, which is not true."*

Participants repeatedly described that the patients they were seeing wanted to get good care and to "do right" by their baby. They described a number of real and obvious barriers stood in their way of doing that. Whether it was the many demands that came from simply trying to live in grinding poverty, the violence and precarity that defined many forms of sex work, or the chaos and violence that often accompanied a life controlled by homelessness and/or substance use, participants described how the complex lives of their patients played a major role in their not accessing care in accordance with routine expectations:

> *There's a rare person we run across that doesn't believe in PNC. It's not really about a belief. Sorry, it's not a belief that it's not something that's needed, it just isn't either an understanding of priority or there's five barriers in the way: functioning mental health, substance abuse, poverty.* (Social Service Worker)

Simply put, according to many participants, survival was seen as the priority for their patients and PNC just didn't make the cut of things that could be managed whilst trying to find a place to stay, something to eat, or drugs to put a brief end to the torturous symptoms of withdrawal or to stay awake amidst the ever-present dangers of life on the street. For those with significant mental health and/or addiction concerns, keeping track of appointments could be an overwhelming responsibility. Participants often described a lack of the usual family or social supports they would see with their "other" patients and thought this contributed significantly to client's reduced access to PNC and more generally to an ability to get organized and care for themselves or their coming child.

The laundry list of barriers to access described includes specifically poverty, homelessness, disability, incarceration, mental health and addiction concerns, violence and being trafficked. But, as one participant described quite succinctly, the individual list of barriers by patient could be generalized as manifestations of underlying social and economic forces:

> *I was trying to think of what are some of the differences, and what are the similarities…* [4] *I think the things that truly stick out as the same in all of these women is that they all have significant aspects of the social determinants of health playing some sort of role in their lives that takes precedence.* (Family Physician)

The burden of not being able to take surviving for granted mapped poorly on to an uncoordinated and unwelcoming health system as described in the following section on logistical barriers to care.

2.13 Logistical barriers: *"…you'd have to blow the system up a little bit in order to make it really, really, I don't know, inclusive."*

In describing patient barriers to care, participants primarily focused their responses on the unwieldy and immense health care and social services systems typically organized around provider needs and system efficiencies. Participants described clinic hours and locations that didn't accommodate high needs populations. Furthermore, lack of accessible childcare and transportation made the already difficult task of getting to the clinic far more trouble than it was worth, especially given the prospect of a 5–10-minute appointment. One practitioner described the way that their clinic wasn't physically accessible, which had prevented some people with disabilities from accessing their services:

> *She … had cerebral palsy and was in a wheelchair. …she also had very limited social supports and there certainly were gaps in her care in terms of being able to arrange transportation to the clinic. There always needed to be at least one person coming with her so that she could be assisted into the clinic because we didn't have the most accessible space, if at all. So, transportation was an issue. Social supports were an issue… There were a lot of complicating factors. Of course, disability and accessibility issues were huge.* (Midwife)

The constraints of an appointment and office-based model of care meant that communicating with patients who commonly had no reliable phone or internet access was next to

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[4] … denotes data has been excised for clarity or brevity
[ ] denotes I have inserted words for clarity and brevity

impossible. Importantly, often the only mechanism described by participants for re-booking missed appointments was a telephone call.

Participants also described how difficult the system was to navigate, including the basic fact that it was not obvious how one got to a PNC provider in the first place. For many, the route of entry to PNC is their family doctor; however, this population often does not have a family doctor. Participants also described waitlists for mental health services, which meant patients were long lost to follow up by the time the appointment (that they likely wouldn't make) was available:

> *Just a waiting list, like the waiting list for [program], it's never immediate. … then they may not get seen till after the baby's born [and] that might be like five or six weeks down the road. So your postpartum care is pretty important in the first 2-4 weeks, but they're saying oh no, we'll see you at 5, 6 or 7 weeks, right?* (Social Service Worker)

Fragmented and siloed care contributed to confusion for patients who had to travel between providers to get all the components of care they needed. This was most notable as it related to addiction, which was described by one care provider as a "non-managed co-morbidity" wherein people were seeing an obstetric provider for their PNC and being told to go elsewhere for their addiction management, adding to the number of appointments people were already struggling to make.[5] Conversely, it was not lost on many participants that patients struggling with substance use were frequently getting opiate replacement therapy (methadone) weekly, but not PNC. Social service workers described even greater system fragmentation, poor coordination and service duplication than those working in the health care system. This exacerbated the confusion and system weariness for this patient population, who were often enmeshed in both health and social service systems simultaneously:

> *Like, a case manager can make referrals for say stuff around employment then they go somewhere else and somebody else is giving them the same work over again and talking about the same things. So, there is a lot of overlap that I think could get streamed out more. If the agencies communicated more, especially around housing. These poor clients, their workers are changing all the time, they don't know who they are consistent with, they've got a housing worker, they've got an addiction worker, they've got an employment worker, they've got all these different people involved, but I don't find that anybody actually gets together as a group to work - like case conferencing for a client to say "okay, this is your role in Billy's case and this is what you are gonna do in Billy's case and here is how" - none of that is happening. So, for housing, for example, like they'd be assigned a housing worker. Next thing I know I'm getting a landlord letter filled out, but I don't know who the landlord is, if they've got the housing allowance and trying to get a hold of the housing worker to see if there is a housing allowance attached. Meanwhile, this landlord is gonna give the place up because he just wants money in hand*

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[5] It warrants noting here that there has been an increase in collaborative approaches since these interviews were done. This will be elaborated on in the discussion.

> *and, so, sometimes the lack of communication amongst people is detrimental for a client.* (Social Service Worker)

The unwieldiness created for patients by the lack of coordination between and among health and social services was compounded by the fact that providers themselves felt that they were unaware of the spectrum of services available to patients and how they could access them:

> *I just think [the providers] really care, and they want to get really connected, and they want to be doing well by them, but we don't have a good sense of the services in the city. I have been on the [committee] for [the service] for a while, and we refer women [to the service] all the time. We don't really know what we're referring to. I think just because people are busy, and it's hard to do it.* (Obstetrician)

Overall, participants recognized that the organization of care within and between services was not conducive to access for people with complex and competing priorities. Additionally, the system was also opaque to the providers, making it difficult for them to help their clients move through it.

I want to highlight two phases of care that presented unique and very high stakes barriers to patients: access to postpartum care and access to abortion care. Access to abortion was not raised by many participants but was described by one seasoned practitioner as exceedingly difficult to access in Hamilton. Here they describe the process of securing an abortion in the context of the story of a patient they cared for who wanted an abortion but didn't access one for the logistical barriers:

> *[Access to abortion is a] huge problem, massive barriers in place. I would have a hard time accessing it, and I have my ducks in a row. It is hard, and again, from the very first time, even just finding the number to call. Do you know it's called the Women's Clinic? Like, why would you know that necessarily? The code name for abortion clinics, so that people don't get shot. … but if you just think right to the very beginning, that is just how hard it is, finding the number, never mind calling the number, never mind getting a call back, never mind getting the bus up there, and then walking in those doors, finding the place, not having someone supportive with you a lot of the time, feeling judged, not just because of your poverty and your drug use, but because you are having an abortion. …I think that is a huge thing that should be recognized and fixed, because…when what you were wanting didn't happen … she's never going to get over that; but she's pretty strong. So, therapeutic abortions are big issue, I think.* (Family Physician)

In terms of postpartum care, providers described that, not so long ago, departure against medical advice, or AMA, immediately after the delivery for those with IPNC was the norm if their babies were being apprehended. In recent years, however, hospital-based providers noted that more postpartum patients were staying for a day or two. They attributed this change to new approaches to newborn child removal that allowed mothers and parents access to their babies in the NICU while they were in hospital, regardless of custody status. They also suggested that a less stigmatizing culture on the ward made people feel less unwelcome. Regardless, it was repeatedly noted that when patients left hospital, whether at 2 hours or 2 days postpartum, there was no clinical connection made from the hospital to the community. With the exception of midwifery services (who see their clients much earlier and more frequently in the postpartum), the discharging provider simply had nothing to offer but "come back to my office in 6 weeks", which almost never happened:

> *If they meet our discharge criteria which is if they meet the doctor's orders which is everything is normal, you just go home. It's: "see the OB in six weeks or call if you have any other concerns. Call them to get in sooner." But that's it.* (Nurse)

Like inaccessible PNC, there are myriad individual and social implications of inaccessible abortion care and postpartum care. An involuntary pregnancy and birth have far reaching consequences for a woman or non-binary person living with little to no resources or ability to care for a child. Participants comments on apprehension reflected awareness of the well described downward spiral that is precipitated by the removal of a child for reasons of extreme poverty, trauma and isolation. The lack of effort toward follow-up in the postpartum period is a missed opportunity to provide clinical care, connect people to community resources. Importantly, neglect of the postpartum period reinforces the stigmatization that inheres in a deleterious focus on the baby (who is thoroughly attended to by health and social services, once born).

2.14 Stigma and fear leading to aversion: *"calling a patient a train wreck might not be…the most appropriate thing."*

Participant descriptions of the widespread, systemic stigma, maltreatment and abuse that people endured at the hands of the health and social services systems offered incredible insight into the depth of the fear people have of accessing the helping professions. Most participants could describe specific incidences of a patient being stigmatized, and often participants would describe the ways in which their colleagues were implicated; behaving in ways that ultimately led to patients not wanting to access the system. Here a social service worker describes their experience of clients avoiding the health care system for fear of how they would be treated:

> *Over at the office and - again it's not pregnancy - but in regard to the violence or the lifestyle, I don't know how many clients came over, they'd get hit by a car; they'd be high, fall off their bike; they'd just be getting into a fight with somebody, and they need to get [healthcare]. They wouldn't go over to the hospital; they'd come over to [the office] looking for bandages because they don't wanna go – they say: "oh I go to the hospitals and all they say is I'm drug seeking… Well screw them, I not going…The last time I was there security kicked me out because I said I needed something, I wasn't drunk, but security kicked me out, I'm not supposed to go in there". So, they give up on going to any health providers at all.* (Social Service Worker)

One of the most often described barriers to accessing PNC was the client's fear of precipitating child welfare involvement:

> *For the girls that end up pregnant - especially the homeless ones that are pregnant - I find the biggest barrier is their trust with anybody … - its not that they don't want to get their PNC, but they are scared to open up and go to somebody because right away CAS is what is on all their minds. So … they've become pregnant, and most of them still have the addiction issues. If they are homeless, they don't have the housing… they know they are on the radar. They know that now they are going to be accountable for their addictions or they feel that they have to be accountable and that they are going to be judged. [It is] very hard for me to convince young homeless girls especially to go to a doctor, because many have had bad experiences and they wanted to get their stuff in order first before they went to somebody of authority that would make the call to CAS. ... unfortunately, for some of them it never ends up working out that way.* (Social Service Worker)

While the dominant narrative was focused on the barriers to trust created by the culture of stigma and a deep seeded fear of the child welfare system, some participants referenced a shifting culture relating to discrimination against PWUD, are experiencing homelessness, or who are involved with child welfare services. They stated that the environment is much more welcoming than it was earlier in their careers. Participants were unable to identify exactly what was leading to this perceived shift in culture but pointed to increased volumes of patients using drugs, and more leadership and provider education by those doing the work to care for marginalized populations:

> *I don't know what the answer is. Honestly, it might be actually a shift in the culture, the team culture, that we're a bit more accommodating now, less judgmental. We're saying, "Please don't go," and we're not saying, "Oh, you didn't have any PNC, and you're using drugs, so you should probably just go" ... I remember many a time where you'd get this call from the nursing staff to say, "What do you mean the baby's going to room in with the - the baby's going to room in with the mom? The baby's apprehended. Why would you let the mom get attached to the baby, or vice versa?" That's not the issue here.* (Social Service Worker)

In addition to the perceived shift in culture, social service participants described a legislated drive away from a practice of family separation:

> *We know that children in care, it's not the best place for them to be, we know that. So, its keeping kids out of care as much as possible and its coming from legislation.* (Social Service Worker)

> However, it's difficult to say whether patients are experiencing that shift in culture and away from family separation. When the social service workers who participated in this study were asked directly if they felt like that change in practice, toward keeping families together, searching for kin relations to parent children who couldn't be kept with their birth families and to avoid state custody was being appreciated by the client population, the answer was a pointed and succinct "no".

In the theme *describing the problem* I have recounted how participants described IPNC as a small but important phenomenon that most significantly impacts people pushed to the margins of society. Providers described the importance of intervening in the phenomenon in terms of the potential for meaningful and long-lasting impact, including interrupting the cycle of family separation. I have illustrated how the marginalization that characterizes the people who don't access PNC translates into logistical barriers to access. Notably, abortion and postpartum care were raised as phases of care that warrant particular attention. Additionally, widespread stigma meted out by–health and social services act as a powerful barrier to accessing PNC. In the section that follows I endeavour to relate to the reader how health and service providers experience the problem of IPNC.

2.2 Experiencing the problem

The theme *experiencing the problem* addresses the ways in which providers experience caring for people who do not access adequate PNC. In this theme we begin to see how the phenomenon is, broadly speaking, experienced differently by those who provide care by choice or design (outreach doctors and midwives and social service workers) than by those who provide it as a default (on-call physicians and hospital shift nurses). The subthemes of *chaotic, worrisome and frustrating, and joyful hard work* all speak to the emotional experiences of providing care that in many instances, moves quite far away from routine. Under the subthemes of *challenges of the population, constrained by the broader health system, constrained by funding models* and *can't treat SDoH,* I consider what health and service providers see as barriers to making care more accessible, either for themselves, as a group/practice or as a health care system.

2.21 Chaotic: *"30 weeks of PNC care in an hour."*

The reassurance of the stepwise and prescribed nature of PNC was seen as being disrupted by patients who were unable to follow the usual regimen of care. For many participants, this created a marked sense of chaos, uncertainty, and worry. The nature of the provider experience seemed to depend in part on whether participants provided care to those not accessing it deliberately and by choice, or by default, as the on-call provider or nursing staff responsible for caring for all comers during their time limited shift.

The adjective of "chaotic" was most often used to describe the intrapartum and postpartum care provided by nursing staff and on call obstetric and pediatric providers, who had very time-limited interactions with adult patients during periods of heightened tension. Intrapartum care providers described relatively infrequent but entirely unforgettable patients arriving with no care, intoxicated, incapable of or unwilling to communicate and/or cooperate, in labour, with no records or information. They described having to make complicated decisions about things like consent, chemical restraints and appropriate obstetric interventions in very short and urgent periods of time:

> *I mean to be honest it's just sometimes so chaotic, if someone has an active substance abuse disorder and they are withdrawing while they are in labour and their pain receptors are just so saturated with so many different things and sensitized, it can be just chaotic. They often come in yelling, crying, hectic or sometimes there is a complication.*

> *So, they are coming in and they are in precipitous labour, or they are abrupting. It can sometimes feel very chaotic in the moment for a number of reasons.* (Family Physician)

Some participants described not having the time to address complicated phenomenon, about which they knew admittedly little, in the confines of short scheduled visits or precipitating events on labour and delivery wards. A lack of expertise was most often described in the fields of mental health and addiction or in de-escalation skills and trauma informed care:

> *That's what I was saying about the crystal meth user who left against medical advice before she was seen with anyone, linked with anyone, before we could do anything for her as somebody who needed health care and needed help. But it's also well beyond sort of our comfort zone, scope, wheelhouse, to have to deal with that.* (Obstetrician)

The chaos of providing care in fast moving, sometimes volatile situations with a lack of expertise paralleled and compounded the worry and frustration that was often described as a part of providing care that strayed so far from routine.

2.22 Worrisome and frustrating: "…*there's no security blanket here."*

For those working in "calmer", more structured clinic or ward settings, the uncertainty that inheres in caring for those who haven't had routine investigations that inform management and intervention sometimes meant worry for themselves as providers being potentially implicated in a bad outcome. More often the worry was for the wellbeing of the client, particularly in the absence of the usual routine follow up, which care providers used as an opportunity to ensure their prescribed investigations and interventions "worked". The emotion most commonly associated with providing this type of care was worry:

> *I think it's underestimated or not talked about enough in healthcare about the way that we worry about our clients.* (Midwife)

Participants described worry that kept them up at night and wondering what they did right, what they did wrong and what else they could have done - worry that left them wondering would their patient sustain a terrible outcome or even survive. For providers regularly engaged in the work to increase access, that worry could also be generative:

> *And I think part of the worrying is helpful because I find if I'm worrying about something all the time or thinking about the same problem all the time, then I'm like oh, well that obviously is something we need to do differently. And so, I think all of my good ideas, when I think about the ideas that I've had that I think are good ones, they've usually come out of a recurrent problem or something like the [program] for example, it's like why are all these people dying? And that distress over like all these young people dying produces this kind of interest or idea to do something differently.* (Family Physician)

Many participants described feeling a loss of control over their portion of the care arrangement and worrying that they were missing or were going to "miss something" without the security of routine investigations and prenatal teaching provided in standard PNC:

> *I do feel … there's no security blanket here. … occasionally we'll see soft markers for things: low set ears, large tongue, stuff like this that we're like: "Well, everything looked fine on ultrasound. - oh, her risk is low." We just don't know any of that with patients who have had no PNC.* (Nurse)

Not having routine and indicated prenatal investigations completed antenatally whilst providing care meant that providers frequently described themselves as doing detective work, trying to piece together disparate, or limited records from walk in clinics, emergency rooms and providers in other jurisdictions. This led to feelings of worry about missing things, described here by a nurse working in a ward setting:

> *They come up to [ward], even within that hour [of delivery]. I always find I'm constantly worried that something was missed. So… remember, you have all your other patients, and you have this patient. So, you have to really go through their chart and what you have so far. Normally if we have prenatal records, you can quickly fan through and know it's all there. … So, did the residents order all the proper tests? I have to back track sometimes to make sure it was done. So, you are worried that things are being missed before your timeframe and then everyone expects you to find out why they didn't get PNC.* (Nurse)

The overall uncertainty created by a lack of routine care had different implications for different providers, with a range of neutral to negative consequences for the patients. For pediatricians, there was an added layer of distress in having to provide prophylaxis for the baby, for Hep B or HIV for example, simply because of an absence of the maternal records that would regularly inform management. In some circumstances, this same uncertainty could precipitate family separation because child protection services didn't have the opportunity or information to assess risks to the child:

> *Whereas our kind of mind frame is if we can do that preplanning with them, it's kind of better outcomes for everyone, because if we know what's going on, we can at least plan for that as opposed to the woman showing up at the hospital, giving birth and then; unfortunately that results in probably more apprehensions, because we don't have any of that preplanning, we don't have any information, we can't take the risk.* (Social Service Worker)

Here we see laid quite bare the potential implications of IPNC, wherein a lack of information and ability or time to plan can precipitate a life changing/ruining event for a family. It is notoriously difficult to come back from an apprehension. Re-establishing custody demands extraordinary efforts and actions of a family that the most stable and secure of us would struggle to accomplish in the weeks following the delivery of a baby.

