Mothering on the Margins: A Narrative Inquiry into the Experiences of Precariously Housed Women Negotiating Harm and Care.

by

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Abstract

This paper-based doctoral dissertation explores the experiences of three women, who are precariously housed, and who disclosed substance use during their pregnancy or early post-partum period. Guided by narrative inquiry's commitment to relational ethics and responsibilities, I formed close relationships with three participants - Nikki, Renate, and Marilynn. I developed relationships with each of the women, which allowed us to explore their complex and challenging experiences with care and harm reduction services. Through regular conversations and times spent alongside Nikki, Renate, and Marilynn during medical appointments, and day-to-day errands, our relationships grew. During this time, I took extensive field notes and tape-recorded some of our conversations. The development of interim research texts, named narrative accounts, were guided by these field texts and ongoing negotiations with Nikki, Renate, and Marilynn. In the final research texts, composed of three papers, I reflect on the substantive and methodological contributions of narrative inquiry in research and nursing care. I also return to the personal, practical, and social justifications that guided this research. This work serves to challenge practices that categorize or classify those who access health services, at the expense of relational care. Sharing the experiences of Nikki, Renate, Marilynn, and our relationships, encourages the recognition of substance use and transition into motherhood as complex, rich, heartfelt, and hopeful.

Preface

While I have always held an interest in maternal health, my involvement in this project would not have been possible without the continued support of a team of researchers. It is within this context that I have come to raise questions about health equity, notions of harm, and recognize the importance of storied lives. This thesis is an original work by Georgia Dewart. The research project, led by Dr. Vera Caine, Marilss Taylor, and Dr. Solina Richter, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board [Pro00040818], Project Name: *Inquiring into HIV prevention and care for pregnant and early parenting women experiencing homelessness.* [CIHR CBA – 1217102]. This research project was possible through funding from the Canadian Institute of Health Research (CIHR).

This thesis includes three academic papers that have been submitted for consideration in peer-reviewed research journals. Georgia Dewart lead the theoretical development and writing in each of these three papers, however the work would not have been possible without the engagement of all contributing authors. The papers are listed in order below:

Dewart, G., Estefan, A., Clandinin, J. & Caine, V. (Submitted, 2018) Waiting as performative and relational: A narrative inquiry study into the experiences of women who use substances. *Scandinavian Journal of Caring Sciences.* [Chapter 3]

Dewart, G., Kubota, H., Clandinin, D.J., Berendonk, C., & Caine, V. (Submitted, 2018). Lugones' metaphor of 'world traveling' in narrative inquiry. *Qualitative Inquiry.* [Chapter 4]

Dewart, G., Caine, V., Richter, S., Taylor, M., & Tootoosis, R. (Submitted, 2018) (Re)considering harm reduction: A recognition of an individual life and gender. *Harm Reduction.* [Chapter 5]

Dedication

This dissertation is dedicated to the mothers, who welcomed me into their homes,
introduced me to their families, and told me their stories.
Their honesty and openness have helped me learn, grow, and see the world differently.
Nikki, Renate, and Marilynn thank you for sharing your knowledge, strength, and hope.

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Reader's Guide

I begin this dissertation by situating the research within personal, practical, and social justifications. The personal justifications begin with a story of my early nursing experiences, one that shaped my return to graduate studies and interest in this research. The practical justifications build on my experiences as a registered nurse and addresses the importance of this research. The social justifications section is divided into two sections: social action and theoretical justifications. Social action explores factors, which disproportionately affect the lives of precariously housed women and their families, while the theoretical justifications addresses the need for a narrative understanding of women's lives. The personal, practical, and social justifications are followed by my research puzzle. The next two sections, methodology and methods, provide an overview of narrative inquiry including details of how this research was taken up. In chapter 2, the narrative accounts of the three participants are shared with detailed explanations of the individual representational choices made during the writing of each account. These accounts are then followed by three publications entitled:

a) *Waiting as performative and relational: A narrative inquiry study into the experiences of women who use substances*
b) *Lugones' metaphor of 'world traveling' in narrative inquiry*
c) *(Re)considering harm reduction: A recognition of an individual life and gender*

My dissertation ends with a discussion on the implications for nursing.

Chapter 1: Introduction

Early in my clinical work as a nurse, I began to wonder often about the care the health care system provided mothers. In particular, I questioned the care system's ability to support women who disclosed substance use during pregnancy. There was minimal collaboration between acute care and community settings. Stigma and shame framed many health care interactions for women who disclosed substance use. Apprehension stories, narratives of infants being taken away shortly after birth, were commonplace, particularly in acute care settings. I worked in an acute care setting where I witnessed this. Yet, in my position as a nurse, I did not feel close enough to patients to engage in conversations regarding complex subjects such as substance use, parenting, and access to health care. In particular, the experience of not being able to engage with pregnant women, in relational and ethical ways, prompted my return to graduate education. The need for more supportive nursing care foregrounded many conversations in my doctoral research. I returned often to thoughts of previous patients as I developed this research and what I saw as the silences around their experiences in the care system. My clinical work as a labour and delivery nurse framed my research puzzle and the focus of my work on the experiences of mothers. Using narrative inquiry as the methodology, this work explores the experiences of three precariously housed women, who disclosed substance use during pregnancy and their early parenting period, to better understand their experiences.

Turning towards Stories of Experience

Why this study?

Narrative inquirers need to clarify the justifications of a study both at its inception and throughout the research process (Clandinin, 2013) These justifications are significant not only to funding bodies supporting the research, but also to the narrative inquirers engaged in this work.

Grounding the research work early on in the design process supports researcher reflexivity; understanding narrative beginnings helps researchers acknowledge their changes in thoughts and understandings. These justifications also help frame the work in a larger socio-political context. In narrative inquiry, the reasons behind a study are often developed in reflection on the personal, practical, and social justifications guiding the research (Clandinin, 2013).

Personal Justifications

I return often to the stories of my early work as a student nurse, not only to reflect on possibilities but also to understand how fundamentally my viewpoint has changed in relation to time, place, and my relationships. It has taken time to appreciate the reasons why I began this narrative inquiry study. It required both an understanding of my own narrative beginnings and an acknowledgement of the person I am becoming throughout the research process. My choice to pursue graduate studies was influenced by many factors: a family that valued higher education, a love of learning, and my clinical experiences, among others. My work as a student and novice nurse were instrumental in grounding the personal justifications for the research. For this reason, I begin my justification section with a story from practice; a story of an experience that I return to often.

Narrative Beginnings.

In the months leading up to my final student placement in obstetrical care, I poured over textbooks and nursing journals. I memorized baseline vitals and studied images of fetal heart rhythms in hopes that I would be equipped for the work on the unit. On an early Thursday morning in February, I finally began my first shift as a student on a labor and delivery unit. I was filled with anticipation and anxiety.

I had not slept well the night before and was anxious about making a good impression. The lack of sleep was easily forgotten though when I stood beside the staff in my wrinkled scrubs. Everything in that experience was new - the smells and the sounds. The nerves that turned my stomach into knots were exhilarating. After four years of school and being a student, I could imagine myself being a nurse in this place. Everyone, myself included, wore matching mint green scrubs. It seemed only natural that together we would attend to the experience of birth in matching outfits. Wearing the green uniform and running shoes made me feel like an athlete on a team. Together, this team – our team - was ready at the call of a child not yet born and a family that had to make fast decisions.

The delivery room was larger than any space I had been in, in a hospital, and it was very different from the packed rooms of a medicine unit, where patient beds, stretchers, and bedside tables were crammed into the space like Tetris pieces. The lights were dimmed and in certain moments, I almost forgot I was in a building marked by humming florescent fixtures and pastel paints. Yet, in this large room filled with new equipment and hospital staff, what I remember most was the sense of fear and frustration from the care providers and the lack of connection between the care providers and parents. As the stress in the room grew, I almost became overwhelmed. I was thankful to be standing out of view and unnoticed. It was there that I thought to myself what am I supposed to do? Who was I in all of this? What was my role as a student? As a beginning nurse?

In this delivery, the baby, instead of being cephalic (head down) in the pelvis, had decided to attempt its entry into the world face first – a position which can make delivering vaginally unsafe for both the mother and the infant. Up to this point, I had read about this in textbooks and had prepared to encounter various obstetrical emergencies. Out of all possibilities, I had never imagined that this would happen on my very first day on the unit. From my place on the side, watching, I began to awaken to the stress caused by concerns around suspected illegal substances, specifically, there were suspicions that the patient and her partner had used illegal substances while admitted in the hospital. This was of particular concern with the impending delivery, as the need for surgery grew. The baby and mother would not be fine without an intervention[1]. The increasing stress on the care team, especially the anesthesiologist, was palpable. Repeatedly he asked what illegal substances the patient had just consumed. I remember thinking that he must be worried about his own decisions for medication administration. I also noticed that with each question she was asked, the patient retreated into herself, avoiding eye contact, refusing to answer. The tension between care providers and patient increased. Eventually, the patient was rushed to the operating room and, rather than receiving a spinal anesthetic, which would have been the usual procedure, she was placed under general sedation. For a brief moment, as she was sedated, a quietness was present. Looking back now, I try to remember when the quietness was interrupted, but I do not remember if the baby arrived into this world crying.

I graduated five years ago. Now, in hindsight, I remember the difficult births where a baby enters this world weak, limp, and barely breathing. These difficult deliveries are the births that stay with me. They are the ones that show up in my nightmares, stirring me from sleep, the ones that scare me, in real life and in my dreams. My breath is held hostage at the back of my throat and not until I hear a baby's desperate cry, or a first forceful breath, can I relax. In difficult births, I am thankful for neonatal nurses, respiratory therapists and sometimes neonatologists that stay close and assist if there is a need to resuscitate. Nonetheless, it was that first delivery that

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[1] Facial presentation in labour is associated with higher rates of fetal distress and failure to progress in labour, leading to a 20 percent rate of cesarean sections (Shaffer, Cheng, Vargas, Laros, & Caughey, 2006).

troubles me. Perhaps, I do not remember the birth outcome, or even if the baby was a boy or a girl, because the baby entered the world screaming – oblivious to how its short life had already been so changed by the encounter with health care. In most deliveries, the baby is taken, cradled in a physician's hands, to the warmer where it is rubbed dry and wrapped in warm blankets and handed to the woman's partner. During this delivery, the father was sent from the unit out of anger, a response to his suspected involvement in the substance use. This time after the baby was safely bundled, the staff in the nursery cared for it. The nurses in labour and delivery then tended to the mother, who now was even more marginalized than when she stepped though the hospital doors.

After the delivery, the patient, still sedated, lay peacefully as the obstetrician stapled her incision closed. She stayed asleep as we rolled her side to side cleaning her, dressing her in a fresh gown and transferred her from the operating table to a real bed. The sense of calm was soon broken. In recovery, as she awoke from the general anesthetic she was in pain. What was I supposed to do? Not in the larger sense of what could be improved in our care system or even our society. No – I wanted to look like I knew how to be a good student and a good nurse. I stood and watched a nurse explain to a confused and hurting mother about the steps she was taking while the monitors recorded her heart rate, blood pressure, and oxygen saturation. As the nurse gave intravenous morphine for the mother's pain, I did one thing I knew how to do - I counted her breaths, sedated and slow from the analgesic. As I counted her breaths, I felt relieved as they returned to a steady, regular rhythm – and was thankful that we would be transferring her soon. It was only then that I returned to my own breathing, quick and staccato from the adrenaline of the situation. Soon she would no longer be our problem.

Suffocating.