In addition to worry and uncertainty, providers also described frustration elicited by providing this type of care. Some providers directed their frustration at the patients, while others were frustrated with their own inability to access or provide what they viewed as the necessary supports and resources to truly impact the health and wellbeing of the person in front of them. Perhaps not surprisingly, the frustration directed at patients generally arose among those who provided care to those receiving IPNC by dint of their position, i.e., those who had not deliberately chosen to work with people deprived of means and resources by economic and social systems. In this passage, a nurse dedicated to providing accessible care describes some of her colleagues:

> *I think about the nurses that my students interact with in the emergency department for instance, and their feelings of frustration with many no fixed abode persons that come in with an overdose, and just the hardenedness that …can happen caring for - and just giving so much of yourself in that process again and again, and not really seeing any results. I think similar to that, some of the nurses that I work with, and I would say unfortunately … the culture is [such that] a person like the [difficult] individual that I cared for would not be a call bell somebody would want as their [patient].* (Nurse)

For those with more experience and understanding of the systemic barriers and shortcomings that prevented people from succeeding or overcoming IPNC, the frustration was almost always directed at the lack of resources and opportunities for people:

> *Some days it's hard … because as a mom myself, you know, in this line of work you can't be judgmental with stuff, but it is hard when you see a girl that's ready to give birth any day and you see her banging the needle in her arm around the corner…Even more frustrating … is when you do get a woman - like come in for your help and everything - and then there is nothing to give to her. There is no encouragement to give to her out there - like for housing - there is no emergency housing anymore to help a woman that's ready to have a baby and she doesn't know where she's going.* (Social Service Worker)

This type of insight into patient's lives and the limits of what was available to them helped providers extend sympathy and understanding to the ways that people engaged or didn't engage in PNC. This often translated into anger and frustration with other providers stigmatizing and judging their patients:

> *I do really feel just anger when I hear someone else speaking about these patients as if they do not care about their babies. You know: "why would she do that, why would she?" …I know it's all ignorance, it is all profound ignorance, but I just think: if you just had one iota of an idea of what these women go through, what many of them have gone through from the time they were being molested by their stepfather at age 4 or whatever. That [judgment] really bothers me.* (Family Physician)

This frustration and disjoint from colleagues will be discussed again under barriers to providing care, where people describe the limitations to providing high quality care engendered by a lack of shared approaches to care.

2.23 *Joyful hard work: "In addition to the stress and the worry and all of that, I find it very joyful and meaningful work."*

Whether measured in hours, effort or emotions, providing less care almost always meant more labour. Participants described the extra hours of liaising with other service and care providers, the transit time for out of office visits and the prolonged visits to address both the inevitable complexities of care, and the amount of "catch up" that needed to be done when patients did eventually present for care. Many participants commented that there was no acknowledgement of this extra work in the remuneration they received for doing it:

> *It felt really great that our model can accommodate for that kind of care. If she hadn't connected with us at any point in her pregnancy she would have showed up in labour with no prior care. So, I love that the model of midwifery care allows for that. I don't love that it doesn't compensate for that extra care provision.* (Midwife)

Either directly or indirectly, participants spoke of the work as difficult because of the vicarious trauma with which they contended. Providers described excruciating stories of the lives of the patients they served and the injustice they had borne witness to because of it. Participants movingly described their patients' life stories and experiences in the healthcare system as impactful, sad and heartbreaking. The high rates of bad outcomes tended to take a toll on providers who did this work regularly:

> *… it's like emotionally like I'm not sure, you know, it's just like almost traumatizing in some ways, right? Because you're watching people so sad and so upset and, you know, it's hard to watch it and be a part of it.* (Social Service Worker)

The corollary to the trauma however was the joy. Despite the anxiety, frustration, distress and extra work that came with caring for those who hadn't accessed care, providers who actively chose to do this work usually remarked on finding immense joy and meaning in it:

> *…it is fun work, I have to say. That's the one thing I would say, it's chaotic but it's extraordinarily like purposeful. You know, it's like it's good work that you enjoy doing and the patients are always, like they're just great, super resilient and funny. Yeah, it's very enjoyable. I'd say like I would really, really miss it if I wasn't doing it.* (Family Physician)

The joy and satisfaction that participants described primarily as the privilege of forming relationships and being a part of occasional "good outcomes" was borne of a perspective that pulled back a bit from the frustration of the day to day and harkened to the reasons many people became care providers in the first place:

> *Then, there's times where it's actually really, really rewarding, and it's really - it feels like you're forming connections, and you're really actually making a difference in people's lives. Kind of the things that you go into, family medicine, or just the healthcare profession in general to help people, you truly feel like this is a patient population where you have the greatest opportunity to make that impact and make that difference. Sometimes it really does work out in the positive, and we're able to help families be together. There are times where it is quite rewarding and feels like you're doing the job that you set out when you were applying to medical school, and doing your interviews, and telling everybody why you were doing this. It really does feel like you're able to do that in some ways.* (Family Physician)

In sum, all participants described the work as harrowing and difficult, while many found great joy and satisfaction in the relationships they built and the impact they could have on the lives of their patients. Rooted in both their experiences of the phenomenon as chaotic and worrisome, but also joyful and impactful, I explored with providers what barriers they faced in providing accessible care. I wanted to know what providers felt prevented them as individuals and the organizations they belonged to from moving to a practice or system that provided the better access to care everyone agreed was needed. Below, I describe the ways in which the patient and system characteristics make providing accessible care a seemingly insurmountable challenge.

2.24 Challenges of the population: *"You want this person to get what they need, and you want to help them as much as possible but it's not what you're necessarily typically doing or wanting to do all the time."*

In the eyes of some participants, the complex lives of patients that made it difficult for them to access care also made them difficult to care for. Some participants remarked that clients who don't access care have a lower baseline health literacy, which is compounded by not having had all the health teaching that is woven into PNC, making care more complicated and time consuming to provide. Further, the fear and distrust on the part of the patients was described as being difficult for providers to navigate and to not take personally:

> *It might just be lack of engagement, being very flat not engaging with you as a provider. It can be distress, whether that's intolerance to pain, intolerance to even their IV, ... it almost seems like they don't want you there. So, it can be manifested that way. You are trying to engage, "Do you know what you're having?" and it's like one word answer, okay. Sometimes you almost want to stay in the room a little bit longer so you can build a bit of rapport and sometimes that's not what they need. I find that challenging because …one of the things that drew me to obstetrics is it's a pretty cool time for someone. So, to feel like that experience is not one that they really want you all that involved or engaged in can be challenging.* (Family Physician)

While several participants did comment on the characteristics of the patient population that made providing care a challenge, most of the barriers providers described to delivering high quality accessible PNC focused on provider and systems characteristics.

2.25 Low morale and high volume in a stigmatizing system: *"We're exhausted though. We work hard and we are undercompensated."*

At the individual level, providers described their own lack of clinical expertise in providing care to this complex and high-risk population. Further, the lack of knowledge about community resources and time to learn about them, left some participants feeling poorly equipped to serve extremely marginalized patients. More often though, providers described their individual inability to provide accessible care as grounded in and constrained by the operating of the broader health care system. They described their existing workloads as oppressive and prohibitive to taking on patients they couldn't see well in the very small window of time allotted to each visit in their current model:

> *…even just from a strictly patient volume, patient clinic visit, how you get those people in and I don't know how you can build your practice to accommodate that, those appointments, are not 10-minute appointments. So, when I look at my PNC days, there are some days I have 27 patients in an afternoon, not over the day, in an afternoon. How do you meet those needs?* (Obstetrician)

Participants described a perpetual feeling of being overworked that was compounded by the current culture in health care in general. Some participants described morale in the system broadly as low, leaving little emotional room for taking on the difficult work of providing care to patients who are not "the nice, normal, easy":

> *I think there's cuts everywhere and so whether its nursing cutbacks, or whether its different supplies that we have to use because they're cheaper; I think we all feel that. I feel everybody's trying, like they're trying to get as much as they can out of every single person. They are squeezing them as much as they can, and they are doing the same to us and as to you and as to nursing. I feel like yes, and it has definitely elevated everybody's stress level…I think people are unhappier; I think people don't want to be at work anymore; and that for sure impacts patient care.* (Obstetrician)

The same participant went on to describe how being human, and providing high volume care in this climate of austerity impacts patient care, specifically the care of those receiving IPNC:

> *I also realize that I have 5 minutes per patient; and that's the problem, but if someone's in the middle of telling me something, I obviously wont cut them off, but I try and get them to access; like I call social work and have them come and see them and try and get them to come next time with a family member or a friend or someone else, but you know, I also have my bad days where I'm busy and I'm tired and I'm grumpy and I got in a fight with my kids this morning. There are all those factors too. On a good day, I feel like I do take the time and I try and help them in any way I can, but on a bad day, no. I say, "ok, well I'll see you next visit.* (Obstetrician)

The high volume, low morale and/or burnout described in the passages above limited the ways in which individual care providers would or could take the time needed to meet the more complex care needs of marginalized populations. In addition, some providers described a culture of stigmatizing this patient population as a barrier to providing high quality accessible care. That is to say that providers who were desirous of providing better care and had the energy to try were prevented from doing so, in part, because they were swimming in an inhospitable milieu, where challenging the dominant narrative of stigma had a minimal impact on the overall patient experience. One nurse described it this way:

> *I mean we say nursing is autonomous, but there's limits to that, and we're often executing orders that have been written for us and following protocols that are medical directives. While we have some ability to do things our way, a lot of what we would be asking for and requesting of in a situation with a patient who had no PNC would be determined for us by somebody else. I think that's just hard. It's hard to enact your own values and your own way of doing things when they might have had just a really negative experience with a pediatrician right before you walk in, or somebody else, or the OB. Then, any progress you feel like you've made kind of takes 10 steps back.* (Nurse)

For this participant, the lack of control over patient care led to feelings of resignation with the status quo of a stigmatizing system and a commitment to doing her best by not adding to the harms it produced:

> *I guess I feel like my ability to do good, or change, or impact is much less, maybe not even there at all. I guess I view my role as more to be atraumatic*. (Nurse)

It is worth considering the differing responses that individual providers have to the broad constraints of the health care system, whether that be to the system wide culture of stigmatization or to the pressures to see high volumes of patients in a short time. In some cases, the result was burnout out type resignation to the dysfunction of the system and implicating oneself in the same, as described by the physician who says: “see you next week”. In other instances, like those described by the nurse above, the response is to drum up the extraordinary resolve it requires to continuously work against the stigmatizing or demoralizing grain.

While many participants had seemingly resigned themselves to the high volume, stigmatizing status quo, others described a desire to challenge this dominant culture. They were reluctant however, because they felt it could result in professional alienation and isolation and sometimes even unemployment:

> *So, if I'm the midwife who is coming in and challenging the nurses, “hey it's not okay for you to be criticizing this person who is on OW [Ontario Works] and having their sixth baby; your job is to provide them care”. Well now I'm the asshole.* (Midwife)

Many providers recognized the limits to what they could do within existing services, articulating a need for innovative models to increase access and improve outcomes. At the same time, most, even those in positions of leadership, felt unable or powerless to enact the change they knew was needed. In addition to stigma, austerity and patient loads, participants described the way in which funding models prevented or disincentivized the collaboration necessary for increasing access to care.

2.26 Constrained by funding models: *"The truth is really the structure by which we provide maternity care needs to be turned upside down."*

All PNC providers described the very real ways in which disparate disciplinary funding models (course of care, salaried and fee for service)[6] disincentivized and/or prohibited the provision of high-quality care. For midwives, this was most evident in the limitations created by a course of care model, summarized here by one participant:

> *I have had lots of concerns in the past about those times when I've had to go above and beyond what we consider to be typical care, whether it's doing lots and lots of extra home visits or going to the ER with someone who is having an early miscarriage because they have no one else to go with and there is mental health concerns and someone is really distressed—I struggle with this idea of I really want to go and be with this person, its two in the morning and this is someone who I can't even bill for.* (Midwife)

For obstetricians, the fee for service model demanded high volumes to bring in enough revenue to cover not only their own remuneration, but that of their staff and all the overhead expenses that came with operating a practice. This meant that the demands of providing comprehensive routine care often cannot be attended to; let alone the complexities of providing care to extremely marginalized people:

> *Then how many obstetricians do you think do a postpartum depression screen at their postpartum visit? Almost none. If the patient falls apart, then there is recognition. But a true screen, a check in about all those things? Because again, they've got 10 minutes and you're paid $33.* (Obstetrician)

In addition to the many ways in which funding models disincentivized comprehensive care, participants often raised that funding was in short supply, period. Many participants noted that they were trying to or needed to provide care that was already difficult to provide in the context of austerity and system strain. Some commented that levers that used to be easy to pull to accommodate someone with high needs were getting harder to move:

> *I saw a patient yesterday: 36 weeks pregnant, refugee, came with refugee status. Last ultrasound was 16 weeks, that's the only ultrasound she had, in Africa, and they refused to scan her. So, I literally wrote that on the requisition and then sent it off to one of our community partners. They're seeing her in a week, which still is a big sort of time lag. She's only 36 weeks so I think we're okay, but it's clear that the health care system, we're going to struggle to meet the needs of that population more so coming up.* (Nurse)

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[6] As described in the introduction, three funding models dominate the maternity care landscape in Hamilton. Midwives are paid per course of care, which means they bill once at the six-week discharge of the parent-baby-dyad for the entirety of the care provided in the prenatal, intrapartum and postpartum period. Obstetricians work in a fee for service model, per visit, per intervention and per delivery (higher fee for c/s than vaginal delivery) and receive an on-call fee for their shifts in hospital. Family physicians doing deliveries in the city work on a salaried model and are paid for their on-call shifts on labour and delivery.

Only one participant spoke about how women's programs specifically suffer from a dearth of funding:

> *Well, no, I mean, but they are happy to have the baby walls and use it as a foundation fundraiser and use it for how they'll obtain money but then the money isn't redirected back to here.* (Obstetrician)

The funding models were described as barriers for clinicians to provide accessible care within their own disciplines, but also as prohibitive to the kind of intra-professional collaboration that participants felt was needed to facilitate patient-centred care broadly and specifically for people whose needs were poorly met by the existing system. This meant, for example, that midwifery course of care models do not work well with obstetrician or family physician fee for service models. Efforts to marry the two models to provide comprehensive, collaborative care would result in "double dipping": two providers being paid for the "same" care to one person. That, or one of the providers not being paid at all. In the case of midwives, the model demands a full course of care be provided before being paid. In the case of the OB, there are limits to the number of consults that can be paid to a provider for a single person per clinical issue. One participant summed all of this up quite succinctly:

> *There currently exists no incentive to create sustainable models to be able to provide interdisciplinary and interprofessional care to optimize the patient journey, really from conception to delivery to postpartum to the early years.* (Obstetrician)

In addition to questions of remuneration, participants were also mindful of the ways in which the various scopes of practice and skill sets across disciplines presented challenges to both care provision and collaboration. According to some participants, the funding and scope prohibitions reinforced a tendency for silos in health care. While the midwifery model of care was often described as most well suited to providing patient-centred care that met people, literally, where they were at it, was not lost on anyone that many of the patients who struggle to access care to this degree are often not "healthy and normal". Despite its suitable model, the midwifery scope of practice was seen as an impediment to integrated programming that could increase access to care:

> *… this came up a few times when we in the past have talked about … models that incorporated midwifery and family medicine care together. Some of what has come up as concerns for my group is around scope: how do you have a model where you're providing seamless care that respects people's scopes and comfort levels? I think in some ways you can make it happen. The labour and delivery piece is where it gets, I think, the most complicated in the intrapartum period. Whereas the antenatal [period] very little of that stuff is actually of an urgent nature. You have the opportunity to do some collaborative appointments or some consultation and passing off of who sees the patient when, and that sort of thing. Whereas, the intrapartum piece, I think, would*

> *require a little bit more creative thinking about how do you make that work, just respectful of scope too?* (Family Physician)

In reflecting on why people struggle to access PNC, participants described the various ways in which the complex lives of people who do not access APNC were incompatible with the current provider-centred model of health care provision. This incompatibility was compounded by profound discrimination against marginalized people at the hands of the health and service providers, which served to not only reinforce fear and system aversion, but impeded willing providers from making care more accessible. Further, participants described multiple ways in which remuneration models and scope of practice limited providers ability to systematically increase access to care. It was repeatedly acknowledged by participants that the unwelcomeness of this population in the health care system was related to being adversely affected by complex social and structural factors that determined their health – commonly referred to as the SDoH.

2.27 Can't treat SDoH: *"The primary issue today is not asthma."*

The final subtheme under the heading of *experiencing the problem* reflects that many participants knew that what their clients really needed was outside of the realm of clinical care:

> *This is the other part. Yeah. If you open up that there is no money. We just had a kid admitted with asthma exacerbation, three-person family sleeping in one room with no money for puffers, primary care I think is through [clinic] but not consistent and a language barrier (which luckily Arabic is spoken by many folks around here) but this isn't—the primary issue today is not asthma.* (Pediatrician)

Participants repeatedly described the ways in which the SDoH impacted their patient's health. Then they often went on to describe by the limits of their knowledge as health care providers about what to do about it, leaving them unable to address what they knew to be the root cause of the disparity in access and health status in question. To the extent that they did comment on what they should/could do about it, health care providers primarily focused on referrals to social services as a route to decreasing the material deprivation they knew was so impacting their client's health, such that their inability to "treat" the SDoH was framed as a lack of knowledge about the proper community resources:

> *Like I have no idea who to call to see if I can get my patient on the list, for example, for housing. I don't know them very well, like they wouldn't know who I was and whatever. So I think those sorts of things. I think within health care, we form these little connections, but you don't necessarily form connections with the social services that are going to actually influence the care of your patients, probably more than being able to get them in with the cardiologist. Do you know? It's like all those sorts of things, so I think it's just a lack of knowledge, a lack of personal awareness of those things.* (Family Physician)

The inability to "treat" SDoH describes the conundrum presented to care providers by the non-clinical nature of the lack of resources to promote and maintain health that characterize the patient population who struggle to access PNC. Despite acknowledging the primacy of these material concerns, providers rarely had measures in place to remedy them.

The theme of *experiencing the problem* elucidated what it was like to provide care in a system not designed to meet the needs of the patients most at risk of adverse clinical and social outcomes. Providers described the experiences as chaotic and emotionally taxing. Some found great joy and fulfillment in building relationships and caring for people not centred in the current system. To the extent that participants had tried to make moves to increase access to care, they had all, in one way or another run up against the constraints and limits of the system. Regardless of their desire to do better or different, they felt hemmed in by both the stigmatizing of their patients that pervades the health care system and funding parameters that incentivized and reinforced siloed and provider-centred models of care. Finally, having recognized that the barriers to care were rooted in SDoH, participants admitted that there was little remedy for them within the health system. In the next theme *conceptualizing the problem* I examine the ways in which providers talk through the issues of power and privilege that undergird the SDoH to conceptualize their role and the role of their patients vis a vis access to care.

2.3 Conceptualizing the problem

The primary aim of this work was to gather provider input and insight into what is needed to increase access to PNC for those not currently accessing it; however, as the interviews progressed, I also became very interested in what assumptions study participants brought to their understanding and assessments of barriers and access to care. Here I try to surface their presumptions about themselves, their patients and the role of health and social service systems in addressing the phenomenon of IPNC. I have divided these outlooks on access to care into three somewhat distinct subthemes: *getting care as a responsibility of the individual, providing care as a responsibility to the individual* and *justice.*

2.31 Getting care as a responsibility *of* the individual patient: "*you are the owner of your life*"

Generally speaking, those providing care to all comers in office or hospital-based settings were more likely to ascribe the responsibility for getting care to the patient. While all three conceptualizations of access described in this theme made some acknowledgement of the extraordinary difficulties that people faced in their lives, for participants who saw getting care as an individual responsibility, the take home message was that patients really needed to try harder to overcome those difficulties. Accessing PNC and changing your life were averred as a matter of choice, even if they were difficult choices to make and follow through on.

The most straight forward declaration of this mind over matter kind of thinking around access came from an obstetrician who gave the following response when asked if they liked providing this "kind" of care:

> *I do and I don't. It's interesting. I do and I don't because … I realize that we got them to this point and there are so many factors in it, but I feel also …that they have access to all these things. They have access to so many opportunities here that other people [internationally] are not given. I have to say - I don't love it - I don't. I think it's important; I think people do need to access it, but I think if maybe I worked with them enough, I would feel better about it. Sometimes it's frustrating, sometimes you say, "these are your resources, this is what you can do, you are given all these options", like do something to make yourself better. At some point, yes you can say all these things that got you to this point, but at some point you have to take ownership of your life. In that way, I'm not as sympathetic. Because there are other people that have nothing and you help them a little bit and they change their life. So, I feel like we are given so many opportunities in Canada and you are born in this country and you are lucky to be born in this country, so make use of the resources you have and people are trying to help you. You see it over and over again, where we also have patients that they've seen social work, they've helped them, they've brought them into the programs, they help them with their depression, and it doesn't work, and it doesn't help and there's again, things that I don't understand about that, but at the same time, I think you are the owner of your own life.* (Obstetrician)

In this quote we see, of all the externally driven things that might account in some way for the difficulties patients face in accessing care, decontextualized will power and initiative are seen as the most significant driver of someone's circumstance. Many things are presumed in this passage. Notably for me, however, is the suggestion that people haven't tried to "make themselves better". Importantly, it is also assumed that the resources (about which most providers admittedly knew very little) work if/when accessed. Lastly, the notion that "people are trying to help you" is contradicted by most of the participant responses in this study which point to overwhelming stigma in the system, to such an extent that people are driven away from seeking care. This is not to say that no one in health or social service systems are ever "helpful", but there is no recognition in this passage of what it would take to allow yourself to be helped by people in a system that have repeatedly not been helpful, and often caused harm.

An interesting expression of this notion of the client's individual responsibility for the outcome of their interactions with health and social services came from a social service worker, in describing the onus for a child's safety as one that belonged squarely to the family:

> *There is at the end of the day; we've done all we can… you know, you've done all that we can do to keep…as long as we've done all the planning that we think we could do and if the family does follow this, then the child will be safe. Ultimately, it's up to the family.* (Social Service Worker)

Importantly here the question of: "How does one keep their children safe in such an unsafe world?' is neither asked nor answered. Most of those who viewed access to care as an individual responsibility did so in ways that were not as blunt as the previous participants' comments. Instead, many participants provided contextualized explanations for their understanding and practices around access, acknowledging the difficulties patients face in their daily lives. Here a family physician working in an office-based practice described their views and the views of some of their colleagues about the responsibility that patients do or don't have:

> *It's somewhere probably in the middle, because I think that there's that balance of at what point do you have to say - especially as a family doctor, do I have to say, I have 1200 patients in my practice, I can't - it's not fair of me to neglect the 1199 for the one. I do have to find some sort of balance too, at which point I cannot be working harder than the patient is trying… but remaining open to if they - keeping the door open for them, and if they choose to re-engage, that I'm willing to do the extra work that it might take, or the extra steps to go above and beyond for them. (Family Physician)*

All of the participant framings that were some variation of "you can't work harder than the patient" served to ascribe ultimate responsibility not to the systems they worked in or to themselves as providers of a service, but to patients as consumers of service. So often, as above, access was framed within the parameters of choice. This fascinating passage below reveals so much about the ways in which the difficulties patients face in accessing care can be at once acknowledged and disregarded:

> *Then, I think doing family medicine or as long as I've done it now, I do appreciate - and I do teach this to our learners, that you do have to at some point reach a boundary of you can't be working harder than the patient is, in the sense that you can't allow the patients choice - whether it's choice or not, and in some scenarios like this it may not be choice, it might just be the way things are for them, and they feel like they have no ability to change that, but you can't allow the patient's actions or inactions to impact how you feel about yourself as a care provider.* (Family Physician)

The patient's inability to access service is here framed as their "feeling" about their own "ability to change things". The framing of the difficulties around the patient's *feelings* directs attention (and presumably intervention) very differently than a framing that focuses on a material reality that gives rise to an inability to *choose* differently. In the former orientation we become preoccupied with the patient, and how we could alter their feelings about their ability to change, so that they might then change. In the latter framing, we are directed to think about and alter the material circumstances as the root of the problem of access. Further, without endorsing that a provider should feel good or bad about IPNC, I ask myself, why is the patient, instead of the model of care that doesn't meet the patient's needs, the frame of reference for the providers feelings about themself? Here again we see a rhetorical turn that deflects from both the material reality of patient lives and the inaccessibility of services to the patient's own "actions or inactions". This time the deflection appears to be in the service of preserving the provider's feelings about themself as a health care professional.

If the viewpoint is that the individual is responsible for getting care and making something of their life, then they are, by definition, *irresponsible* for not getting it or for whatever prevented them from getting it. The upshot of this orientation toward individual responsibility is that one is logically therefore *responsible* for the consequences of not getting care. The stigma and discrimination that participants described as permeating the health care system, stemmed, in part, from a belief on the part of care providers that patients had "done this to themselves" and therefore were deserving of the disdain and suffering:

> *A lot of times - we are healthcare providers, we're supposed to be compassionate, and we're supposed to be treating people with respect regardless - but you see people rolling their eyes like "why is she asking if the baby's okay when she did this to the baby?"* (Obstetrician)

For those who understood accessing care as an individual responsibility the importance of the SDoH were subordinated to the importance of individual initiative on the part of the patient. Ultimately, in discussing their own role in the care pathway, providers who espoused an attitudinal approach of "getting care as an individual responsibility" expressed that there were limits to what they could do to support people into care (within the confines of their model, which they didn't argue for moving beyond). The ramification of the individualization of access was that the onus to get care was on the patient and that they were thus responsible, for better or for worse, for the outcome of their own efforts, failures and successes.

2.32 Providing care as responsibility *to* the individual patient: "*can I do a good job here; can I get her on board?*"

Those who had deliberately taken up providing more accessible care to people on the margins were the most likely to see themselves, if not the system, as having a responsibility to provide care outside of the box. While care and service providers who viewed the onus for accessing care as belonging to the individual, those who viewed it as their responsibility or that of systems saw it as needing to act on or accommodate the individual:

> *So, there is some excitement there too at the idea that this is a chance, like we are in a golden opportunity here, to help someone the most because that's what's exciting about providing this care for women who are pregnant is because it can be a time in their life when they are more motivated than any other time to get help for things because they are doing it for two people instead of just one. So, there is excitement - okay, can I do a good job here; can I get her on board? ... and bringing in the other people that are necessary for that, like the street outreach workers, how much can I get, and every time I see her, just how much can I do right now. What can I, push her?* (Family Physician)

This provider, like most in the study, connected issues of health and access inequities to the SDoH, and goes on to describe how the health and social services systems should and could facilitate the needed change in individual patients, to overcome their socially determined circumstances. This individual change/improvement was to be accomplished, as described in detail below under the theme of *Addressing the problem*, by service delivery reform and better referral pathways to social services to address on a case-by-case basis the SDoH, implicitly conceived of as an attribute of the individual in question.

In this passage, a healthcare provider laments that we can't facilitate the needed change earlier in life, before things become irremediable:

> *You can't judge people for the situation they are in. Sometimes its poor decisions, but sometime there's so many other factors that we have no control over, or they have no control over. I think the problem is how to address those issues early on in life to try and help prevent them from getting to that point. It's really hard.* (Obstetrician)

Here we see how the provider acknowledges that (when they are not the result of poor decisions) people's situations can be driven by factors outside of their individual control. Yet the locus of intervention, instead of what gave rise to those factors, or even the factors themselves, remains the individual. Further, when they state that we have no control over these factors, not as a matter of opinion, but as a matter of fact, this provider hints at a widely implied belief among participants that the factors that drive the difficulties in their patients' lives are immutable.

Clinical practice by definition happens at the level of the individual and so it is expected that participants would describe individual level interventions to address the impacts of the SDoH on the health of their patients. What is notable to me, however, was how this provision of care aimed at individual level mitigation of the SDoH was the ceiling and not the floor. Very few participants articulated the need, much less ideas about how to intervene in systems of power to address the SDoH at a societal level, so that people in general "don't get to that point". To the extent that most spoke of the need to act on systems of power instead of individuals as a more effective means of increasing access, doing so was always subordinated to the organization and provision of one-on-one patient care:

> *I think if we truly as clinicians want to make a difference in someone's heath, that's probably a far more significant thing for us to advocate for on a more public health level. I think it's just hard, because - while I say that, I think it's hard for even me to engage in some of that because you think about - it comes back to that time. The balance of, yes, while I think it's important for me to do that, it's also important for me to take care of the 1200 people I have and do a good job at all of my leadership roles, and be a good educator, and be a person who has a life outside of work. How do you find the time and the space to do that? It's not an easy ask of the clinicians.* (Family Physician)

This refrain of not having the knowledge, time or capacity to address the SDoH outside of clinical care was common among those participants who wanted to address the primacy of the SDoH without conceptualizing them as attributes of individuals. Participants frequently retreated into the constraints place on them by the demands of their clinical practice when trying to explain why they acknowledged but didn't address the admittedly paramount SDoH. Ultimately, this self and system recusation from addressing the SDoH served to entrench in practice an ideological commitment to individualizing them that characterizes this subtheme.

The language used by most providers in describing the responsibilities for access as either one *of* the patient or one *to* (change) the patient, revealed conceptions of the problem as firmly rooted at the level of the individual. Rarely, participants accounted for the broader power dynamics and social systems and located themselves and their clients within them to speak about their understanding of access to care and why they worked to increase it.

2.33 Justice*: "this is an equity issue and a social justice issue and not just a health care issue."*

As much as care providers broadly conceived of the patient in individualized terms, they also, conceived of the problem of IPNC and their potential to intervene therein in terms of themselves as individual providers, and thus often felt powerless to change things for themselves or their patients. Here one midwife proposes a counter-narrative to that of powerlessness as it relates specifically to physicians:

> *You have to believe that those changes are actually possible, and they are. If you got 100,000 physicians in Ontario to stand up and say:" enough, we're not going to let everyone who is homeless on the streets of Toronto die this winter, we're just not." That does something. But people aren't doing it and I don't't' know why because I believe that doctors care. I genuinely give them the benefit of the doubt and I believe the most doctors care very much about these things; but I think everyone feels that impotent. I think they don't know what to do. They feel stuck and I don't understand why we can't be at a level now, of saying no, no, you actually can do something, and you occupy such a position of power in our society that I feel that you are compelled to do something. That's me being a little bit moralistic but do something with your social capital.* (Midwife)

Where many participants spoke to the impossibility of change outside of the context of changing the patient, in this passage the midwife implores health providers to reflect on their relative position of privilege and imagine ways to use that to systemically address the origins of health inequities. They tap into notions of powerless that wend throughout many participant responses and call on us to reckon with that. They further implore us to not shy away from these questions of power (here described as the structural determinants of health) as it relates to providing care:

> *Not just what we now classically understand as being a social determinant of health but what are the structural determinants as well. These are like big, big issues and big conversations to be had but it doesn't mean the conversations can't happen and I think that to bring these ideas into how we provide care in our community is the only way*

> *forward. That you have to kind of call things out for what they are. There might not be easy solutions, but I think just having that conversation is so important.* (Midwife)

Importantly, the midwives who provided fodder for this theme highlighted that incorporating an analysis of the SDoH into our clinical work is not a question of either/or. Here we see what an orientation of individualized access to mitigate the impacts of SDoH as the floor and not the ceiling of care provision looks like conceptually:

> *I just think this world is really messed up and the health care system is really messed up and is influenced by patriarchy and capitalism and all those gross things and people like we talked about don't access care in the same way that many people do, it's not an individual issue. It's a social power system at play that is preventing them from being able to access care in particular ways and they deserve care. So, I feel that it's just the right thing to do. It's just the only thing to do, I think, that feels right and consistent with my political analysis.* (Midwife)

For this midwife, recognizing the primacy of systems of power (not deficiencies or choices of individuals) and the impact they have on her client's lives was the impetus for providing accessible care. An orientation toward justice meant that to recognize societal inequities necessitated providing care that mitigated them, all the while acknowledging that the wider "social power system" is what is at issue.

With some exceptions to be found within the uncommon social justice orientation, I suggest that the underlying assumptions revealed through participants descriptions of access could broadly be categorized into the ones that put the onus either on the patient (getting care as a responsibility of the individual) or on the system (providing care as a responsibility to the individual). In both instances the SDoH are implied to be attributes of the individual, as evidenced by a description of access which is oriented toward blaming, accommodating or changing the individual patient. This despite almost all participants locating the origins of the patients' difficulties in the SDoH. Rarely, participants harmonized the patient provider dichotomy to think through and try to address difficult and complicated issues of power, privilege and disenfranchisement. Their orientation toward their patients, their own role and that of the health care system in accessing was also manifest in how participants spoke about addressing the problem.

2.4 Addressing the problem

In this section, *addressing the problem*, I provide an overview of strategies providers used and suggested could be implemented to address many of the systemic barriers to access identified in sections 2.1 and 2.2 of this chapter. Under the subthemes of *no dedicated effort to increase access*, *flexible care with better accommodation to the existing system* and *the transformative power of trust*, I summarize how various participants are currently working (or not working) to increase access to PNC. The subtheme *Still can't treat SDoH* revisits the socio-economic undergirding of health access disparities and limits of clinical care. Under the subthemes *shared commitment and leadership* and *directed programming* I provide an overview of the suggestions that participants provided for future strategies to address IPNC. Finally, in subtheme of *still won't be able to treat SDoH,* I address the disjuncture between what participants have thoroughly described as an issue of health equity access as rooted in the SDoH and their suggestions for addressing it.

2.41 Existing strategies for increasing access to care

Contextualized in their perceptions of the barriers to accessible care and their experiences of providing care, I asked participants to describe what they were currently doing in their own practice to decrease barriers to access to care for a population they had universally described as in need of specialized and deliberate intervention.

2.411 No dedicated effort to increasing access[7]: *"You missed the appointment. Can we rebook you?"*

Those working in appointment-based settings described the least robust efforts to accommodate patients for whom their model admittedly didn't work well. Missed appointments were rebooked by phone or by mail. At one clinic with a mandate to provide low barrier care, there was no explicit way of identifying if one of the hundreds of patients attending the clinic was recurrently missing appointments and then intervene. This meant that patients could be seen in early pregnancy, and it might not be noticed, if at all, if they didn't attend again until late in the third trimester. When it was noticed that the patient wasn't attending the strategies used to support them to get *into* the clinic were telephone calls and letters. The following anecdote of a patient with myriad barriers to accessing PNC, well into her third trimester with only one PNV, captures this strategy well:

> *I feel like what's happened is she calls to cancel. She speaks to our receptionist who is lovely, and has been with us for a long time, and knows a lot, but is a receptionist who is busy doing many other things. She'll call and cancel, and she gets rebooked, or she just no-shows and then gets a call to say, "You missed. Can you rebook?* (Family Physician)

Here we can clearly see the manifestation of a conceptualization of access that hinges on individual agency, as described under the subtheme of *you are the owner of your life.* It is really left to the client to overcome whatever it is that is repeatedly preventing them from getting to the clinic.

When patients were able to present to clinic, providers in these settings described efforts they made to individually accommodate them when they did not attend on time or just "showed up" looking for care. Recognition that it was important to accommodate this disruption to an always tightly scheduled clinic day was juxtaposed with a refrain that there was little that could

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[7] An important reminder that these interviews were conducted before the onset of the COVID 19 pandemic, which has spurred some new initiatives and increased collaboration in Hamilton as it relates to access to PNC for pregnant women and non-binary people who are extremely marginalized.

be done, given the volume of patients these providers had to see. In the following passage, this inability to provide people with the standard of care is interestingly presented as providing patient-centred care:

> *Yeah. I think I'm a little bit, I don't want to say desensitized, that's not the right way, I think I look through things in a different lens now as well because yeah certainly I would view it as patient centred in a way that these folks… we just work in a model right now which unfortunately is not conducive to being able to provide them with standard of care at times. But we are providing them with the best care that we can.* (Family Physician)

It is notable that an office and appointment-based service provider who acknowledged that their services are inaccessible and thus prevented them from providing the patient with the standard of care would describe their services as patient-centred. This assertion is particularly perplexing when we know that the hallmarks of accessible, and thus patient-centred care for highly marginalized patient populations are low barrier, co-located drop-in services or mobile outreach care models.