Years later, I feel so far removed from that first experience on the labour and delivery unit. Sitting at a desk in the nursing faculty, looking out towards cement buildings and an empty sky, I exhale and begin to inhale a new breath. This intake of air reminds me of the relief in hearing a baby cry, clearing its lungs of fluid and sound. I am drawn back to the experience in the hospital when I slowly counted respirations of the patient rushed for a cesarean section. During my relaxed exhalation, I remember the relief in knowing we would transfer her care, relieving the nurses on my unit, my team, of responsibility. This first day on the hospital unit, I recollect how impressed I was by the expertise of the staff. They acted quickly, efficiently, and worked together as a team better than any group I had ever seen. Looking back now, I remember that I did not feel empathy or even sympathy for the mother and her baby. Instead, I mostly felt admiration for the care team. They were the professionals I sought to emulate. I wanted to be skilled enough to work on a team where a nod would set in motion systematic delivery of care. As the stress and need for the cesarean section grew more and more pressing, the staff stayed composed, completing the necessary steps for a delivery. I trusted their precise and seemingly rational decision-making. They cared about the baby and that the baby was delivered alive and healthy. They and I were not the ones who left the hospital room, with its monitors and call bells, to get *high*. I thought, then, if the mother woke up in pain without her partner at the bedside, it was because she and her partner had been stupid and irresponsible. They were not doing what needed to be done to ensure their baby was born alive and healthy. I recollect that I wanted to look after a patient who was not so challenging. I wanted to do more than count respirations, both the patient’s and my own. How was I supposed to learn skills and techniques just standing to the side? How could I show the unit I was a good nurse if I merely stood there? Together, these feelings and questions meant that in the minutes I helped care for this mother, restless in the recovery bed from pain, I felt disappointment, but disappointment mixed together with disdain. I lived, I think now, with a kind of arrogant perception (Lugones, 1987).

Now, as I write, I feel embarrassed and guilty about how this family's experience unfolded. I know now that this could be different. At the time though, I did not say anything. As a student nurse, I did not speak. Not out of a need for good grades or possible employment opportunities at the end of the clinical placement, instead, in that first moment of admiration for the care team, I did not recognize my behavior or the behavior of the care team as unethical. Additionally, if I had acknowledged this as unethical, it was unlikely that I would be able to imagine a different story than the one told that day.

As I reflect on this experience now, I recognize that the woman's story was already set within an institutional narrative that was hard to be disrupted. I wonder why as a student nurse, I could not imagine other possibilities for the mother's care. To understand this perspective, I think back to my impression of the many individuals present in this experience. I did not question why the anesthesiologist did not take the time to explain his concerns in a nonjudgmental tone. His abruptness with this patient was probably grounded in his own fear and anxiety for her wellbeing. I did not blame one of the many nurses in the room who stood alongside the physician, shaking their heads at the mother who would not put the health of her infant first. Perhaps shaking their heads and doing nothing was a way they coped. I was offered an easy solution, one I did not question: blame the parents. Substance use during pregnancy remains highly stigmatized with the mother being viewed as a source of harm in her infant's life (Boyd, 2015). For this reason, the decision to look down with contempt on parents who use illegal substances is socially acceptable. On my first shift in the hospital, my respect for the education and experience of the care providers meant I only knew one story; the only possibility was that the mother was at fault; that she did not care.

Sitting at my desk now, I can change nothing about this past experience and when I remember the patient's pain and fear, I feel my chest tighten. To help with this guilt, I regulate my breaths. As I slowly exhale, my mind relaxes and I begin to inquire into my experiences from my early days of working as a nurse. It is a call for me to rethink how I work with others. As a newly qualified nurse with little experience in obstetrical care, I focused on my matching scrubs and being part of a team. I was not aware of how I was already complicit in the institutional stories that designate women into categories of fit and unfit mothers. I was placed in a position to judge if a person is worthy, or deserving of care, and, at times, deserving of being and becoming a mother. Now reflecting on this dichotomy, I wonder more about how the women understood their lives and question how the care system shaped their experiences.

How does a life, which is evolving and changing over time and in different social contexts, conform to narrow and rigid categories such as fit and unfit mothers? What could have been different? What changes, both in and beyond the hospital walls, would have helped my first patient have a fulfilling delivery and a transition into motherhood that she welcomed? What stories do I tell of the lives of mothers on the margins? These questions fueled my disappointment in the care system and, on a deeply personal level, led me to return to graduate education and research. Nonetheless, these same questions are also rooted in larger practical and social issues, with implications for many nurses and care providers.

Practical Justifications

Practical justifications call researchers to consider the importance of their work, in relation to shifting their and others' practices (Clandinin, Pushor, & Orr, 2007). The story of my first patient in labour and delivery formed the center of my personal justification for this research but it also helped me consider the practical justifications. It called forth questions of care, and nursing practice that extend beyond my personal experience. While grounded in my experiences as a care provider, understanding the stories of patients holds implications in how mothers access services and may change how nurses and others practice. Specifically, it has led me to wonder about institutional narratives that frame patients and women in particular ways. What ways can health care systems respond to the needs of marginalized populations and communities? Returning to my experiences as a student nurse, how could my education prepare me to recognize ethical issues? What are the ways nurses can advance ethical care?

Addressing these practical questions however, requires a general understanding of the social circumstances that shape many women’s lives and lead towards the social justifications of this research.

Social justifications

Social justifications, specifically, the social action and theoretical justifications of a study, provide a means to answer the larger questions at the heart of each narrative inquiry study (Clandinin, 2013). The following section begins with the social action justification for this work. It explores some of the factors, which disproportionately influence the lives of marginalized women including homelessness, HIV, and illegal substance use. This is necessary background information to understand the context of the women who participated in this research. From there, I introduce harm reduction as a strategy to support the needs of individuals who use substances. Lastly, this section explores the theoretical justifications, and the importance of narrative understandings of marginalized women’s experiences.

Social Action.

Housing and Health.

Extensive research on health disparities of marginalized communities, in particular individuals who are homeless or precariously housing, demonstrate how the current care system is inadequately meeting their needs (Teruya et al., 2010)**.** Access to stable housing is a well-known protective factor in the lives of men, women, and children (Thomson, Thomas, Sellstrom, & Petticrew, 2013). Yet, lack of housing remains a significant concern both globally and within Canada. Rates of homelessness within Canada continue to rise with current national figures estimating that roughly 235,000 people experience homelessness each year (Gaetz, Gulliver, & Richter, 2014). Beyond these statistics, however, is the number of hidden homeless, those whose living situations remain precarious, but who are not counted in national surveys or data (Echenberg & Jensen, 2012). The hidden homeless include families living in between stable housing, those staying with friends or family, and those moving between provinces. A significant body of research explores the impact that housing has on health and well-being as well as how a lack of access to housing leads to further risks and harms (Lee, Tyler, & Wright, 2010; Schanzer, Dominguez, Shrout, & Caton, 2007; Teruya et al., 2010). Individuals who are homeless suffer from a lack of nutrition, experience difficulty accessing medical care, and are at greater risk for contracting HIV (Kidder, Wolitski, Campsmith, & Nakamura, 2007).