By and large, those who worked in office and appointment-based settings readily identified that they were not, as a service, even thinking or talking about implementing organizational changes that would identify or reduce barriers to care for those who struggled to access it:

> *Yeah, for sure, but we don't actually…It's interesting, we should, but we don't talk about how we can help people. Our weekly meetings or monthly meetings are more about staffing and who are we hiring, who are we firing. The business part and we can't even get that stuff done, so, it would be ideal if we could do more. We just hired an office manager so maybe once this kind of stuff is done; we always talk about potentially how we can improve patient education; we talk about it a lot, but there's not enough hours in the day.* (Obstetrician)

Importantly, one well documented barrier to care that participants did not raise in their enumeration of the many barriers that clients face in accessing care was racism. I regret that, with few exceptions, I also didn't raise it as the interviewer. In one setting, however, that has been particularly public about its reconciliation efforts, I did ask what measures were being taken up amongst healthcare providers to address racism in the healthcare system?[8] Their response:

> *I don't think it happens. I think there's pockets of those conversations happening, but I don't think it happens on any level that gains provincial or national recognition.* (Family Physician, II)

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[8] These interviews were conducted before the most recent global uprising in response to racist police brutality in the US. Since then, many health institutions have taken more deliberate efforts to acknowledge and/or address systemic racism.

It was not unusual that participants who worked in office and appointment-based settings described few, if any measures, either individually or collectively to proactively increase access to care for those who struggled to access it. For those who deliberately worked with people pushed to the margins, the efforts were decidedly more pronounced.

2.412 Flexible care with better accommodation to the existing system: *"If you can minimize the number of places that people have to go to access care, then that just really makes life a lot easier."*

Recognizing that getting high quality care meant first getting there, many midwives, outreach doctors and social service workers did their best to provide care that was either mobile or at sites frequented by the people they hoped to serve (shelters, drop in spaces, on call assessments for high-risk pregnant patients). Further, they worked to ensure they were available to their patients in a steady, reliable way. Additionally, participants working in office-based settings described the importance of in-house supports (social work, nutritionist, systems navigator, counselling) they had established to reduce the amount of travel and visits needed to access comprehensive care.

Interestingly the most thoroughgoing logistical strategies for increasing access to service were described by child protection workers, who attributed their innovation to the fact that they were mandated by law to actively engage families. The strategies that they had adopted that were not discussed by any other participants included making extensive use of Facebook and other social media tools and liaising with workers in other parts of the system whom they knew their clients would eventually connect with: OW and Ontario Disability Benefit Program (ODSP) workers and parole officers. As one worker described it:

> *I think the difference is [that] we're mandated, we can't go away. So, we have to keep trying and trying to engage mom, like we have to. It's not just a service where you…go in and then "oh, mom's not willing to work with us, we are a voluntary service, mom's missed two or three appointments, okay, we are closing her file, gone". Right, we can't do that…. So, the family service worker is working with mom, meeting with mom a minimum every 30 days to check in, to say "hey how's it going", those types of things. …it's hard because we do get busy, but what I found is if you are having more regular contact, you're going to know when that phone number changes, or when she moves, or those types of things…. Because if it ever; especially if the child is not in the mom's care, its usually court involved, and we have to show to the court that we're doing whatever we can to make sure that we try to get the baby home.* (Social Service Worker)

The fact that workers were mandated to see their clients and that they had to prove the efforts that were made to the courts meant that workers were far more persistent and innovative in their efforts. Notably, they also seemed to speak less about how hard they were working as compared to how hard their clients were working.

Because meaningful contact with patients was rare and fleeting, those whom I would describe with the most expertise providing more accessible care emphasized the importance of eschewing stepwise, algorithmic care plans and “getting as much done in the moment as possible”, in accordance with the patient’s needs, abilities and wishes. Here we revisit the story of the patient above referred to in describing the barriers to abortion in Hamilton:

> *I just think, my god, if that [abortion] had just happened at [hospital], they had transferred her up to [site] to help her navigate that - recognize that this is someone, who is for a whole host of reasons, is going to have a hard time navigating this on her own; if they had just taken the opportunity when she was an inpatient, because that is what I see so much, that opportunities are not taken when we have an active audience. A time where people actually have a roof over their heads, have three meals a day and they’re not struggling for those basic necessities. They are in hospital, okay, how can we help you and how much can we do? So, that was a missed opportunity; then she came to see me and the abortion didn’t end up happening, she ended up bringing this baby to term, or at least close to it.* (Family Physician)

This provider is confident that adopting the philosophy of “as much as we can, when we can” in this and other instances meant the difference between carrying an unwanted pregnancy (and all the concomitant trauma of an apprehension) and not. This approach to care meant recognizing that investigations and interventions not done at the first available opportunity might not get done, despite everyone’s, including the patient’s, best intentions and plans.

Providers working in settings aimed at serving extremely poor communities had developed some informal networks and personal connections to clinical and social services that they could leverage to help their patients better move through the existing system. Years of working with high needs populations and with other service providers doing the same had led to a fluency in navigating the system, knowing who to call to circumvent requirements for appointments and name recognition that allowed their clients to be seen or assessed outside of the “normal” channels.

> *I've been working in the field for a while - so when I call [clinic], they know me, they know that my patients don’t have phones, they know that that’s a barrier, and [they] tend to be pretty good. I can call an OB and they know what I do and know the questions I am going to be asking with this particular patient and they know that I need an appointment right now; it’s not like calling the patient back with an appointment time. You just need to tell me something right now because this patient is sitting with me right here, right now. Maybe it’s because I have some recognition in the community … but I find also just because … I know the ones to call, I know where they can go…* (Family Physician)

Ultimately, for those regularly working with people who struggled to access care, necessity was the mother of invention. Providers worked to accommodate the complexities of their clients’ lives and recruited and compelled others to do the same, as needed. Given the ways in which people are stigmatized in the health and social service systems, this accommodation was viewed as part and parcel of the trust building that was so essential to facilitating access to their own or the care provided by the broader health system.

2.413 Transformative power of trust: *"If we want to get to the most vulnerable, we have to stop expecting them to negotiate a system of strangers to get there."*

Trust building was an oft described approach to care that helped providers engage patients and support their clients. Several providers described this trust building as a process, rooted in an understanding of the adversity the patient faces day in and day out. For many, establishing trust was not the result of a single interaction, but an ethic on the part of the care provider. Some described how important it was that each and every patient encounter convey that ethic, not in the least because of how it might influence the possibility of another opportunity to work with someone:

> *She was just so grateful and you could see just hope that maybe there is a way and no, she never ended up showing up sadly, but I also know this is what commonly happens. When you have been working for quite a long period of time that you know that just one interaction with a patient is enough to have them come back down the road, so when they are ready, they will walk through those doors and ask for me or whoever else that they have had a good interaction with and then they know that that person is there, so that's very important.* (Family Physician)

Similar to the idea of providing as much care as possible when you have someone in front of you, as it relates to trust building, every encounter was premised on the idea that the usual rules of providing care didn't apply. There was no taking for granted that the patient would return as planned because it is what is routine and expected. Instead, patient interactions were approached with an ethic of creating the possibility for returning.

For patients who could more reliably attend care, essential to this process of trust building was also creating a rapport that could be engendered through continuity of care provider:

> *It's gotten better, I think, since the introduction of our [program], because there does allow for there to be some continuity of provider, and that rapport building, which I think in this particular patient population is so important, so that they can actually connect with someone who they truly trust and feel like has their best interest at heart.* (Family Physician)

For this provider to suggest that patients find it novel or remarkable that their provider would have their best interest at heart speaks to the tenor of people's overall experiences in the health care system. It is what participants often described having to overcome to provide care and why they explicitly focused on building trust as a way of increasing access.

For some participants, that trust facilitated not only access to their own care, but to the care in other parts of the health and social service systems. A few participants leveraged their recognition in the community and the trust they built with patients together to address and mitigate the harms experienced by their patients in the health care system:

> *So, where they might have a hard time trusting people off the top, when I can say this is someone I've worked with before, they are really good, they can really help with housing, can I get you guys in touch, and then be able to call that person, they are on my phone; this person doesn't have a phone, she's here with me right now, can you guys maybe chat. So, that sort of thing.* (Family Physician)

Here we can see how the endorsement of a trusted provider allows the patient to access at other points of entry to the system for needed care or service. This strategy of facilitated access through trusted partners extended to connecting patients to advocacy services for appointment accompaniment to increase the likelihood of both getting to and benefitting from appointments and service provision,

In a similar vein, a midwife described the work they did to navigate a very difficult decision to call the CAS *with* their client, even though they had enormous reservations about the agencies and their role in care specifically and society at large:

> *I feel like with the calling of CAS, I just tried to be really honest with her and we actually had a really good meeting, we just went for a walk, we went to Tim Horton's, then we went back to her house and we called together. I just said, look, I can't not do something in this situation since I have witnessed this and she was very understanding and I just said look, you can clean up your house, they are not going to come right now. We can sort this out and I don't think there is going to be any sort of apprehension. I can't guarantee anything but—I actually felt like it built our trust rather than broke it which was a unique situation when CAS is involved.* (Midwife)

Engaging honestly with the difficulties clients faced and potential ways in which people could be treated in the health and social service systems that had harmed them before, helped to affirm the experiences of clients and communicated to clients that the provider was on "their side" and wanted to work with them instead of against them.

Further, the transformative power of trust came up in a conversation about the ways in which one midwife perceived health and social service workers' failure to reflect on the ways that they and the systems that they work in are often harmful to the people they purport to help. They described how this trust building serves to humanize both patient and provider and can catalyze a move outside of the status quo:

> *Then once you have that rapport and that connection and you're treating this person like a human being, then there is space to be start doing work differently than just calling CAS.* (Midwife)

This idea of humanizing was antithetical to the stigmatizing that was the through line of the experiences of many participants' clients in the health and social services systems. At the heart of the matter of trust building was providing the patient with positive health care experiences that could act as a counter to previous negative experiences within the services that were purported to be helping, but often were causing harm.

Providers who actively worked to increase access to care invariably described strategies that centred and humanized the individual patient. The strategies were designed to circumvent and mitigate the impacts of a system that almost all participants agreed wasn't designed to meet their clients' complex and important needs; needs that were described as rooted in the SDoH.

2.414 Still can't treat SDoH *"Everyone understands the social determinants really well and I think you'd have to be so blatantly ignoring it to not understand how it's influencing your patient…I think it's probably just knowing how."*

Importantly, as described above, many providers were not making collective moves toward re-organizing care to better accommodate a population identified as in need of different and better services. Also notable was that none described collectively or individually working on ways to address the social and political *roots* of their patient's barriers to care. Even for providers deliberately working with marginalized clients, strategies for increasing access by addressing SDoH were limited to increased collaboration among health care providers and social services (which they struggled to navigate):

> *It's a huge part of our job, especially, I think, from my perspective being primarily family medicine. I think when housing's not there or someone's living in poverty or just has no supports, like I think those are the things that are always going to be the prominent concern, right? Like everything's always going to fall secondary to not having housing. So I think it's a huge part of our job and I think the problem is that we get no real formal training in how to do that, and I think there isn't enough interfacing between health care professionals and social services, for those sorts of things* .... (Family Physician)

For many participants the social services system was unchartered territory about which they received no or little formal training, as described here. For those who were proficient in navigating the spate of services available to clients, the unwieldiness of it all prevented them from making meaningful use of services. One participant remarked on the inability of busy care providers to take on the role of coordinating between health and social service agencies. They further commented that even if providers could take on that role, a strategy referring to patchwork, multi-agency charity model, didn't really work. This led them to casually remark on something that might help; increased income:

> *I feel like it's a big burden for lots of care providers to try and navigate a system of all these piece meal community agencies and charities and stuff that can kind of provide one or two pieces of maybe some help towards something but isn't going to solve the issue either but can put band aids on different parts, but it might take eight difference agencies and then who is coordinating that? The health care provider? The family? Probably neither. Probably somebody else and then that feels you're adding another piece to them. Basic income would make a huge difference.* (Pediatrician)

For the small number of participants who were conversant in the landscape of social services, none described successfully interfacing with that system in a way that they felt could address the non-clinical factors influencing the health of their patients. Despite this, in more than 20 hours of interviews about barriers to care for people living in extra-ordinary poverty, this relatively offhand comment about Basic Income was virtually the only time a participant suggested increased income as way to increase access to care and address the SDoH.

Despite a lack of formal infrastructure in Hamilton to systematically address the barriers people face in accessing PNC, several providers had taken it upon themselves to work within their own practice to build networks and develop skills and practices that make their care more accessible. Participants' existing strategies to increase access to care seemed to depend largely on how deliberately they had chosen to work with a population of people who struggled to access PNC. Accordingly, strategies spanned a broad spectrum, ranging from non-existent, to providing mobile, community-based care, to creating a culture of trust building, to leveraging a curated knowledge of the system to circumvent bureaucratic barriers to timely access to care and resources.

2.42 Suggested strategies for increasing access to PNC

This research project was born of desire to address the difficulties providers (including myself) face in trying to care for people in a system that is entirely out of step with their needs, and in fact often causes harm to those it is supposed to help. In this section I lay out what care and service providers think is needed to help them and others to increase access to PNC, despite the barriers to bringing it about described in sections 2.24 through 2.27.

2.421 Shared commitment and leadership: *"I do feel an ethical responsibility, but I can't do it alone."*

Throughout the interviews participants emphasized the ways in which the health and social service systems stigmatized their clients. They also described enormous obstacles in challenging and changing that culture of stigma and victim blaming. Given the inhospitable nature of the health care system to care providers and clients of this population, participants described a longing to carve out a community of providers with a shared commitment to creating a culture of access and decreasing stigma:

> *I have been pretty heartbroken on dozens of occasions in terms of the things I've heard said about people and I know that I can't fix that, but it really leaves me with the sense of I want to sort of find my people in a sense.* (Midwife)

The widespread recognition of the need for expertise in providing care to this important population, be it clinical or social, was translated by some participants into a call for stronger leadership. One participant suggested that part of the work to increase access to care would be to amalgamate all of the ad hoc work and galvanize a champion to move the agenda forward:

> *The fact that we've got a number of individuals who are really truly dedicated to trying to make things better and are willing to look past some of the bigger errors that we've identified certainly helps. I think having someone who's championing it, but also having buy in and support from all of the different leadership groups is really important.* (Family Physician)

For those who provided care exclusively in an office or a hospital ward, it was sometimes, though not always, difficult for them to imagine their way out of their own institutions. For others, their own success in reaching people through low barrier models informed their suggestions for increasing access at a system or population level.

2.422 Dedicated programming: *"It's not like that's a hard thing. All you need is funding to make that happen."*

Participants with expertise in the field largely built on the work that they were already doing to prescribe less ad hoc ways of providing care within a system that didn't work for their patients. They proposed funded, interdisciplinary and supported programming tailored to meet high needs of this important population.

The imagined services would be mobile and/or drop-in at locations that people were already frequenting. One experienced social service provider suggested that there be a way to provide care that is anonymous, to shift the balance in the favour of the client who wants care but fears entering into the system. A postpartum nurse, unable to keep up with the health teaching even when patients had spent time on the unit antenatally, perceptively suggested that antenatal inpatient care should include the educational components of PNC, not just clinical care.

Participants urged creative thinking about building links for referrals from services that clients were reliably and regularly accessing, namely OW, ODSP offices and opiate substitution clinics. Several also raised the tried-and-true strategy of incentivizing care with gift cards and providing for transportation to and from services. Many remarked on the need for better communication and documentation infrastructure, including electronic medical records accessible to the various care providers who might interact with this population.

One participant who has been close to the work to improve PNC in Hamilton for people experiencing homelessness, summarized a midwifery-led, collaborative model of outreach that they had been working to build for some time:

> *Decentralized care. Two full-time street midwives, who are helping out all care providers in the city and provide PNC, as well as doing women's health, i.e., Pap smears, contraception… and lots of health promotion. …I think also that having a regular clinic in a women centred place. … So, expanded scope would be important for the midwives that are doing that type of work, I think. Close relationship with one or two OBs, as per the Ottawa model.*[9] *A huge part of it would also be the staff education, education in the ER, education on labour and delivery, education on the postpartum ward.* (Family Physician)

Recognizing that any tailored programming that may or may not be developed will be reliant on and provided within the larger health care and social service system, participants spoke of a need to accommodate their patients to existing care delivery models. Peer support in programming was proposed by two respondents as a way of increasing acceptability of services and helping patients to feel more welcomed and supported. Participants also suggested increased collaboration with social services and front-line education on what providers described as the moving target of ever-changing community resources (the development of care pathways and lunch and learns, for example).

Participant suggestions for increasing access to PNC were decided manifestations of the conceptualization of access as a responsibility *to* the individual patient in that they worked to either accommodate them through system reform or change them through collaboration with social services. Despite the widespread acknowledgement among participants of the material deprivation experienced by patients that propelled their inability to access care, relatively few providers spoke about strategizing to address those economic drivers as means of increasing access to care.

2.423 Still won't be able to treat SDoH: ***"It is not going to change the power structures at play that lead people to be in those situations; it will just make it easier for them to get care once they are in that situation."***

A few participants imagined moving beyond clinical medicine and referrals to social services and into strategies of political advocacy to change material conditions more broadly. However, any move toward systemically addressing the SDoH was curtailed by the problem of not knowing what to do outside of the confines of one-on-one clinical practice:

> *So, yeah, we talk about advocacy at patient level, a community level and at policy level. I think most health providers struggle do it at a patient level. So, to ask the same people to work at a community level and a policy level is almost impossible. To some extent they are different skills. Right?* (Pediatrician)

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[9] ORACLE model is a midwifery led collaborative outreach PNC practice for people who are socially high-risk in Ottawa.

Here we revisit the idea of patient level intervention as a ceiling instead of a floor, where most providers, by this participant's account, struggle to advocate for their patients, on a case-by-case basis. This idea is further contextualized by the remarks of this same participant who described that sometimes the healthcare system's inability to address the SDoH was a function of a lack of acceptance of the importance of the SDoH on the part of providers:

> *I think there is lots that we can say—all Gary Block's work around if you give them a few thousand dollars more by helping someone fill out their income tax then their health improves far greater than treating their diabetes or vascular health issues. We know that a bit more money that's discretionary… will make a difference to many people's health. But I think most care providers don't trust that yet. They think they need medicine; they need to just have money only dedicated to that. So, I think what we can do is advocate for Pharmacare, National Pharmacare and basic income and maybe less expiring OHIP or more flexible approach of care providers servicing people without an OHIP card and figuring it out later. Just less stringency around stuff.* (Pediatrician)

It is notable that this provider broadly speaking, doesn't see her colleagues as allies in the struggle to improve people's (their patient's) living conditions. Here the provider is essentially advocating for policies that will work *despite* what they see as the ideological commitments of the health care profession. They are describing a work around for what they see as the medical community's disbelief about the impact of social interventions on health.