Rates of homelessness among younger women are rising in Canada (Gaetz, Dej, Richter & Redman, 2016; Richter & Chaw-Kant, 2008). In the United States, families are the fastest growing homeless population, with the majority of these families being female led households (U.S. Department of Housing and Urban Development (HUD), 2013). In Canada, there is a lack of affordable housing and many homeless programs focus on crisis management, a service delivery model most suited to supporting predominantly single men (Gaetz et al., 2016). Many women who are homeless have a history of trauma; face higher rates of intimate partner violence and fears for safety can directly influence ability to access social supports (Anderson & Rayens, 2004; Tutty, 2015). Mothers who are homeless face considerable challenges in their daily lives; for mothers with few social or economic resources, the multiple demands of parenthood are nearly impossible to meet (Hatton, 2001). One significant difficulty faced by street involved and homeless pregnant women, lies in their feelings of incompetence and serious isolation (Radcliffe, 2009; 2011a; Wen, Hudak, & Hwang, 2007).

Substance Use.

While not all women who are homeless use alcohol or use substances, the rates of substance use and mental illness remain significantly higher for women in precarious housing situations compared to the general population (Bassuk & Buckner, 1998; Torchalla, Strehlau, Li, & Krausz, 2011). Moreover, just as they are overrepresented in national homelessness figures, Aboriginal and Indigenous women represent a group with a higher likelihood of substance use and poor perinatal health (Kramlich & Kronk, 2015). Aboriginal families also remain overrepresented in instances of child apprehension (Boyd, 2015).

Illegal substance use remains a heavily stigmatized aspect of Western society with criminal penalties associated with the majority of drug offences (Kulesza, 2013; Lester, Andreozzi, & Appiah, 2004). Substance use during pregnancy is a challenging figure to measure. A recent Public Health Agency of Canada (2009) survey found that 1.0% of women reported substance use during their pregnancy. Within the Alberta context, an estimated 1.5% of women use illegal substances during their pregnancy (Reproductive Health Working Group, 2009). Elsewhere these numbers are much higher (Cleveland & Gill, 2013). The discrepancies in statistical reporting of these figures remain, one reason being that most data derives from self-reports, even with research showing that many individuals underestimate substance use, partially due to negative stigma associated with use (Garg, et al., 2016).

In the areas of addiction and mental health, the majority of health care professionals express negative attitudes towards patients with substance use (Room, 2005; van Boekel, Brouwers, van Weeghel, & Garretsen, 2013). Stigma associated with substance use is compounded by social perceptions relating to gender. Women who use substances are seen to lose control both over their physical characteristics, as well as their perceived ability to manage and organize a traditional family household (Boyd, 2015; Radcliffe, 2011a; Stengel, 2014). This negative perception is particularly evident when pregnancy and children are involved.

Public discourses often frame women who use substances as either fit or unfit mothers (Room, 2005; Stengel, 2014). While the reasons for this are complex, one aspect is that the social value of women remains highly connected with reproductive capabilities (Benoit, Magnus, Phillips, Marcellus, & Charbonneau, 2015; Anderson, 2001). Specifically, the discrimination many women who use illegal substances face is rooted in the social perception that they are solely to blame for the harm to their unborn fetus (Boyd, 2015; Ettorre, 2004). Pregnant women who use illicit substances are considered by some as “lethal fetal containers” (Ettorre, 2004, p.331). However, the impact of substance use varies depending on drug type, amount of exposure, as well as on environmental factors. Moreover, systemic social problems, specifically poverty, has significant impact on birth outcomes and fetal wellbeing, which is often overlooked in relation to perinatal substance use (Boyd, 2015; Ettorre, 2004). Stigma surrounding addiction is multifaceted, given that illegal substance use is considered to be both a health concern (addiction) and a criminal behavior (Room, 2005). In the context of maternal health, there is a wide spread view that substance use is a choice and a sign of immoral and bad mothering (Boyd, 2015). Nurses' expressions of blame and judgment towards women who use illegal drugs are common (Cleveland & Gill, 2013; Radcliffe, 2011b; Selleck & Redding, 1998). The experience of being stigmatized for women with a history of perinatal substance use directly impacts pregnancy outcomes. Worried about judgment and discrimination, many women with a history of perinatal substance use avoid care providers and health services (Cleveland & Gill, 2013; Selleck & Redding, 1998; Seybold et al., 2014; Wong & Kahan, 2011).

HIV.

HIV significantly changes individual lives and shapes identity; unlike other sexually transmitted or blood-borne infections, HIV calls forth stigma and discrimination, and a lifelong need for treatment. Factors associated with homelessness including childhood trauma and substance use, as well as an outcome of their living situation through transactional sex acts and lowered access to harm reduction resources such as condoms or clean injection supplies, means that marginalized women are at increased risk for contracting HIV (Cederbaum et al., 2013). The face of HIV has changed dramatically over the last twenty years with women now accounting for half of those living with HIV worldwide (Carvalhal, 2010). In Canada, women make up 26% of all new cases of HIV (Public Health Agency of Canada, 2011). Many women living with HIV become pregnant and, while advances in treatment means that women who are HIV positive are able to delivery sero-negative infants, this outcome is reliant on access to antiretroviral treatment. Research shows that homelessness remains a structural barrier that interferes with adequate antiretroviral treatment (Milloy et al., 2012). Moreover, despite improved understanding of the disease physiology, transmission and treatment of the disease, stigmatization remains a key aspect of the illness and a key aspect of daily life for persons living with HIV/AIDS (PLWHA).

HIV stigma is complex, and while the causes of this stigma vary, a positive diagnosis can cause social isolation and serious harm to an individual's mental health (Earnshaw & Chaudoir, 2009; Weiss, Ramakrishna, & Somma, 2006). Carr and Gramling (2004) explored the experiences of HIV positive women in their ethnographic work and found that many of their participants felt shamed and scorned by care providers. Greene et al., (2014) found that many women's pregnancies were overshadowed by fear of an unwanted disclosure of their HIV status and concerns about discrimination from care providers. Stutterheim and colleagues (2009) found that PLWHA report that stigma from health care providers has significant impact on their lives. In the context of HIV, stigma and judgment in the healthcare setting negatively impacts patient care and many patients' willingness to access services (Mahendra et al., 2007).

Harm Reduction.

Harm reduction is both a philosophy and approach to care. Harm reduction seeks to reduce the harms an individual experiences from the use of legal and illegal substances (Hilton & Thompson, 2001; Riley, Pate, Monaghan & O'Hara, 2012). The approach differs from typical addiction-based programs, as abstinence is not the main goal of treatment (MacMaster, 2004; Riley et al., 2012). Instead, harm reduction approaches offer a pragmatic solution to consumption of both legal and illegal substances (Marlatt, 1996; Riley et al., 2012). It aims to reduce the negative consequences of substance use and is commonly associated with programs for intravenous drug users (IDUs) in the form of needle exchanges, safe injection sites, methadone administration, and overdose prevention services (Riley et al., 2012). Harm reduction has gained increasing support in recent years as an ethical approach to previous prohibitionist policies that punished individuals for their substance use (Boyd, 2015; Hilton et al, 2001).

The acceptance of harm reduction as a viable health service is discussed often in terms of cost, fiscal saving, and risk management; that by reducing the greatest harms associated with activities and behaviors, the care system can avoid the high cost of these behaviors. The Canadian Centre on Substance Use argues that merits of harm reduction programs should be evaluated using impartial and scientific methods (National Treatment Strategy Working Group, 2008). The requirements to assess harm reduction programs require careful consideration and often rely on quantitative, positivistic measures. Needle exchange programs are able to demonstrate measurable data such as lower rates of HIV and Hepatitis C, and more recent research has explored the excellent cost savings of needle exchange programs (Bruggmann & Grebely, 2015; Kerr, Mitra, Kennedy, & McNeil, 2017; Kwon et al., 2012). However, many benefits of these services are less tangible (Aspinall, et al., 2014). Individual relationships fostered with care providers, positive community support, and an acknowledgement of people's rights are challenging to measure (Penn, Strike, & Mukkath, 2016). It is also necessary to acknowledge that harm in a criminal sense cannot be divorced from moral judgments, social norms, and ethical frameworks (Greenfield & Paoli, 2013).

A question of equity.

The fact that many marginalized communities face complex challenges related to housing and health raises questions of equity. The increased need for housing, HIV services and supportive programs to address substance use signal the need for further social action. The justification of focusing on these areas are rooted in a belief that all individuals should have access to housing, adequate health care and nonjudgmental services. Addressing questions of equity are important and necessary. However, the development of programs and care plans are often shaped by incomplete understandings of what harm means, and rarely do they focus on experiences, wishes, and needs of those for whom care is intended. One possible direction for addressing this issue is the use of narrative inquiry to explore experiences. Returning to people's experience offers possibilities to not only address the lack of connection to programing but can also help imagine a system where individual experiences are recognized as a valuable source of knowledge.

Theoretical Justifications.

That first day on labour and delivery, with the mother who ended up in a cesarean section, I did not recognize or question the ways we cared for her and her family. Yet, if I had acknowledged the mother's unethical care, I doubt I would have been able to imagine a different alternative to the judgmental services that we provided. In my beginning days as a nurse, I was unable to think of different possibilities. Over the past few years, I wondered often where this lack of imagination came from. Was it, as Lugones (2003) states, a symptom of arrogant perception, that is, that the "failure to love lies in part in the failure to identify"? Would a relational shift in understanding, that is, identification with the women who accessed services, disrupt these unethical care practices?

The idea of shifting focus drew me to Greene's (1995) work on multiple ways of seeing. In her work, Greene (1995) discusses the concept of seeing things as small and seeing things as big. She states that seeing small means looking through a "lenses of a system – a vantage point of power or existing ideologies – taking a primarily technical point of view." (p.11). Seeing small risks disregarding, as Greene states, "actual living persons". Greene proposes instead the opportunity to see big. Offering the perspective of seeing things in a broader sense provides the opportunity to understand the uniqueness and individuality of an experience, instead of a reductionist approach. Greene does not call for an end to either particular kind of seeing, instead seeks to find a balance between these.

Greene (1995) states, “All we can do, I believe, is cultivate multiple ways of seeing and multiple dialogues in a world where nothing stays the same” (p.16). Thinking back to my beginning stories, I am struck with how little we knew of the patient’s life, beyond the short moments we spent together in care. When I reflect on the care provided during her hospital stay, I wonder if seeing her life *big*, in larger and more expansive ways, would have changed how she was treated. Would it be possible to disrupt the care practices that determines who is worthy of care? If we heard more of her story, would we care for her differently?

Greene (1995) and Lugones’ (2003) work both supports, in different ways, the importance of shifting the perspective back to individual experience. Instead of focusing on care providers’ perspectives and understanding of the care they provide, this work begins with the stories of the women who access services. The opportunity to inquire alongside these women and their families, offers a chance to understand a different narrative.

Telling and listening to stories is what makes us human - it is a way that we make sense of our experiences (Coles, 1989; Crites, 1971; King, 2003; Okri, 1997). Narrative methodologies can take a variety of forms. Variation between methodologies and even teaching approaches demonstrate that there are different perspectives on narrative and experience. Postmodern approaches focus on the description and analysis of research results in story form, while other methodologies focus on the use of narratives or stories as a tool to convey and disseminate final research findings (Clandinin, 2013; Butler-Kisber, 2010). In many research approaches, narratives are examined and isolated from an individual’s life and the contexts in which they live.