Moving beyond service delivery reform to increase access to health systems, or efforts toward increasing collaboration between social services and health care providers, one midwife cut right to the chase in addressing the limits of any kind of health and social service programming in the context of existing power structures:

> *I think a collaborative interprofessional team of people dedicated to providing care to people in a way that reduces barriers is meaningful, is a meaningful project on like a micro level that's going to change the way people interact with the health care system in a meaningful way. It is not going to change the power structures at play that lead people to be in those situations; it will just make it easier for them to get care once they are in that situation. So, it's great but it's not perfect.* (Midwife)

Here we see how a social justice orientation to the idea of access informs an understanding of the limits of one-to-one care on the roots of the barriers in the first place. Here by "perfect", the midwife is referring to an approach that would indeed work to address and remedy the root causes of health and access inequities. What that looks like in practice will require a more widespread recognition of the limits of clinical care that they described here.

Under the theme *addressing the problem* I have summarized how participants do (or don't) address or think we should address the problem at a local system level. Office and appointment-based practices were the least likely to be undertaking measures to increase access to PNC. In some instances, participants identified themselves as working in a low barrier setting while describing inaccessible service provision as patient-centred care. Those working in an outreach or drop in model more readily described measures they had undertaken to make care more accessible, most notably providing as much care as possible when and where the patient presents. Providers described an ethical approach to care that was rooted in trust building that could mitigate distrust of the broader health and social service systems. They described independently developing an expertise in clinical care and system navigation to better serve their patients.

When asked to imagine how health and social services could be delivered to better meet the needs of and increase access to this important population, providers spoke of the need for development of expert leaders to build a community of practice and champion the work. There was a call from many for the creation of dedicated and funded interdisciplinary programming, targeted at those who don't access PNC. Lastly, whether it was in the current reality or the imagined future, participants at once implied or identified the need and couldn't see their way clear to intervening in the broader social fabric to address the SDoH that overdetermined their client's ability to access PNC and improve their health and social outcomes.

Summary

Participants agreed that the phenomenon of IPNC is a small but important problem that cannot be addressed within current care and service provision models, already under strain in a landscape of austerity. This coupled with a lack of specialized knowledge about addiction medicine, trauma and mental health, left providers feeling like the provision of care was chaotic and stressful. Efforts on the part of some care providers to increase access to PNC were thwarted by the constraints and limits of the broader health care system. These constraints included funding models, scope of practice and the stigmatizing of patients of low SES that pervades the health system, as well as the lack of recourse to intervene in the SDoH. This combination of chaos and constraint left many clinicians and service providers feeling powerless to impact both the lives of their patients and the organization of care more broadly.

I have described how, broadly speaking, providers experienced, described and conceptualized the problem differently based on their relationship to IPNC as a provider: whether they were doing this work by chance or by choice. Those who deliberately provided care to those on the margins took up in their own practice, measures to mitigate the inhospitable, stigmatizing climate of the very systems in which they worked. They did this by developing knowledge of and relationships in the service systems to best facilitate their patients moving through them. They developed a level of expertise that dampened some of the chaos of providing the care, and they built trusting relationships with their patients and clients that countered prior deterrence inducing experiences in the health and service sectors.

Moving forward, participants imagined the development of a community of care providers with the expertise to lead the work. Taken as a whole, participant insights into IPNC suggest that reducing the existing barriers to accessible care for patients and providers alike could best be accomplished through carving out space to provide a kind of care that centers the patients and not the providers, through a targeted, funded, interdisciplinary mobile outreach model.

Finally, regardless of their clinical context, descriptions, experiences or conceptualizations, almost none of the participants were able to bridge the disjuncture (either in theory or practice) between what they described as the roots of the problem of disparities in access and outcomes (the SDoH) and what they did or proposed to do to address the problem (better service provision). Further, almost all participants viewed access to care as either a responsibility of the patient or the provider, ellipting the role of the wider power structures that limit and constrain individual agency.

In the next chapter I will synthesize the findings to highlight the most salient and relevant features of these findings and relate them to the existing research and thought landscape. I will identify some limitations of the work I have done and conclude with what I view are important implications for policy, practice and education.

Chapter 5. Discussion

In this chapter I apply a critical lens to the findings, theme by theme and remark on what is missing from the data. I then discuss the limitations of this study. Finally, I provide some recommendations for practice and some comments on implications for research and education.

1.0 Synthesis of findings

In this section I synthesize and interpret each of the four themes from the findings chapter and relate them to the relevant literature reviewed in chapter two. I introduce each section with a "Key finding" to reflect what I find to be most significant and needing to be incorporated into the recommendations for practice, research and education under section three of this chapter. I conclude this section by discussing what is most notably absent from participants' responses and explore what that might mean or say.

1.1 Describing the problem

Children need a childhood they don't have to recover from.

~Cindy Blackstock and Leanne Betasamosake Simpson (131,132)

Key finding #1: IPNC is a problem worthy of attention for clinical, social and moral reasons. The complexities of patients' lives prevent them from accessing service as conventionally delivered. Stigma in the system also acts as a strong deterrent to access. Abortion and post-partum care warrant specific consideration when thinking about access to PNC. Addressing IPNC offers providers a justice-oriented opportunity to intervene in the ongoing cycle of family separation, particularly as it relates to addressing the colonial legacy of the residential "schools".

While none of the participants interviewed collected data regarding IPNC, they all recounted a small but important population of people, pushed to the margins, who struggled to access care. Their descriptions mapped well onto the existing literature regarding those who do not access adequate PNC in Canada generally and in Hamilton specifically – people deprived of housing, precariously housed or incarcerated, people living in poverty, PWUD, victims of violence and human trafficking, as well as those suffering from mental health concerns and intellectual disabilities. These are all groups of people who must contend with a complexity in their lives that makes participating in the existing health care system very difficult. (33,34,53,54,90) A notable exception to the way that participant responses aligned with the literature was that, aside from the way it was implied through references to linguistic and cultural barriers in the broad category of newcomers, participants made very few references to racial identity or racism as it relates to groups of people who struggle to access PNC. This will be discussed further in section 1.5 below. The described characteristics that providers associated with IPNC must broadly be understood as being rooted in the SDoH.

The ways in which participants described how the population's characteristics, writ large, translated into barriers to accessing care in the form of complex and competing priorities also lined up with the Canadian literature. For example, Heaman et al., in their studies of patients and providers concluded, similar to participants in this study, that financial considerations, lack of support and lives preoccupied with surviving prevent people from accessing PNC in the routine fashion. (50,90) However, the complexities of people's lives do not prevent access to PNC in and of themselves. Consistent with the existing literature, participants described a spate of systems organization issues like clinic hours and locations, transportation, siloed and overlapping services and telecommunication barriers. (53,62,83,85,89)

Despite describing a slowly shifting culture in health care, stigma against people who are poor, who use drugs or who have mental health concerns was tied to several aspects of the phenomenon of IPNC, including as a barrier to access to care. Maltreatment by health care providers is an oft cited and stand-alone barrier to PNC. In a 2021 scoping review of the literature on barriers to harm reduction and child welfare services for pregnant women and mothers using drugs, Wolfson et al. determined that experiences of stigma translate into fear and mistrust that lead to system aversion. They also talked about the ways in which people experience and view entire institutions, not just individual providers, as stigmatizing, compounding personal experiences and further contributing to aversion and fear. (82)

Two aspects of PNC were afforded special attention in the theme of *describing the problem:* abortion and postpartum care. I was surprised to find only a small body of literature on the issue of access to surgical abortion[10] in Canada. Much of it focuses on access as it relates to a total absence of service in the community or province, and not the barriers people face accessing service where there are facilities theoretically within reach. (133,134) Similarly, access to postpartum care is not well explored in the Canadian literature. I could not find any studies related specifically to the lack of postpartum care received by people who typically do not get enough PNC.

These two neglected aspects of reproductive care are highly consequential clinically and emotionally and socially for the clients themselves and more broadly to the community and society. While there is, as mentioned, nothing specific in the literature on the impacts having no postpartum care, participants in this study spoke of how the lack of effort to connect post birth discharge contributed to messages of worthlessness and unworthiness that can overwhelm people who do not access PNC. Further, inadequate postpartum care represents a missed opportunity to engage people in preventative health and social services and identify risk factors for complications and intervene accordingly. As it relates to access to abortion, the ramifications of carrying to term an unwanted pregnancy likely to end in apprehension are beyond the scope of this paper but are likely far reaching. As noted briefly in the review of the literature in chapter two, women and non-binary people who have their babies taken from them are carrying around an unbearable and unavowed grief that destroys their lives and can propel an inter-generational cycle of theft and loss. (71,75,76) In circumstances like this, we can imagine the usefulness of robust, trauma informed postpartum care in countering messages of worthlessness and unworthiness and addressing and acknowledging the grief of having a child taken away.

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[10] I focus here on surgical abortion because 1) many people are of too advanced a gestation for medical termination when pregnancy is diagnosed and 2) there is capacity among the providers to prescribe and access free medical abortions for those who present to their office or outreach service in time.

Participants affirmed the need for innovative service provision to improve access to care for this population, again, not because it is a large population, but because of the disproportionate possibilities for long term impact through meaningful intervention. There is often the desire to intervene to mitigate the well documented adverse neonatal outcomes described in chapter two, like PTB and SGA. Of particular importance however, as it relates to program development, is the potential to intervene in a well described cycle of family separation, and the concomitant fall out, so thoroughly connected to IPNC. (34,52,74) A few Canadian examples support the possibility for a reduction in child custody removal through innovative PNC delivery designed to increase access to high quality PNC. (47,135)

The moral and legal obligation to Indigenous peoples on the question of child welfare are clear and set out in Canadian law in the 2020 federal bill *An Act respecting First Nations, Inuit and Métis children, youth and families*.[11] (136) It is well established that Indigenous people are over-represented in the child welfare system and in populations of people who do not access PNC. (5,137) The calls to action of the Truth and Reconciliation Commission of Canada (TRC) and the calls to Justice of Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls (MMIWG) call for an end to the targeting of Indigenous families for separation at the hands of child welfare services. (138,139) In both reports, health and social services are singled out as disciplines that have been complicit in the injustices of residential "schools" and MMIWG and identified as sites for transformational practices to rectify past and ongoing transgressions. (138,139)

With the exception of commenting specifically on access to abortion and postpartum care, the findings are consistent with the literature and add little to it other than volume. This theme stands on its own merit as a call to action for local providers. It speaks not only to the lack of system accountability to an extremely marginalized heterogenous group of people, but to a legal and moral imperative to do better.

1.2 Experiencing the problem

A problem is a chance for you to do your best.

~Duke Ellington

Key finding #2: Provider experience IPNC as chaotic, worrisome, frustrating and joyful. Numerous systemic barriers prevent the provision of accessible care to the client population. Skillful care provision requires developed expertise in the intersections of reproductive care, addiction and mental health care. There is a satisfaction that people derive from doing this work that needs to be harnessed in an era of provider burnout and lack of fulfillment in the workplace.

There is very little in the literature that describes IPNC from the point of view of the *experience* of the provider. However, studies that do explore provider experiences of caring for

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[11] Section 14(2) of the act: To the extent that providing a prenatal service that promotes preventive care is consistent with what will likely be in the best interests of an Indigenous child after he or she is born, the provision of that service is to be given priority over other services in order to prevent the apprehension of the child at the time of the child's birth.

marginalized populations during pregnancy generally reiterate that providers often feel unprepared or unsupported to care for people outside of the dominant, privileged hetero-normative context.[12] Mitra et al. discuss this with respect to caring for physically disabled women in pregnancy, calling for the creation of disability-focused research and practice guidelines. (93) Similarly, work exploring the experience of providers caring for refugee populations highlights a lack of expertise as a central barrier. (94–96) A Nova Scotia-based survey of health providers revealed that non-LGBTQ providers are poorly equipped, due to a lack of information and comfort, to provide care to the LGBTQ community. (140)

A study of Irish midwives' experiences of caring for "non-Irish women seeking asylum" speaks to the frustration (often manifest as racism and stigmatization) that providers experienced in caring for people with IPNC. (95) Tobin et al. found, similar to my findings, that providers who coped best with the strains of caring for those whose needs were not met by the system, were those who had taken a special interest in providing care to "challenging" populations, in her case, asylum seekers. (95) Tobin also described the frustration and powerlessness that providers felt at not having supports to offer their clients when their needs fell outside the realm of their clinical care provision. (95)

As described in the review of the literature in chapter two, there is very little documentation of the barriers providers face in improving access to PNC, from their own point of view. The studies about caring for refugees by Shorey, Tobin and Winn corroborate the findings of this study that the systems are unwieldy, siloed and difficult to navigate. This fragmentation makes understanding how to access care and social services difficult for patients and providers alike. (94–96) The work of Darling et al. exploring barriers midwives in Ontario face to increasing access to care for clients of low SES bolsters the findings of this study regarding siloed systems and widespread stigma that inhibits collaboration among practitioners and entrusting the care of clients to the health care system broadly. It further endorses, from a midwifery perspective, the constraints created by conflicting or incompatible provider specific funding models, like course of care and fee for service. (92)

Finally, the COVID 19 pandemic has exacerbated job dissatisfaction and burnout in the healthcare system described herein by many participants, pre-pandemic. (141,142). The joy and the fulfillment described by providers who deliberately engage in working with those pushed to the margins serves as an important counter narrative to the many described drawbacks to providing care to people struggling to access PNC. I think that efforts to harness that joy and fulfillment provide an important opportunity to inspire better health care and push back against the downward pressures of austerity on morale. For me, there is joy and energy and purpose that come from being a part of a collective working against the race to the bottom, and instead collaborating for the betterment of all our lives.

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[12] Here I mean the materially stable, white, western straight person who can access care in the way it is currently delivered, without a need for anything "extra", or support in navigating or relying on other systems, like immigration, income supports etc.

1.3 Conceptualizing the problem

Individualism is another weapon against humanity.

~Dr. Vivi Camacho, Quechua woman and General Director of Traditional Medicine for the Plurinational State of Bolivia (143)

Key finding #3: Despite well-established theoretical understandings of the SDoH as originating in social and economic structures and processes, the ways in which providers speak about overcoming the impact of these determinants of health suggests that, in practice, the SDoH are primarily viewed as individual attributes. This conception that the SDoH should or can be addressed at the level of the individual directs and constrains how providers strive to increase access to care both in theory and in practice.

The way in which most providers described the barriers to care as being rooted in the SDoH, while they conceived of the problem as being addressed through the individual is interesting fodder for analysis. This conceptualization occurred whether participants viewed accessing care as responsibility *of* or *to* the individual client. Provider conceptions of access to PNC are not well explored in the literature. However, Shorey et al. do touch on some of these conceptual ideas in their systematic review of views and experiences of caring for migrant women as a way of exploring their perceptions of cultural competency. (94) Similar to my research, the reviewers found that providers conceptualized the responsibilities for access as either belonging to the patient or the care provider. In this instance that meant that care providers either conceptualized themselves as having a responsibility to learn to provide culturally appropriate care, or they viewed it as the responsibility of the migrants to acclimatize themselves to the culture of the health care system. (94)

Beyond Shorey's work, we can make inferences about how IPNC is conceptualized by looking at how it is framed in the literature. Heaman's study of providers' perceptions of barriers and facilitators to care in Winnipeg, Manitoba takes a position that providing care is a provider responsibility to the individual. We see this through its proposal of health system-based changes to service delivery to better accommodate (not change) the life circumstances of inner city women, who have the lowest rates of PNC uptake locally. (50)

In fact, most of the literature in the review in chapter two points to this same conception of the SDoH as individual attributes, or at least in need of remedy at the level of the individual. Proposed and evaluated interventions range from improved provider communication skills, and care coordination to public education and system navigation to mobile and community-based clinics. (47,50,61,88,97,103,106) These are all health system-based reforms. Importantly, none of the studies go on to call for addressing the systems that give rise to the health inequities the interventions are meant to address.

While most of the literature implies the conceptual outlook that increasing access to care means acting on or accommodating the individual, there is very little exploring this viewpoint of getting care as a responsibility. This is perhaps because the small amount of literature that does exist focuses on the viewpoints the people choosing to do the work of caring for people pushed to the margins. However, in a qualitative study on Irish midwives' experiences of caring for non-Irish asylum seekers, assumptions similar to those found in this study are revealed about getting care as an individual responsibility. Tobin and Murphy-Lawless ascribe participant perceptions that migrant women should just get PNC like all Irish women to a "deep level of ignorance and lack of insight into the lives of women seeking asylum", i.e. a lack of awareness of the implications of the SDoH. (95, p. 164) They described the ways that these attitudes and beliefs were more often found in those that provide care to people on the margins by circumstance rather than by choice. (95)

In all of these studies, the analysis does not move far beyond the description of what providers do and say: there is little explicit exploration of the viewpoints of the care providers on these more philosophical or ideological aspects of access to care. As Shorey et al. put it: "It is noteworthy that only a few of the included studies expressly discussed whether, and if so, how expressed attitudes and beliefs might be translating into specific behaviors." (94, p. 8)

From where I stand, there is a complicated intellectual and theoretical turn that happens when the problem is widely defined as being rooted in the SDoH, but the remedy is conceptualized as needing to happen in the client. Whether conceived of as a responsibility *of* the patient or a responsibility *to* the patient, I would say that participant understandings of access and health service intervention revealed in this study and similar studies on access to PNC lend themselves to what Muntaner et al. call the "individualization of social class", wherein social disparities are viewed as attributes of individuals and thus, so too is the site of their remedy. (10, p. 269) In my view, this individualist expression of the SDoH blames the victim, and/or stunts critical reflection on the origins of the complexities of our patient's lives and obscures the need for broader social transformation to intervene in health inequities.

These findings suggest that there are some ideological limitations that both inform and arise out of the ways in which providers address IPNC. We can see the difference in how participants conceive of intervening when they conceive of health access through a lens of justice. Here we see calls for providers to leverage their relative power in systems to alter the conditions of their patients lives through political action. This understanding is aligned with the internationally agreed upon interpretation of the SDoH as put forward by the WHO. (13,14) A justice orientation to IPNC ignites the possibility of a marriage, not a subordination, of political action to clinical practice. I think this orientation holds exciting possibilities for thinking about and acting on the phenomenon of IPNC.

1.4 Addressing the problem

> *Nothing happens in the "real" world unless it first happens in the images in our heads.*
>
> Gloria Anzaldua
> ~Borderlands/La Frontera: The New Mestiza (144)

Key finding #4: Community Centred Care (CCC) describes an ethic of care rooted in trust building and maps well onto what participants envisioned in building programming that meets the needs of people who struggle to access PNC. While an improvement on a provider-centred model, the imagined solutions of flexible, interdisciplinary models of outreach-based care do not address the described roots of the barriers to access, which are based in systems of power and privilege.