Challenging a reductionist approach to understanding stories, narrative inquiry represents a shift in thinking; it is both a methodology and a way to understand human experience (Caine, Estefan & Clandinin, 2013). Narrative inquiry holds central to its philosophical grounding, the understanding of "experience as a storied phenomenon" (Clandinin, Murphy, Huber & Orr, 2009, p.82). Within this view of experience, individual lives are both lived and expressed narratively. I turned to narrative inquiry for this research, for its resistance of generalizability and its commitment to social action marked by the telling of, and learning from, experience (Clandinin & Rosiek, 2007).

Research Puzzle

During my first experience in labour and delivery, the patient's interaction with care providers was shaped by our health care team's assumptions about her life and who she was as a person. Her voice was absent from the conversation about care and her experiences, thoughts, and wishes were not heard or considered. The care team participated in an assessment and intervention with real effects on her transition into motherhood based on a very small amount of information. We, as a collective, made the decision whether she was worthy of care. In hindsight, even with a yelling physician, constant whirring, beeping machines and a crying baby, our relationship with her was marked by silence. The experience was indicative of a care system that does not treat people, but rather focuses on problems. It was a story, shaped by institutional narratives and social expectations grounded in judgmental ideas of mothering, substance use, poverty, and privilege.

My experience, told and retold and shared in my narrative beginnings of a patient being over looked and disregarded by care, was unacceptable. This experience, however, is not an isolated incident. As a nurse, I have found that women's stories of experience lack the space, time and support to engage in relational care. My return to graduate education came with the emotional understanding that, in a short time in practice, I had already become a nurse who often viewed patients, not as complete persons, but as problems to be solved. I returned to research with the hopes to hear the stories of patients I work with outside the walls of a hospital, and understand their lives in a more ethical way.

My research is embedded within a larger Canadian Institute for Health Research (CIHR) grant: *Inquiring into HIV prevention and care for pregnant and early parenting women experiencing homelessness.* As such, the participants were recruited within the approved ethical agreements of the larger project (see Appendix A, B& C) The study design reflects the work of the larger grant.

Positioned against the social perception of "normal" pregnancy and motherhood, my doctoral research explores the stories of three participants, all women with young children and their negotiation and understanding of harm. Using narrative inquiry as the methodology, the focus of this work is to understand how the concept of harm is defined narratively, both within a life story and by social contexts, with a specific focus on the harms associated with illegal substance use. This research focuses on how the participants' stories to live by have been shaped by current and past substance use and how the stories that the women share about their experiences with illegal substances are different from the institutional narratives present in nursing.

Methodology.

Narrative Inquiry.

Narrative inquiry is both phenomenon and methodology. Both are rooted in narrative conceptions of experience, in stories, and in lives being lived (Clandinin, 2013). A narrative inquirer seeks to understand not only these personal and unique experiences but also how these stories are shaped by larger social, historical, and institutional forces across time and place (Clandinin et al. 2009; Clandinin & Rosiek; 2007). This approach to studying human lives "is a way of honoring lived experience as a source of important knowledge and understanding" (Clandinin, 2013, p.17). The methodology puts into practice a perspective that is best articulated in King's (2003) statement, "The truth about stories is that's all we are" (p.2).

Narrative inquiry draws inspiration from the work of feminist scholar and critic Maria Lugones (1987), psychiatrist Robert Coles (1989), and writer Thomas King (2003) among others (Clandinin & Connelly, 2000). Narrative inquiry is explicit in defining its philosophical traditions, drawing on pragmatism, in particular the work of the educational scholar and philosopher John Dewey (Clandinin & Connelly, 2000). While Dewey (1905), a pragmatist scholar at the turn of the 20th century, remains a key figure in the philosophical underpinnings of narrative inquiry, developments of feminist pragmatism are also relevant to consider when exploring the methodology of narrative inquiry.

Pragmatism.

While many consider pragmatist philosophy as a 20th century philosophy, the American roots of much of the theoretical works can be traced earlier to the mid-1800s and ideas beginning at the time of the American civil war (McKenna & Pratt, 2015). With advancements in science and technology, pragmatism developed further in the 20th century with a continued focus on social change and progress (McKenna & Pratt, 2015; Talisse, & Aikin, 2008). It aimed to move beyond traditional academic philosophy and returned to ‘life’ as the source of knowledge (Ghenea, 2015). Disagreements and alternative perspectives among pragmatists means that the philosophy’s purposes, epistemology, and ontology vary. However, Ozmon and Craver (1999) considered one key aspect of the pragmatist philosophy to be that of growth; specifically, in the form of social renewal: addressing societal concerns and helping promote equality and respect for the human condition.

Less interested in aims to understand God, consciousness, or ideals, pragmatism offers a different perspective to understand what those ideas mean to people living their daily lives (Dewey, 1905). Dewey argued that experience should serve as the source of knowledge and developed two criteria upon which this should rest: continuity and interaction (Dewey, 1938; Smith, 2015). Dewey (1938) discussed the criterion of continuity, noting that growth and individual experiences always change over time. Central to the criterion of interaction is the recognition of internal and external forces within a particular environment, which shape each person’s experience (Dewey, 1938). For Dewey, individual lives are understood as always in context, a perspective which respects subjective truths while at the same time acknowledging the social, historical, and institutional forces shaping a person’s experience. Together, continuity and interaction “[p]rovide the measure of the educative significance and value of experience” (Dewey, 1938, p.45).

The importance and role of pragmatism, however, is not limited to Dewey and his philosophical contemporaries. Instead, current discussions in pragmatism offer a continued reflection on the role the philosophy holds for narrative research and the field of knowledge development as a whole (Rosiek, 2013). Pragmatism has been positioned as a philosophy in keeping with feminist traditions as well as forward thinking ideas about social change and progress. Clough (2013) argued that pragmatism and feminism in collaboration can serve as a solution, or at least strategy, for reducing inequities within scientific knowledge. Clough argued that, positioned together, these philosophies can help bring embodied knowledge from marginalized populations to the foreground, offering both perspective on these experiences and an emphasis on development. Taking up similar discussions on embodied knowledge, Rosiek (2013) provided his perspective on the renewed interest in the pragmatist philosophy and its application to social sciences. In particular, he stated that this was partially due to the acknowledgment that pragmatism's reflexivity takes into account the cultural and historical bases of individual knowledge. Rosiek (2013) also contends that pragmatism's emphasis on a temporal view of understanding rather than a focus on describing experience encourages future development. This temporal view draws on Dewey's (1938) statement: "[e]very experience both takes up something from those which have gone before and modifies in some way the quality of those which come after" (p.35). Pragmatist philosophy and Dewey's work in particular, both his ontology and epistemology, serve as the foundation for the methodology. Narrative inquirers' commitment to relational research practices is shaped by Dewey's philosophy. Dewey (1909) stated, "Go to experience and see what the thing is experienced as" (as cited in James, Capps, Capps & Dewey, 2005, p.194). Clandinin and Connelly (2000) take up this work in the commitment to living alongside participants and in the writing of research texts. Dewey's criteria for experience, continuity and interaction, support his position that experiences are both adaptive and socially constructed. He (1938) stated "[e]very experience is a moving force" (p.38), and he argued that in this sense, experience is transactional, both changed by social conditions and able to influence the environment. This perspective is taken up in narrative inquiry through the methodology’s emphasis on the dimensions of temporality (across time), sociality (personal and social interactions), and place (Clandinin et al, 2009). These three dimensions ground a narrative conception of experience as well as the recognition that people’s lives and experiences are understood and shared though lived and told narratives (Clandinin, 2013). As such, the methodology enables consideration of larger social, familial, and institutional narratives, which shape an individual experience (Clandinin & Connelly, 2000). Narrative inquiries also consider the connection between researcher and participant to be integral in knowledge creation, or co-creation.

The Philosophy of Narrative Inquiry.

Narrative inquiry puts Dewey’s (1938) philosophical principles into practice by returning to everyday life as the source of knowledge, and by viewing experience as a storied phenomenon (Clandinin & Connelly, 2000; Clandinin et al., 2009). The importance of possibility and the evolving nature of stories means that final answers are not the aim of the methodology (Clandinin & Caine, 2012). What is paramount to narrative inquiry, however, is the commitment to expressing the complexity of storied lives (Clandinin & Caine, 2012). This is made possible by explicitly demonstrating the three dimensions of narrative inquiry, comprised of temporality, sociality, and place.

Within a larger study, this exploration of temporality, sociality, and place, occurs in relation to a research relationship. Narrative inquiry is a grounded by a relational ontology (Clandinin, Caine & Lessard, 2018). This ontology means that in narrative inquiry, the participants as well the research relationships are under study. As participants and researchers begin in the co-composition of stories, there is an examination of both the stories shared and their relationship developing throughout the research process. The commitment to a relational understanding of experience extends from the ontology to the ethics of narrative inquiry (Clandinin, Caine & Lessard, 2018).

The Ethics of Narrative Inquiry.

Ethics are primarily focused on questions of morality and judgment, specifically questions about what is good or just (McIntyre & McDonald, 2013). In a broad sense, all research brings with it significant ethical challenges. In qualitative research though, the number of participants is usually smaller and may be invited from a close-knit community. Researchers that work with small and distinct populations must be more attentive to questions of privacy as it may be easier for those outside of the study to recognize participants who would prefer to remain anonymous (Damianakis & Woodford, 2012). There is also the risk for participants to share more private thoughts and experiences than they initially planned when they are sharing stories rather than answering a specific set of questions (Holloway & Freshwater, 2007). Research conducted with marginalized populations, while well intentioned, has, at times, been a further source of harm and victimization within the community (Mkandawire-Valhmu, Rice, & Bathum, 2009). To mitigate these risks, researchers are bound by standards from overarching institutions such as universities, which offer guidelines and terms upon which to base their ethics. Narrative inquiry takes up these ethical questions in a different way.

Clandinin and Murphy (2009) stated, "[o]ntological commitment to the relational locates ethical relationships at the heart of narrative inquiry" (p. 600). As a relational methodology, these responsibilities are grounded in an ethics of care, a distinction which sets narrative inquiry apart from other methodologies that rely more heavily on ethical frameworks and guidelines (Clandinin, 2013). Narrative inquirers draw upon Bergum's (1994) work on relational ethics and Nodding's (1984) work on the ethics of care as well as other ethical theorists, to advance how relational ethics can inform methodology and how researchers understand experience (Clandinin, Caine & Lessard, 2018). The relational ethics of narrative inquiry is embedded in all interactions with participants, from the development of field texts, to the co-creation of narrative accounts. In her work on relational ethics, Bergum (1992) argued that ethical decision-making based largely upon traditional social contract theory is inadequate at addressing moral dilemmas in care. Instead, ethical theories must ground philosophical questions in the context of relationships and caring. She stated, "[t]he ethical encounter in health care is not merely a means to an end but finds its meaning in the relation itself" (p. 82). Positioned against traditional bioethical frameworks, Noddings' (2013) work on care ethics, explored ethics from a perspective of caring rather than moral reasoning. In care ethics, rather than seek justification for particular actions, care providers are obligated to uphold caring principles and must instead explain the reason for not providing support (Noddings, 2013). Noddings (2013) stated "[c]aring itself and the ethical ideal that strives to maintain and enhance it guides us in moral decisions and conduct" (p.105).

"By using the term 'relational' we stretch past the relationship, not excluding the individual relationship but including it within the relational, to encompass questions of ontology. In this sense, relational understanding recognizes that what and how we know is always dependent on the ways that knowledge and knower are deeply contextual, always embedded within the other" (Clandinin, Caine & Lessard, 2018, p. 20). A commitment to the relational ethics of narrative inquiry requires a personal understanding from researchers about who they are as people and who they are becoming in relation to others. This reflexive process often starts as inquirers return to their past and current experiences, to gain understanding throughout the course of a study. Writing narrative beginnings requires researchers to write about these experiences and, for many, these beginnings serve as a starting place for an inquiry (Clandinin &

Caine, 2012). While these texts may not be used within the final research texts such as articles and dissertations, they provide openings for a researcher to reflect upon their life and how their experiences influence their relationships with participants (Clandinin, 2009).