Without exception, participants in this study identified the need to better serve the population of people accessing IPNC whose barriers were rooted in the intersection of the SDoH and the organization of care provision. For many, the constraints of busy clinical practices and administrative duties precluded deliberate efforts to address the issue of IPNC, either on a case-by-case basis or at a broader systems level. Further, in some instances, care provision that was viewed by the providers as accessible (appointment and office based) wasn't accessible by any measure of access described in the literature (incentivized, decentralized, outreach/drop in based care). (47,85,91)

Despite the Ontario Health system's widely adopted mantra of patient-centred care, I would describe office and appointment-based care as provider-centred. The example in the data of explaining that one is not providing the standard of care because of the way care is delivered and then further reframing of it as patient-centred care warrants serious consideration. In my view, the listing of SDoH as barriers to access and then using them to justify why you can't provide the standard of care creates an amnesty for the care provider, even while acknowledging the power and resource imbalances. There are important theoretical assumptions at work here, which we would do well to excavate and make more explicit. Consideration of this is taken up under the heading of implications for practice, research and education.

Trust building was the foundation of accessible care as described by those most invested in providing it. Through the provision of flexible, often mobile care and service which met patients where they were at, providers communicated that the care was intended for the patient and not centred around the needs of the providers. This decentralized approach to care is consistent with what is described by patients and providers as low barrier in the literature. (47,85,100)

Also under the rubric of flexible care, the provision of as much care as possible in the moments when the patient is in front of you, is akin to the "no wrong door" philosophy, which is emerging in health and social services policy and literature, though it remains poorly described. (145) Essentially "no wrong door" means, just as it sounds, that wherever (and hopefully whenever) one presents in the system, it becomes the route of entry to the care or service that is needed. (59)

The "no wrong door" approach was also raised by social service worker participants who advocated making links with services with which pregnant people "at risk" of not accessing PNC interacted (OW/ODSP, parole workers, child protective services). In discussing how pregnant women in situations of intimate partner violence (IPV) are less likely to attend PNC, Jamieson et al. make obvious the importance of a "no wrong door" approach to care provision. They describe how women experiencing IPV are likely to engage with emergency and legal services before

PNC services, and that these more subscribed services make for obvious routes of entry into PNC. (59)

This same “no wrong door” approach was made possible or enhanced by the network building and systems knowledge some providers took on as part of their work to support their patients to better access beneficial care. The leveraging of individual social capital is likely a necessary foundation upon which to build better routes of entry to a system (that by all accounts, serves people poorly, once they get in). However, this strategy to mitigate the lack of infrastructure and dedicated programming leaves patients vulnerable to the availability of specific “players” and maintenance of these relationships. Personal connections are not a substitute for true and sustainable patient-centred care, and will only lead to sustainable benefits to patients, providers and the community more broadly, if they evolve into formalized and funded pathways and programs.

Overall, providers working to increase access to PNC described trying to create a culture of accessibility and an ethical approach to care that was rooted in trust building. This ethic of care worked to counteract client’s broader experiences in the healthcare and social service systems. It served to humanize the clients, so often dehumanized by their treatment at the hands of the systems alleged to be there to help them. The qualitative component of the PIIPC evaluation spoke to the value that patients and providers both place on trust building. This quote from a client who participated in that evaluation sums it up very well, and better than I could:

> *Well first of all I got to trust them [providers] and that’s a big huge thing for me. Because you know sometimes because of where I live and how I live my lifestyle, trusting your practitioner is really hard. … They [providers] helped me connect with them so that I could trust them enough to say hey you know what, in the first three weeks in my pregnancy I did drugs ‘cause I didn’t know if I was pregnant, and by being able to open up and tell them that and not be afraid that they are going to send down the police and everyone else…, it helped them to help me to get the proper care to check to make sure everything was okay… it made me want to go to my appointments. It made me want to ask questions.* (47, p. 14)

This statement is at once so simple and so profound. It speaks volumes about what people really want and need from health providers. In my own work as a clinician and community organizer I have found that people simply want to be listened to, trusted, respected, and treated with kindness. Why it is so hard for health systems deliver on these simple acts of human decency to large swaths of the population (people who are racialized, people who are poor, people who are disabled, people who identify as LGBTQ+ and people with mental health concerns, to name a few) is definitely a worthwhile (and potentially dangerous) question.

In addition to describing the ways in which providers work to increase access to care, I have highlighted in the paragraphs above the ways in which some who identified the need for solutions were not actively working toward them. It is important to note however, that none of the participants were opposed to the development of more accessible programming. To the contrary, all supported its development, even if they wouldn’t be a part of it. There was widespread acknowledgement that caring for those with complex lives was a specialized form of care. The repeated admission of a lack of knowledge and expertise, clinically and socially, translated into a call for targeted clinical programming, leadership and a community of practice that could first address the care needs of this small but important population, but also build the capacity of other providers in doing so.

The creation of targeted programming to both increase access to PNC and improve clinical outcomes is supported in the Canadian literature in the form of the evaluation of the PIIPC project in Manitoba. (47) The positively evaluated Winnipeg model of embedding midwifery care at existing community drop-in programs, providing mobile/outreach PNC, facilitating access to PNC for those presenting to hospital without a care provider, and a social media campaign promoting PNC and how to get it is congruent with the suggestions raised by participants in this study.

The incorporation of people with lived experience or “peers” into program design and delivery is gaining currency in the health and social services sector. Rooted in a philosophy that those who live it are the experts, meaningfully working with peers in program development and delivery has the potential to transform power relations and thereby improve outcomes. (146) Interestingly, only two participants suggested peer support workers as part of the programming response to the barriers to care.

The incorporation of peer workers in PNC is not well explored. Olding’s study exploring the experiences of PWUD in accessing mom’s groups is instructive. Importantly, their work brings us back to this question of trust. Their study highlighted that participants were able to develop trusting relationships with peer workers, who had lived through experiences similar to their own, that they couldn’t with other care providers. (147)

All the ideas raised under the theme of addressing the problem are well captured in our 2020 work on the work of midwives to increase access to care for people of low-SES. Our team found that midwives had adopted strategies as individuals and collectives to increase access to care that ranged from maximizing the low barrier aspects of the midwifery model of care (home visits, relationship and trust building, prioritizing intakes) to orienting their entire practice toward being a part of and response to the community that they serve. (135) We theorized the latter orientation of select midwifery group practices in Ontario as Community Centred Care (CCC). CCC is a locally based, midwifery-led, interdisciplinary approach to improving access to high quality, relevant care for people for whom the provider-centred model of health care provision simply doesn’t work. (135) CCC involves taking one’s lead, as a midwife, practice or health service, from the community - here we can see the importance of working with or even being led by peers. The CCC model is inherently guided by the ethic of trust building, rooted in an understanding of the material forces that give rise to the marginalization and distrust on the part of the client population in the first place. It calls on midwives to develop the necessary expertise in a given domain, to both provide excellence in clinical care and to take on leadership roles. Midwives providing CCC have reported changing the landscape of PNC more broadly in their communities, whether it be by reducing the number of people presenting to hospital with no PNC or providing culturally competent care to Indigenous people flown in from remote locations to a local tertiary care centre. In short, CCC calls for responsive programming that is based on a perspective in which providers see themselves as part of, not set apart from, the community they serve, thus addressing the needs of the clients and communities alike. (135) This concept of CCC embodies and enhances the needs and suggestions for service delivery modification described by participants in this study.

The strategies described above all fundamentally avoid or even obscure the underlying *cause* of IPNC: social and economic injustice rooted in systems and structures that privilege the few at the expense of the many. Very few participants moved from describing the roots of the problem to addressing them in the same vein. For example, only one participant mentioned giving people more money, in the form of basic income. Her suggestion is supported by what little research is available to evaluate the impact of income on perinatal outcomes. Brownell et al. showed that, in Manitoba, a modest $81/month unconditional income supplement to low income families decreased rates of PTB, SGA and LOS, while increasing breastfeeding rates (known to decrease adverse health events throughout the life course). (107)

A qualitative study of the program that delivered the income supplement described above found that recipients used the augment in their income to buy healthier food, prepare for the baby, and reduce money-related stress. The researchers concluded that while there are challenges to implementing an unconditional income supplement, it might be more effective than a conditional one like the Ontario Special Diet program, for instance, where even though you are low income, you must prove to a government ministry that you are in special need of additional income to purchase food needed to address your health condition (148,149)

This noted and recurrent disjoint between the SDoH roots and the clinical- and service-based proposed solutions is given full consideration (within the scope of this thesis) under the "Implications" section. However, importantly, to the extent that participants did comment on the need to address their patient's material needs, they often viewed it as a matter of making referrals to the appropriate social services, where (while describing themselves as knowing little about them) they presumed those needs could be met. This interpretation of meeting social needs is echoed in the systematic review by Reyes, which looked at social interventions to address the same in perinatal care. Reyes et al. found that the interventions were largely limited to screening and referral to other services, which had varied impact on health outcomes, to the extent that they were studied or measured. Reyes concludes her paper by reminding the reader that none of the interventions reviewed address the underlying causes of inequity in a tangible or long term way. (150) This sentiment of exasperation was mirrored in the words of some of my participants, who felt powerless to address what they knew to be the real barriers their patients faced in achieving positive health and social outcomes.

1.5 What is missing from responses

> *There are these two young fish swimming along and they happen to meet an older fish swimming the other way, who nods at them and says "Morning, boys. How's the water?" And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes "What the hell is water?"*
>
> David Foster Wallace
> ~Commencement Address at Kenyon College, 2005 (151)

Key finding #5: The impacts of sexism, patriarchy and racism and the potential contributions of people with lived experience were markedly absent from the data. The neglect of these framings reflects a lack of consideration and thus attention on the part of providers. These noted absences must motivate a commitment to incorporate questions of patriarchy, racism and patient inclusion into ongoing and future clinical, research and organizing work.

In keeping with Gladstone and Eakin's "Value-adding" analysis, I turn my attention in this section to what is not said by "reading the data for silence". (128, p.7) The authors invite us as researchers to ask: "Is silence a personal and individual response or is it an, "elephant in the room," that may be more socially governed?" (128,p.7) Given that the silence transcends almost all the respondents, in a way that maps well onto my experience with and analysis of power in health care, I lean more toward the latter explanation.

1.51 Patriarchy and sexism

What better example of a conspicuous silence than an investigation into a phenomenon of women (all the participants in this study identified to me as female) providing care to (predominantly) women and sexism or patriarchy come up but once? It's as though it's hard to recognize the water when you are swimming in it. I find it interesting that the impact of access to care for the poorest most marginalized women in the city doesn't get framed as an issue of gender discrimination.

The neglect of the impact of gender on access to PNC can be unearthed in many ways. Here I will briefly touch on two of them. First, research and services focused on women and non-binary people have historically been systematically underfunded. (152,153) This has left people on the front lines scrambling and working with meagre resources in the face of tremendous obstacles.

Second, we should consider the gendered impact of the socio-economic disparities suffered by the people pushed to the margins. (154) Important considerations like gender-based violence, the relationship between child custody loss and homelessness, and the gendered nature of precarious, low wage work/poverty are rarely discussed explicitly in relation to sexism and patriarchy. (75,155,156) One wonders what could be added to the analysis and efforts to intervene were sexism and patriarchy held explicitly front and centre.

Here too the datedness of the data needs to be acknowledged- the last of my interviews were completed in January of 2020. The impact of the COVID-19 pandemic on people experiencing homelessness has been profound, as life saving services shuttered their doors in the name of public health. The damage of the COVID-19 response and the dearth of services for pregnant people was taken up in the City through a partnership between McMaster Community Research Platform, the Community-University Policy Alliance (McMaster School of Social Work) and the YWCA. (35) This push to recognize the disproportionate and gendered impacts of the COVID-19 pandemic may have raised the profile of the gendered nature access to PNC, beyond the fact that is primarily women who use the service.

1.52 Racism

Health disparities between Indigenous and settler populations are well established in Canada. (157) To the extent that it is documented, almost every measurable adverse health or social outcome is higher among racialized people than white people in Canada. (137,158) As it relates to access to PNC and maternal and newborn outcomes, it is also well established that racism is an important determinant of inequity. (48,52,159) In addition, Indigenous people are over represented in the population of people experiencing homeless. (160)

Despite these well-established facts, discussion of the role of racism and colonialism in access to PNC was markedly absent. This silence is consistent with the general discourse in the public health literature, even in the US, where raced-based data is at least collected. (161) When it rarely did enter the conversation, it was usually when I explicitly raised it, which I should have done more. Because it wasn't even raised as a problem, there was obviously no attempts to think about how to redress it. Any work that flows from this study must correct this glaring and damaging omission.

Importantly, while I did not collect data on racial identity of my participants, the vast majority of them presented as white (as do I). I have a profound memory in my Participatory Action Research course, offered by the Department of Social Work, being schooled by the professor on this issue, as I lamented, after the data collection, that I had not done more to elicit this discussion on racism. She rightly pointed out that I likely wouldn't have been able to not raise it were I a racialized person.

I refer in the limitations section below to the mainstreaming of the impacts of racism and colonialism through the uprisings in response to the murder of George Floyd in the US and the high-profile resistance of the Wet'suwet'en to the Coastal Gas Link pipeline in British Columbia. It is impossible to know how these movements might have impacted my leading of the interviews or the responses of the participants.

1.53 Peer involvement

The literature on the role of peer workers in increasing access to or satisfaction with PNC is sparse. However, the literature in addiction medicine and mental health care points to the value of peer involvement in programming. (147,162–164) Interestingly, very few people spoke about peer support and none spoke of including participants in the design of the programming itself. As discussed above, not withstanding the evidence that peer involvement could improve program development and delivery, this omission on the part of participants speaks to the us/them dichotomy in health care broadly, wherein the provider is considered the expert and the patient the recipient of said expertise. Moving forward, just as we must work to incorporate the role of racism and sexism in our analysis and planning, so too must we be sure to be driven by the needs and desires of the community of people using the services we are trying to create[13]. This is not only a matter of justice, but efficacy: we need to keep working to have clients inform the creation of this programming as it grows so that it is based in what will be acceptable and appropriate and beneficial to the people who will (hopefully) use the services.

Each of these topics and the reasons for and the consequences of their exclusion from the discourse could be the focus of a master's thesis in and of themselves. It is beyond the scope of this work to delve into the omissions much further than mentioning them and ensuring they are part of my work moving forward. For me however, it is important to note, that what these three topics highlight are the ways in which ideological commitments can masquerade as neutrality in health care. Neglecting the *ideas* of sexism, racism and peer involvement necessarily neglects care needs of the people impacted by them. Here we should take our lead from the movements that have been fighting sexism and racism for centuries and the call of the disability justice and PWUD communities rallying call of "nothing about us, without us". (165)

The critical interpretation of the data presented in this work reveals compelling moral, legal and clinical arguments for deliberately addressing the phenomenon of IPNC. The current system of care and service delivery exacerbates the marginalization of the people already experiencing extraordinary pressures in their everyday lives. Further, the efforts to provide care in a provider- centred system makes for a chaos that leaves providers feeling demoralized and powerless. This can be mitigated to a certain extent by the development of expertise related to mental health and addictions, trauma-informed care, crisis de-escalation and systems navigation. The fostering of a skill set and community of practice to better care for people on the margins has the potential for mutual benefit in that patients receive better care and providers may be propelled by the fulfillment of providing better care.

Preliminarily, I would suggest that an individualistic understanding of access to PNC shapes both the ways in which providers view their patients and their relationship to them. Further, I think that there are unacknowledged limits being placed on what providers see as both necessary and possible for intervening to increase access to PNC. This is evidenced both in how they conceptualize care and how the gap between the socially determined root causes of health inequity and the individually targeted interventions is never closed. CCC provides a model for service delivery that attends to provider described current and recommended practices for increasing access to PNC. It remains to be seen if CCC could be leveraged as a model to traverse the terrain between SDoH and interventions to meaningfully address them.

2.0 Limitations

While I did interview a large sample of providers for this study, because of my role in the community, almost all of them were known to me personally. It is difficult to say if or how this impacted the data collection and responses people provided. One could consider this a strength

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[13] A brief reminder that part of the larger mixed methods research program involved interviewing people who received IPNC. Those interviews served to inform the development of this study as well as funding and program proposals that have come from the research program as a whole.

of the work, or a limitation. However, it is certainly worth noting from a transparency point of view.

While hospital staff and providers are well represented in my data sample, it is noteworthy that I did not interview labour and delivery nurses, who would provide an important and useful perspective on this phenomenon. Labour and delivery nurses are most likely to be the first point of contact for patients without PNC presenting in labor or in need of assessment. I regret that I was not able to successfully recruit participants to contribute to the study from this important vantage point. Additionally, I was not successful in recruiting PH nurses to the study.

For primarily practical reasons, I decided not to undertake member checking of either the transcripts or the findings and my interpretation thereof. First, because I conducted the interviews myself and reviewed the transcripts shortly thereafter, I was confident that I was working with accurate representations of the discussions. Second, I did the bulk of the analysis and writing work during the ongoing COVID 19 pandemic. Almost all of the participants in this study are on the front lines of responding to the crisis and it would have been inconsiderate to ask more of people among those who were pushed to the brink by the management of the pandemic. Importantly, while my thesis certainly represents an important juncture in the work to build more accessible PNC in Hamilton, it is definitely not an end point in and of itself. I intend to return to the community to present my findings and solicit feedback and input that will be incorporated into the work going forward.

Finally, as outlined in chapter one, the world has undergone some seismic events since this data was collected in 2019/early 2020. The COVID 19 pandemic forced a shift in the landscape of care and service provision for people pushed to the margins, namely those experiencing homelessness and using drugs. The upshot has been modest collaboration between and among health and social service providers to better meet the needs of those who struggle to access care. It is not possible for me to evaluate the extent to which this impacts the relevance of my data and analysis; however, there remains no funded, targeted programming to increase access to PNC in Hamilton as proposed by this work.

The movement to #shutdowncanada in response to the ongoing construction of the Coastal Gas Link pipeline on Wet’suwet’en land in BC took place just as the data collection for this study was ending, and another uprising is currently taking place as I write these words. The global uprisings for racial justice sparked by the murder of George Floyd in Minneapolis also took place after the data for this study was collected. The long fights for justice on the part of Black and Indigenous people were pushed into the mainstream by these two movements. Academic and health care institutions were forced to reckon with their own racism in ways that they rarely have been and many released statements of solidarity and resolved to enact change.

While racism and colonialism are long standing and foundational problems in health and social services, the degree to which they were forced to be accountable to that may have shifted in 2020. This possible shift is not reflected in this work because the data was collected after those public reckonings took place. Like the impact of COVID, it is not possible for me to speculate on how those grass roots movements could have impacted the discourse of my participants were the interviews to be timelier. I do know that I personally would have approached the interviews differently; I would have ensured that racism was centred in the conversation, were I to do it again. It is a profound limitation of this work that the question of racism is not more thoroughly addressed.

3.0 Implications for practice, research and education

In this section I formulate concrete recommendations for practice by outlining an interdisciplinary, midwifery-led outreach model that is based in my own experience as a care provider and founding coordinator of the HMOT, the recommendations that come out of the participant interviews and the relevant literature as described in this chapter and chapter two. Having considered the lack of implementation of what is already known in the literature and what I view as the ideological assumptions of care providers that have been revealed in this study, I then go on to make some high-level recommendations for a research orientation that might lead to making explicit those and other possible ideological underpinnings of the health systems and service delivery. Finally, I consider, again at a high-level and within the scope of this thesis, some considerations for the field of health education, specifically the soon to be launched Master of Science in Midwifery program at McMaster University.

3.1 Proposed program: CCC, interdisciplinary, midwifery-led outreach team

Several recurrent themes and ideas in this study point to the need for specialized programming that meets the needs of a small but important population of people. Participants have woven together for me a picture of a chaotic, uncoordinated system that stigmatizes patients on the margins and whose boundaries are so entrenched as to make system-wide change and accommodation next to impossible. Considering my personal experience as a clinician and organizer in the context of my findings and the research on increasing access to PNC I conclude that one needed intervention is a targeted, low-barrier, interdisciplinary, midwifery led, outreach model that meet patients where they are at and treats people with the kind of respect and kindness that allows them to want to get care. This kind of programming could not only benefit the patients who would receive care, but the providers who would provide it, by mitigating the chaos and frustration that is currently created by trying to provide community centred care in a provider centred system. Further, the potential to scale up and model a culture of accessibility locally and for the broader health system in Ontario should not go unmentioned.

In keeping with the purpose of this study and solution-focused ID methodology, I have synthesized the suggestions provided by participants with the most current research to outline a program which could better meet the needs of people who struggle to access PNC care in the city of Hamilton.[14]

A midwifery-led, interdisciplinary, mobile, community-based outreach team could help to increase access to prenatal, postpartum newborn and reproductive care for clients who cannot

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[14] This description is taken from a proposal for an outreach midwifery team submitted to the Ministry of Health in August of 2020 and again (in revised and scaled back form) in July of 2021. This study, though unfinished at the time of submissions, heavily influenced and informed those proposals.

access conventional streams of such care. The program should see people where and when they wish and be guided by the philosophies of harm reduction and trauma-informed care and grounded in the principles of CCC.

In keeping with the “no wrong door” philosophy, the program should provide various low-barrier, client-centred points of entry by:

- Providing on-the-spot intake and ongoing care to pregnant clients who present to birthing triage units with no or minimal PNC. Care should be coordinated as necessary with the referring physician in keeping with the midwifery scope of practice.
- Providing on-the-spot intake to pregnant clients presenting to the emergency departments in three Hamilton hospitals, these sites being the most common point of contact with the health care system for pregnant people not accessing PNC
- Providing postpartum and supplementary reproductive and supportive care for patients who are discharged postpartum having received minimal PNC, especially those who have their newborns apprehended.
- Providing on-the-spot and in-person intake to clients referred by opiate replacement therapy clinics (where people are seen at least weekly for substance use disorder treatment, but rarely provided any other health care).
- Providing on-the-spot and in-person intake to clients referred by child protective services.
- Providing on-the-spot and in-person intake to prenatal, postnatal and newborn care to people living in shelters.
- Establishing referral pathways with social services like Ontario Works and the Ontario Disability Support Program.
- Establishing and staffing a regular reproductive care drop-in clinic in locations where clients currently access a suite of other social services. At these co-located drop-in clinics, the midwives would provide cervical cancer screening, sexually transmitted and blood-borne infection testing, and drop-in PNC. Telemedicine with a network of community and hospital-based physicians could be used to consult and provide care for pregnancy complications and health conditions outside the scope of midwifery care.

The program should maintain connection with its own clients and support the care of the patients of office base providers by:

- Offering outreach services to clients who are homeless and precariously housed on a mobile, retrofitted van.
- Providing supportive and collaborative community-based outreach care to OB, family medicine, and midwifery patients who repeatedly miss scheduled prenatal visits.

- Providing client-centred outreach-based access to medication abortions, early pregnancy loss management and contraception management.

The program should work to address stigma in the health and service sectors more broadly by:

- Providing harm reduction and anti-stigma education to hospital workers, at both nursing huddles and staff rounds.
- Coordinating peer-based supports for clients, and the participation of clients in program development, which have been shown to increase uptake of PNC and increase client satisfaction.

The program should work to address the material barriers to accessing care by:

- “Incentivizing” care through provision of cash or gift cards
- Providing transportation to and from non-outreach-based visits
- Facilitating access to eligible government and other income supplements, like the Special Diet allowance, Child Tax Benefit, etc.

The program should carefully attend to questions of patriarchy and racism in its development, implementation and practice. How to do this will require deliberate and careful consideration and should look to the leadership of the people and grass roots organizations who are at the forefront of resisting these intersecting forms of oppression. Additionally, while these recommendations are based in part on background work done with people who received IPNC, the actual development and implementation of targeted programming should meaningfully involve people with lived experience of IPNC.

In my research on the work of midwives to increase access to midwifery care for people of low SES, however defined by the midwife participants, we learned that midwives doing the most careful and deliberate work to increase access to care were providing CCC. (135) Two particularly salient findings came from that work: with some exception, the midwifery practices most thoroughly engaged in their communities were the Indigenous midwifery practices and what they were doing had been described and practiced for long periods of time, globally, under the umbrella of Indigenous Primary Care. Models of how to better provide care exist. We should look to them for inspiration and guidance.

3.2 Research

We understood then that we would need to develop a research agenda that could assist in changing living conditions rather than just providing palliative treatment.

Rita Giacaman
~ Institute of Community and Public Health, Birzeit University, Palestine (166)

I have discussed several small gaps in the clinical literature in the preceding sections. Notably, access to abortion in urban centers and the impact of inadequate postpartum care are understudied and poorly described in the literature. Additionally, the concept of CCC is not yet well described in the literature or in practice. Further elaboration of what constitutes CCC, its implementation and evaluation as a way of increasing access to care and improving outcomes, however defined and measured, would be worthwhile endeavours.

Despite having identified these potential areas for future investigation, I am loathe to recommend more research from the orientation that characterizes the existing research on IPNC generally. We have known for 30 years that access to PNC and maternal and newborn outcomes are deeply tied to SES. (46) Further, we know from the literature, from our own experience, and from listening to patients that what is required to address this from a health services point of view is low barrier, mobile, humanized health care that is organized around the needs of patients and not providers.

Given the persistence of the problem in the face of decades of research exploring it, I want to consider that research on barriers and facilitators to access or making care accessible is not what is needed here. The question for me really is, given that we know what is needed, *why* has it not been done? And, as someone who is trying to build this type of programming, *why* is it so hard to do? Why are there so many systemic barriers to creating accessible care? These to me, are questions ripe for investigation. I think we need research that excavates, makes explicit and *mainstreams* the ways in which we think health care research "works" and account for when and how it doesn't.

Another interesting question for me is how to bridge this repeatedly observed conceptual gap between the SDoH origins of health inequities and individualized understandings of access and remedies. To my mind there would be great value in excavating the assumptions buried in the transit from externally driven SDoH origins of inequity to its remediation through individual intervention, agency and responsibility. We could then map that on to what we know, from experience and the (primarily) social science literature, about the ways the conditions in which people are born, live and grow are *determined.* These kinds of investigations could explore how ideological assumptions might be directing or limiting what is viewed as both possible and necessary to intervene in this question of IPNC specifically and access to health care more broadly. They might also get at why it is that health system change is so difficult and elusive, despite the evidence that tells us what to do.

Importantly, I do not want to suggest that I have struck upon a novel idea of how to conceptualize health or health research work. Many have and continue to apply critical theory to concepts of health inequities and access, Waitzkin, Navarro, Giacaman, and Allende to name just a few. (166–172) I suggest that it would be wonderful to take up more broadly the thinking of these and others doing the work of implicating social and economic structures in health and therefore focusing on them (too) as sites of intervention.

Some might proport that the use of critical theory and examination of power structures belongs in public or population health; that it is too unwieldy or even overwhelming for those who "just want to be clinicians". Even at the level of clinical care, however, I would suggest that understanding power should shape how we practice. Understanding the role of systems and power in the creation of poverty, homelessness, gender-based violence, addiction etc. can move us from viewing our patients as deficient in character or as individual embodiments of the SDoH, to seeing a whole person, whose plight as a patient is bound up with that of the provider. Understanding and addressing systems of power humanizes and connects us all.

The writing and advocating for better health for people persistently pushed to the margins that resonates with me is that which calls for thinking to guide action. Thinking that contextualizes and resolves the cognitive dissonance between the socially determined origins of health inequity and health system responses so plainly woven throughout my interviews and the literature. Health is political. We need to theorize it politically. We need to be willing to reflect on our own history and current practices, and how they may be contributing to, not solving the problem.

PNC is important. On a case-by-case basis, it offers access to life saving preventative and therapeutic interventions. If done well, it can transform a person's relationship with hitherto oppressive and dehumanizing health and social service systems. It can be a mechanism for keeping families too often separated, together. But we need to be explicit about what it can do and grapple with the importance of what it can't do. Then we must decide how to implicate ourselves as health workers in that reality. If we take as *fact* that injustice and oppression are at the root of what keeps people from accessing PNC and over determines adverse outcomes, we need a "radical honesty" about what the answers to those health problems are. (173) "The answer to oppression is liberation. The answer to inequity is justice." (174)

3.3 Education

We are what we do, especially what we do to change what we are….

~Eduardo Galeano, 1978, Days and Nights of Love and War (175)

There was repeated longing for expertise and leadership on the question of increasing access to PNC throughout this work. Certainly, one valuable route to expertise is through experience, as is largely the case in the current Hamilton context. But as McMaster prepares to launch its Master of Science in Midwifery program with a focus on leadership and social justice, it seems timely to ask some pointed questions about the development of social justice-based leadership and research agendas in midwifery.

I do not have a background in pedagogy, and so will make only some cursory and very broad suggestions about what such a program and others might consider were they to decide to tackle these kinds of questions around the roots of and remedies of health inequities. These suggestions are founded in a reflection on what has brought me to a place where I am perpetually troubling the context and assumptions of the places and ways in which I live and work.

In thinking about teaching to redress health inequities, we could:

- reflect on and excavate what we have been taught about health and the causes of disparities therein.
- orient away from individualizing of SDoH and toward a conceptualization of the social determination of health. (169)

- ground learning in histories of movements and peoples in relation to power and oppression.
- study counter examples of justice-oriented health systems and community organizing that address the health of people from a perspective of challenging power structures (solidarity, not charity).
- be deliberate about the development of course syllabi and citation practices that prioritize works written by and centering those who experience and are deprived by systems of power and not those who administer or benefit from them.
- read and teach foundational texts and practices in social justice: Roland Chrisjohn, Paolo Freire, Angela Davis, Frantz Fanon, Amilcar Cabral, Salvador Allende, bell hooks, Norman Bethune, Eve Tuck, James Baldwin, Walter Rodney, CLR James, Che Guevara, Lee Maracle and Edward Said, Aimé Césaire, for example and to name just a few (suggestions non-systematically drawn from my own transformative reading experiences).

When I think about educating health care providers to address the health of people, at the level of the individual or a population, this is what I think about: How can education be a vehicle for stepping outside of the status quo to see what we take for granted as natural, trouble it and understand it, so we might act to change it?

The implications for practice, research and education that I have put forward as responses to this work are both systematically derived and contained (funded targeted programming) and ontologically imputed and unbounded (deliberate theorizing of ideological underpinnings of health services and education that follows suit). A CCC approach to service provision has the potential to foster a reciprocal relationship between practice and analysis that addresses what I view as the need for both individual clinical interventions and broader structural change. A research agenda based in those CCC based experiences, I believe, would lead to a research agenda aimed at changing living conditions not mitigating them. This work has affirmed for me what I have learned over a career of contextualizing my clinical practice in an explicitly political understanding of the world: we need to look outside of the systems that gave rise to or perpetuate inequity and injustice in the first place for inspiration and learning.

Summary

In this chapter I have tried to answer my research question: *How do healthcare and social service providers understand the problem of IPNC in Hamilton?* Of course, the answers to the question are neither simple, nor monolithic. Healthcare and social service providers understand that the phenomenon of IPNC technically impacts a small number of people but has far reaching clinical, social and moral implications. At the heart of the matter for providers is the incompatibility of the existing provider-centred health and service delivery model and the complex lives of the people it is not designed to serve. Suggestions for increasing access revolve around better accommodating service delivery to meet the needs of clients. The proposal coming out of the work is an interdisciplinary, midwifery-led outreach team that meets people where they are at.

Reading for what is not in the data has offered important insight into what may not figure into providers understanding of IPNC. Namely that sexism and racism did not figure centrally in any responses speaks of more work to do to attend to the realities and needs of racialized people in care and for the application of a feminist lens to the question of how to deliver a service provided by a predominantly female labour force to care for women and gender non-conforming people.

Ultimately however, I end this chapter with more questions than I have answered. The provider discourse herein is haunted by a failure to reconcile the avowed SDoH underpinnings of health inequities with the ongoing and proposed individually mediated interventions. For me, the descriptive work of enumerating barriers and facilitators to care and collating them into suggestions for practice has been subsumed by a longing for more fleshed out answers (than space, time or ability permit here) to the questions of how we theorize our understandings of health inequities and therefore our practiced and imagined responses to them.

Chapter 6. Conclusion

This ID study of provider understandings of IPNC confers with the existing research on the subject and adds to a relatively small body of literature proposing and/or evaluating novel service delivery models aimed at increasing access to PNC. It further points to prospective areas for future investigation, including access to abortion and post-partum care, the elaboration of the concept of CCC and subsequent implementation and evaluation of potential models of CCC.

This work punctuates almost a decade of my thinking, writing, practicing and organizing around IPNC. Having twice used what I learned from the mixed methods program of which this study is a part to apply for base funding from the Ministry of Health and Long-Term Care, the goal of a robust, fully funded interdisciplinary midwifery-led outreach practice remains elusive. However, the process, from that very first meeting with shelter workers to writing this conclusion has been part of a transformative process, for me as a provider and a thinker. The work has also had ramifications in the community at large. The HMOT continues to care for pregnant people experiencing homelessness and it has generated interest in the phenomenon of IPNC among other care providers in the city. It has positioned midwives as potential leaders of novel care delivery models in the city. I would also suggest that the HMOT and this research program have been part of creating a greater awareness of the problem of IPNC and a willingness to work across disciplines and sectors to address it that I did not see even 5 years ago. Factors independent of this work have also forced the issue in the PNC community. The extent of and the exploding drug policy and housing crises and their impact on health are almost impossible for clinicians to ignore. One quickly runs up against the limit of their individual clinical tool kit when caring for people so deprived of resources by systems of power. The COVID 19 pandemic has only exacerbated those crises and has propelled increased collaboration between health and social services, the impact of which has yet to be appreciated.

Finally, while it was not explicitly part of the original intention of my research program, I have learned and been convinced that there are fundamental ideological barriers to clearly seeing the scope and source of the problem of access to care as rooted in power structures. It was beyond the scope of this thesis to explore those findings in depth, but they have provided fodder and inspiration for future exploration and investigation. This cursory interpretive critical analysis has very helpfully informed how I will continue to engage on this subject of access to health care and the role of health care providers in maintaining or working to undo health inequities. This process has convinced me that challenging the systems that breed inequity instead of trying to make the patient less unequal, whether by their own volition or the intervention of health and social services, is fundamental and is the work that I am interested taking up moving forward.

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Appendix A- Email Recruitment Script

Inadequate prenatal care in Hamilton:
An investigation into how to improve prenatal care access for marginalized populations

Email Recruitment Script (Copy & Paste)

E-mail Subject line: McMaster Study – Inadequate prenatal care in Hamilton: An investigation into how to improve prenatal care access for marginalized populations

Dear *[name of participant]*,

We are conducting interviews/focus groups about the experiences of care providers in caring for people with inadequate prenatal care. We aim to identify facilitators and barriers to accessing prenatal care and how to improve access to care. We are doing this as part of research at the McMaster Midwifery Research Centre in Gynecology and Obstetrics in Hamilton, Ontario. Our research team includes Dr. Liz Darling, Lisa Nussey, Dr. Andrea Hunter, Sarah Simpson and Dr. David Small.

Study procedures:
We're inviting you to do a [one-on-one interview OR participate in a focus group] that will take about 60-90 minutes. Interviews will be conducted by me or one of the other researchers on our team. We will ask you questions about your experiences providing care for people with inadequate prenatal care. We will take handwritten notes to record your answers as well as use an audio recorder to make sure we don't miss what you say.

Risks:
It is not likely that there will be any risks with the interview. However, you may feel uncomfortable answering certain questions. You do not need to answer questions that make you feel uncomfortable or that you do not want to answer. You can stop taking part at any time.

Benefits:
It is unlikely that there will be direct benefits to you, however, by better understanding access to prenatal care, researchers and others may be able to improve access in the future.

Confidentiality:
Due to the nature of focus groups we cannot ensure complete confidentiality. We will not identify quotes or ideas from any one person of this group but rather summarize the ideas as a group. We will not use your name or any information that would allow you to be identified. No personal information will be on the recordings of the discussions and they will be kept in a locked filing cabinet or password protected computer until the end of the study, at which time these files will also be destroyed. Any information from the focus groups will be reported in

collective form only (i.e. without identifiers to the study's participants). Participants will also be asked to use a pseudonym (false name) to help with confidentiality.

Eligibility
Eligible participants include: obstetricians, pediatricians, family physicians, nurses, social workers, and midwives involved in providing care to people with inadequate prenatal care in Hamilton, ON.

I have attached a copy of a Letter of Information about the study that gives you full details. This study has been reviewed and cleared by the Hamilton Integrated Research Ethics Board (HiREB). If you any have concerns or questions about your rights as a participant or about the way the study is being conducted, you can contact:

Office of the Chair
Hamilton Integrated Research Ethics Board (HiREB)
905-521-2100 x 42013

If you are interested in participating or simply want to know more about the study, please contact:

Lisa Nussey, RM
lisa.nussey@gmail.com
905-966-0242

We would like to thank you in advance for your time and consideration.

Sincerely,
[Insert name of sender]
On behalf of the research team
McMaster Midwifery Research Centre
McMaster University, Hamilton ON

Appendix B- Interview Guide Generic

INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS

In our study we have defined inadequate PNC as four or less visits, as per the WHO guidelines on PNC at the time the study was initiated. We also consider people who only access care in the second and third trimester as having received inadequate PNC. We are interested in exploring health care providers' perceptions of the barriers and facilitators to PNC, as well as your ideas about how PNC services could be redesigned to reduce disparities in PNC utilization.

To start, can you describe your experiences of providing prenatal care to patients/clients who do not access adequate care?

> *Prompts: What is it like for you to provide intra-partum care or urgent assessments for patients/clients who have had little or no prenatal care?*
>
> *What is it like for you to provide care to newborns of mothers who do not access adequate PNC?*
>
> *When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care?*
>
> *Are there any other problems that inadequate prenatal care creates?*
>
> *Do you think inadequate PNC use as a problem in Hamilton? Why or why not?*

Is there anything else about your experiences in providing care to people or their newborns who do not access adequate PNC that you would like to share before we move on talking about to barriers to care?

What do you think are some of the reasons why some pregnant people don't access PNC?

> *Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)*
>
> *What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)*
>
> *What people do you think are least likely to access adequate PNC?*

Do you or your colleagues currently have any measures in place to help decrease some of these barriers you have described? Can you tell me about them?

> *Prompt: Why did you institute this?*

What services currently exist in the city to help pregnant people access PNC? Do you make use of those services? Why or why not?

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

> *Prompts: Decentralized care, incentives, more flexible clinic hours, mobile care, better use of existing resources- strengthening of care provider and service provision networks, more responsive care, interdisciplinary "one stop shopping".*

What do you think should be the priorities in Hamilton in terms of services for people who struggle to access adequate PNC?

> *Prompts: Who do you think should take the lead in developing new services? Would you be interested in participating?*

Appendix C- Interview Guide CAS Workers

INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS-CAS

In our study we have defined inadequate PNC as four or less visits, but want you to think about this in terms of what would warrant the development of special programming.

To start, can you describe for me examples of cases of your experiences of providing prenatal care to patients/clients who do not access adequate care? GET AT SOME EMOTIONS AND EXPERIENCES.

> *Prompts: What is it like for you to service for patients/clients who have had little or no prenatal care?*
>
> *When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care? Talk to me about feelings you have around this difficult work.*
>
> *Are there any other problems that inadequate prenatal care creates?*
>
> *Do you think inadequate PNC use as a problem in Hamilton? Why or why not?*
>
> *Talk to me about what you see for moms in the postpartum. How does that make you feel?*

What do you think are some of the reasons why some pregnant people don't access PNC?

> *Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)*
>
> *What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)*
>
> *What people do you think are least likely to access adequate PNC?*
>
> *CAS aversion persists: messaging of changing practices is not getting to families. Changes to CYFSA?*

What is your protocol or management plan for clients who are not accessing PNC? Do you or your colleagues currently have any measures in place to help decrease some of these barriers you have described? Can you tell me about them?

> *Prompt: Why did you institute this?*

What is your relate with the HC system like?

> *Talk about methadone docs. Others obstructing/facilitating care.*

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

Prompts: Decentralized care, incentives, more flexible clinic hours, mobile care, better use of existing resources- strengthening of care provider and service provision networks, more responsive care, interdisciplinary "one stop shopping".

Talk about being mandated to reach people.

Specialized teams? Part of OHT's?

Cut backs.

Appendix D- Interview Guide Pediatricians

IPNC STUDY INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS- Peds

To start, can you describe your experiences of providing prenatal care to patients/clients who do not access adequate care?

Prompts: Can you give me an example of an experience that you have had.

What is it like for you to provide care to newborns of mothers who do not access adequate PNC?

When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care?

After the initial "problems" of care plan to account for missing info, what things follow in caring for this population. Interestingly, you (and social work) probably have the most contact with moms after the birth.

Do you think inadequate PNC use as a problem in Hamilton? Why or why not? How often do you feel it happens in your nursery? Do you have a sense of who's patient's they are? What is it like at Mac vs SJHH?

What do you think are some of the reasons why some pregnant people don't access PNC? Laundry list it.

Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)

What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)

What people do you think are least likely to access adequate PNC?

Do you or your colleagues currently have any measures in place to help decrease some of these barriers you have described? Can you tell me about them?

Care pathway?

My perception is that there has been some shift in thinking and acting since this project started, what is your perception?

What services currently exist in the city to help pregnant people access PNC? Do you make use of those services? Why or why not?

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

> *Usual model change stuff: incentives, drop ins etc…*
>
> *How does the peds piece feed into that?*
>
> *Should there be a specialty? For mom's it seems clear that some special programming and thus HCP might be useful. Is this true of peds?*

Talk to me about the CAS.

HIV rates in IV drug users is on the rise. PH issued an alert in summer. Does that info get back to you. Does it impact care.

Stigma by care providers. Interestingly many providers have raised nursing as an issue.

You can't work harder than the patient.

Mat care providers have commented on how they don't follow the baby. What is your perception of that clinical divide? *How often do you meet moms antenatally?*

Appendix E Interview Guide Midwives Focus Group

IPNC STUDY INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS- Midwives

In our study we have defined inadequate PNC as four or less visits, as per the WHO guidelines on PNC at the time the study was initiated. We also consider people who only access care in the second and third trimester as having received inadequate PNC. We are interested in exploring health care providers' perceptions of the barriers and facilitators to PNC, as well as your ideas about how PNC services could be redesigned to reduce disparities in PNC utilization.

To start, can you describe your experiences of providing prenatal care to patients/clients who do not access adequate care?

> *Prompts: Can you give me an example of an experience that you have had.*
>
> *What is it like for you to provide intra-partum care or urgent assessments for patients/clients who have had little or no prenatal care?*
>
> *What is it like for you to provide care to newborns of mothers who do not access adequate PNC?*
>
> *When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care?*
>
> *Are there any other problems that inadequate prenatal care creates?*
>
> *Do you think inadequate PNC use as a problem in Hamilton? Why or why not?*

What do you think are some of the reasons why some pregnant people don't access PNC?

> *Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)*
>
> *What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)*
>
> *What people do you think are least likely to access adequate PNC?*

So many describe this work as difficult, why do you do it?

> *Would you do it full time?*
>
> *Do you think it should be a specialty?*

What services currently exist in the city to help pregnant people access PNC? Do you make use of those services? Why or why not?

Who is doing this work in the city?

Funding cuts are repeatedly raised as an issue. Do you feel that in your work?

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

Prompts: Decentralized care, incentives, more flexible clinic hours, mobile care, better use of existing resources- strengthening of care provider and service provision networks, more responsive care, interdisciplinary "one stop shopping".

What do you think should be the priorities in Hamilton in terms of services for people who struggle to access adequate PNC?

One of the issues for midwifery is a lack of leadership in the decision making circles. Angela has

Described how none of the 58 privileged midwives in the city volunteered to be part of the OHT, I am often the only midwife in the room…

Who do you think should take the lead in developing new services? Would you be interested in participating?

One thing that is certain is that the work to care for this population needs to be collaborative in that MWs have the mobility and time and OBs have the medical expertise. Talk to me about collaboration in general and for this type of work in specific. The good and the bad.

Territoriality

Funding models

Distrust between providers

Mw's opt in, everyone else just has to do it

Involving social work and reluctance to do it

The final thing I want to talk about is more of a curiosity at this point. But talk to me about the role of health care in social change. That is our responsibility to attend to the SDoH at a broader level. The barriers to care are in one sense systemic, but the barriers to health really aren't. So what is the role of health providers on that front and how do you see that working or not working now and in the future?

Appendix F Interview Guide Obstetrician

IPNC STUDY INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS- Obstetrician

In our study we have defined inadequate PNC as four or less visits, as per the WHO guidelines on PNC at the time the study was initiated. We also consider people who only access care in the second and third trimester as having received inadequate PNC. We are interested in exploring health care providers' perceptions of the barriers and facilitators to PNC, as well as your ideas about how PNC services could be redesigned to reduce disparities in PNC utilization.

To start, can you describe your experiences of providing prenatal care to patients/clients who do not access adequate care?

> *Prompts: Can you give me an example of an experience that you have had. ASK FOR MANY How does it make you feel? How do you think the patient feels? How does how the patient feels make you feel?*
>
> *What is it like for you to provide intra-partum care or urgent assessments for patients/clients who have had little or no prenatal care?*
>
> *When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care?*
>
> *Are there any other problems that inadequate prenatal care creates?*
>
> *Do you think inadequate PNC use as a problem in Hamilton? Why or why not?*

Is there anything else about your experiences in providing care to people or their newborns who do not access adequate PNC that you would like to share before we move on talking about to barriers to care?

What do you think are some of the reasons why some pregnant people don't access PNC?

> *Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)*
>
> *What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)*
>
> *One of the things that has surfaced in patient interviews is the HCP's inability to relate to their lives, just how difficult they are. Violence, loss, trauma.*
>
> *What people do you think are least likely to access adequate PNC? THIS IS WHERE CAN ASK ABOUT DEFAULTING TO HOMELESSNESS AND DRUG USE?Are you seeing more cases of HIV positive women?*

Do you or your colleagues currently have any measures in place to help decrease some of these barriers you have described? Can you tell me about them?

Prompt: Why did you institute this? Talk to me about what it has meant to have this work put on the agenda by this project? Now the OHT's are going to focus on this…

What services currently exist in the city to help pregnant people access PNC? Do you make use of those services? Why or why not?

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

Prompts: Decentralized care, incentives, more flexible clinic hours, mobile care, better use of existing resources- strengthening of care provider and service provision networks, more responsive care, interdisciplinary "one stop shopping".

What do you think should be the priorities in Hamilton in terms of services for people who struggle to access adequate PNC?

Prompts: Who do you think should take the lead in developing new services? Would you be interested in participating?

Can you talk to me a little bit about the collaboration piece?

So for example, this is often a high risk population we are talking about, but there are many barriers to accessing high risk care, as we know. You and I have talked before about midwives caring for high risk and not even necessarily recognizing it, then it falls to you to manage that patient's care, when you would have managed it up front differently. Or what kind of collaboration do you see as possible with the PROSPR clinic, for example?

We recognize that most of the barriers to care are structural, ie poverty, homelessness, addiction (which is a mechanism for coping with the structural inequities in the view of many), racism. These are "causes" that lie outside of the health care system proper, but are obviously not unrelated to health. Do you think there is a role for HCP in making changes in those structures, as the people in society vested in health. So for example, if you know as a physicinan that the thing that is going to help your patient most is actually housing, do you see yourself as having any role in dealing with the housing issue?

Appendix G Interview Guide Family Doctor/Nurse Practitioner

IPNC STUDY INTERIEW GUIDE FOR HEALTH CARE PROFESSIONALS- Family Doctor

In our study we have defined inadequate PNC as four or less visits, as per the WHO guidelines on PNC at the time the study was initiated. We also consider people who only access care in the second and third trimester as having received inadequate PNC. We are interested in exploring health care providers' perceptions of the barriers and facilitators to PNC, as well as your ideas about how PNC services could be redesigned to reduce disparities in PNC utilization.

To start, can you describe your experiences of providing prenatal care to patients/clients who do not access adequate care?

Prompts: Can you give me an example of an experience that you have had.

When people present with no/little PNC, do you ever wish you had access to more information about them? If yes, what information? Can you tell me more about how that impacts your ability to provide care?

Are there any other problems that inadequate prenatal care creates?

Do you think inadequate PNC use as a problem in Hamilton? Why or why not?

Talk about your experience on inpatitent addictions caring for pregnant women please.

Is there anything else about your experiences in providing care to people or their newborns who do not access adequate PNC that you would like to share before we move on talking about to barriers to care?

What do you think are some of the reasons why some pregnant people don't access PNC?

Prompts: What do you think are some of the personal factors that are barriers? (finances, childcare, chaotic lives, transportation)

What do you think are some of the systemic factors that are barriers? (fear of CAS, fear of judgement by HC providers, long wait times in offices for short visits)

What people do you think are least likely to access adequate PNC?

Do you or your colleagues currently have any measures in place to help decrease some of these barriers you have described? Can you tell me about them?

Prompt: Talk about Claudia's interview: why would I facilitate care if I am providing them care, I just assume others are doing that work, so entrenched I don't see the barriers, and more we could do to bring people in. Don't really strategize as a group about this.

Maternity Centre is thought to be the place for "this" population, but there seems to be some issues with collaboration, as described above or a recognition of need to be proactive. What do you think about that?

What services currently exist in the city to help pregnant people access PNC? Do you make use of those services? Why or why not?

What changes do you think could be made to the way care is delivered that would facilitate access to PNC for those who struggle to or don't want to access it?

> *Prompts: Decentralized care, incentives, more flexible clinic hours, mobile care, better use of existing resources- strengthening of care provider and service provision networks, more responsive care, interdisciplinary "one stop shopping".*

Barriers to collaboration?

-funding

-territoriality

Let's try to talk about racism in health care for a bit. Do you think it exists? How does it manifest? How does it impact care and care providers?

What is your sense of what is possible?

Appendix H Participant Consent

MACMIDWIFERY

McMaster University

Inspiring Innovation and Discovery

LETTER OF INFORMATION & CONSENT FOR PARTICIPANTS:

Inadequate prenatal care in Hamilton: An investigation into how to improve prenatal care access for marginalized populations

Principal Investigator:

Dr. Liz Darling
Associate Professor, Department of Obstetrics and Gynecology
Associate Member, Department of Health Research Methods, Evidence, and Impact
Adjunct Scientist, ICES McMaster
McMaster University
905-525-9140 x 21597
Email: darlinek@mcmaster.ca

Co-Investigator:
Lisa Nussey, BHSc, RM

Funding Source: Association of Ontario Midwives (AOM)

Inclusion of anonymized data in learning process: I am doing this research for my Masters thesis. This follow up consent is to request that I be able to use a part of the transcript of our interview for learning purposes in a research methods course I am taking that is made up of 3 PhD students, the instructor and myself. Before being discussed in class, your name and any other identifying information will be removed from the transcript. The focus of the class discussion and training is on how researchers like me gather, understand and analyze the information that study participants share with us. Both the students and the faculty instructor will sign an agreement that the transcript from your interview will remain confidential. If you do not want the transcript used in the course, your interview will still be a part of the research study as originally agreed. The remainder of this consent is exactly as you have previously seen it. Thank you for considering this request.

Purpose of the Study:

You are invited to take part in this study to examine the topic of inadequate prenatal care (PNC) in Hamilton, specifically looking at how to improve prenatal care access for marginalized populations. This study explores the experiences of healthcare providers who provide intrapartum and postnatal care to people with inadequate PNC and their babies. We also aim to understand the barriers and facilitators that impact access to PNC for marginalized populations, as well as how to overcome them to improve access and outcomes.

Procedures involved in the Research:

Your involvement would include a single interview/focus group, approximately 60-90 minutes long. The focus group will be conducted with 3-8 participants. You will be asked questions by a trained facilitator about experiences working with people with inadequate PNC during the antenatal, intrapartum and neonatal period. The focus group will be audio recorded and transcribed verbatim.

Potential Harms, Risks or Discomforts:

You do not need to answer questions that you do not want to answer or that make you feel uncomfortable. You may decline to participate, decline to answer any questions or withdraw from the study at any time.

Potential Benefits

The research will not benefit you directly. We hope to learn more about how prenatal care access can be improved for populations at risk.

Confidentiality

Due to the nature of focus groups we cannot ensure complete confidentiality. We will not identify quotes or ideas from any one person of this group but rather summarize the ideas as a group. We will not use your name or any information that would allow you to be identified. No personal information will be on the recordings of the discussions and they will be kept in a locked filing cabinet or password protected computer until the end of the study, at which time these files will also be destroyed. Any information from the focus groups will be reported in collective form only (i.e. without identifiers to the study's participants). Participants will also be asked to use a pseudonym (false name) to help with confidentiality.

Please be advised that although the researchers will take every precaution to maintain confidentiality of the data, the nature of focus groups prevents the researchers from guaranteeing confidentiality. We remind all participants to respect the privacy of your fellow participants and not repeat what is said in the focus group to others.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to withdraw at any time, for whatever reason, even after signing the consent form, or part-way through the study. If you decide to withdraw, there will be no consequences to you. In cases of withdrawal, any data you have provided will be destroyed unless you indicate otherwise. If you do not want to answer some of the questions you do not have to, but you can still be in the study.

Information about the Study Results:

If you would like a brief summary of the results, we can send this to you when it is available.

Questions about the Study: If you have questions or need more information about the study itself, you can contact the Principal Investigator at:

Dr. Liz Darling
Email: darlinek@mcmaster.ca
905-525-9140 x 21597

This study has been reviewed by the Hamilton integrated Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them.

If you have any questions about your rights as a research participant, please call:

Office of the Chair

Hamilton Integrated Research Ethics Board (HiREB)

CONSENT

☐Yes I have read the information presented in the information letter about the study being conducted by Dr. Liz Darling of McMaster University.

☐Yes I have had the opportunity to ask questions about my involvement in this study and to receive additional details I requested.

☐Yes I understand that the interview will be audio recorded and that the interview cannot be conducted without the use of audio recording.

☐Yes I understand that if I agree to participate in this study, I may withdraw from the study at any time.

☐Yes I will be given a copy of this form.

☐Yes I agree to participate in the study and to share anonymized data with the PhD course as described.

☐Yes I agree to maintain the confidentiality of the information discussed by all participants and researchers during the focus group session. *[If you cannot agree to this condition, please discuss this with the researcher(s) as you may be ineligible to participate in this study.]*

____

Name of Participant (Printed)

____ _________________________

Signature Date

1. I agree to have my responses used for this project and for future related projects.

☐ Yes

☐ No

2. I would like to receive a summary of the study's results.

☐ Yes, please send them to me at:

Email address: ____

OR

Mailing address: ____

☐ No, I do not want to receive a summary of the study's results.

3. I agree to be contacted for future research, and understand that I can always decline the request.

☐ No

☐ Yes, I would prefer to be contacted by:

Phone: ____

OR

Email: ____

Signature of person obtaining consent

In my judgement, the participant is voluntarily and knowingly giving informed consent and possess the legal capacity to give informed consent to participate in this research study.

_______________________________________ _______________________

Name & Title (Printed) Date

Signature _______________________________________