The continued importance of relational ethics can be seen in the development of connections between researchers and participants. Researchers enter the research relationship from a place of privilege: they have had access to higher education, support, and often funding. They are also, often considered to hold expert knowledge and perceived authority (Huber et al., 2006). Narrative inquiry has in place measures to alleviate some of the power differential, including that ownership of stories and narrative accounts are always linked to the researcher participant relationship rather than to the researcher alone (Clandinin, 2007). Central to the methodology is a position of co-creation: researcher and participant become partners in knowledge development, writing and, at times, sharing of narratives. Recognizing the difficulty of entering into the midst of someone's life, narrative inquirers begin research relationships with attentiveness to the complexity of a participant's life. In this sense, narrative inquirers find ways to negotiate meaningful relationships with participants, often by finding ways to support or be helpful to participants and their families (Clandinin & Caine, 2012). Clandinin, Caine and Lessard (2018) acknowledge that there may be times when research conversations may be too difficult or that research relationships reach natural ends. Throughout the entire research process, there is an understanding that relational ethics guides this process. Within a narrative inquiry, researchers do not only observe participants, relationships are formed and lives intersect (Clandinin, 2013).

The Processes of Narrative Inquiry.

Forming lasting research relationships and sharing the co-created stories in narrative inquiry takes time and openness from both participant and researcher. In narrative inquiry, this is an iterative process; the development of field notes, interim, and final research texts is not a linear process and can vary greatly depending on the research relationships and the landscape of an inquiry. Narrative inquirers take time to constantly reflect and to delve deeper into the experiences that shape which, and how, stories are shared.

In the initial stages of an inquiry, steps are taken to establish a starting place for connections in the field (Clandinin & Caine, 2012). In many inquiries, starting with telling stories can be a strategy of building a relationship, and through telling and retelling of experiences within a conversational space an inquiry space can form. In some cases, artifacts can help encourage story telling, for some mothers these objects can be photographs, memory items such as a hospital bracelet or a child's toy. Clandinin (2013) provides the suggestion of working through an annal or timeline to help understand the social and historical factors within a participant's life.

After a researcher and participant have co-created a space of comfort or ease with one another in the field, the process of developing initial field texts or data begins. Field texts represent various sorts of data within a narrative inquiry, including but not limited to annals, artifacts, photographs, journal entries, conversations, and field notes on activities and observations (Clandinin & Caine, 2012). The choice of type of field text is a negotiation between participant and researcher and depends upon what is most appropriate to both the research relationship and the inquiry purpose (Clandinin & Caine, 2012). Clandinin (2013) stated that "[a]s we negotiate relational spaces with participants, including places and times to meet and events to become part of, we also negotiate a diversity of field texts" (p. 46). Multiple types of field texts can help open up alternative viewpoints and untold stories (Clandinin, 2013). These field texts also serve as the necessary first step in moving to later compositions, interim and then final research texts, which are shared with a larger audience.

Clandinin and Caine (2012) explained that moving from field to field texts and to interim and final research texts is a challenge, stating that this iterative process is "full of twists and turns" (p. 172). For Clandinin and colleagues (2009) this process is also marked by moments of tension and challenges, as researchers are finding the means to record their relational research work. Narrative inquiry does not rely on structured guidelines, such as coding, triangulation, and thematic analysis, which are present in many qualitative methodologies (Butler-Kisber, 2010). Instead, moving from field to final research texts in narrative inquiry requires negotiation as well as shifts in perspective that involves researchers sharing final research texts with a larger audience (Clandinin & Caine, 2012). These final research texts are composed in ways that open up possibilities for the audience to position their stories alongside research findings. Final research texts make visible not only the stories of experience but also wonders, puzzles, and future opportunities (Clandinin, 2013). Before these texts are presented to public audiences though, they are often brought back to peers and colleagues to be explored, challenged, and questioned. The process of writing in narrative inquiry is done alongside the support and encouragement of peer or response communities, groups seen as central to the work of narrative inquirers (Clandinin & Caine, 2012). Response communities in narrative inquiry offer alternative viewpoints and support for researchers as they inquire into experiences.

Methods.

Turning towards participants.

My dissertation combines narrative accounts with a theoretical discussion on the nature of nursing care, the role of the profession in addressing larger social factors such as poverty, homelessness and substance use. As part of the larger research team, I connected to community agencies and Edmonton Inner City programs. Within these various agencies, I took on the role of volunteer to assist in the day-to-day tasks, while connecting to participants who accessed these services. I was connected to each research participant through a different agency; many of the women who utilize these services receive support from a range of programs.

Throughout the inquiry, I took detailed field notes on my experiences as a researcher and volunteer in the field. Conversations, both recorded and not recorded, were shaped into interim research texts, shared often with participants. Ongoing field notes and observations helped in writing these interim texts (narrative accounts). The negotiation of the number of conversations was different for each participant and was based on our level of comfort, depth of conversation and the daily reality of our lives. I have written the final research texts with the aim of encouraging recognition of the experiences of women and beginning places for dialogue, rather than as conclusions about the lives of mothers and their families. Dissemination goals include sharing these texts with care providers, policy makers, and most of all, the mothers who shared their stories.

For all the mothers, our research relationships were composed in ways that were meaningful to them, often through running errands or being alongside at appointments. All of our relationships required time, and patience in order for there to be trust and openness. The development of my individual research relationships and the process of moving from the field to the writing process was unique in each research relationship. For this reason, I provide an overview of the development of each narrative account.

Nikki & Cora.

Nikki was the first woman who agreed to participate in the research and our relationship changed greatly in the years since we started this inquiry. When I met Nikki, she was almost 6 months pregnant and our very first recorded conversation took place just hours before she delivered her beautiful, feisty daughter Cora. I have been alongside for many changes in Nikki's life. Fears and worries regarding health, addictions, and family have been at the center of many of our most difficult conversations. The most significant amount of our time though, was filled with laughter.

The development of a friendship and time spent together meant that putting Nikki and Cora's narrative on a page was challenging. Firstly, our relationship spanned more than three years with numerous field notes, transcripts, and memories to draw from. Secondly, a narrative structure was difficult to connect with the circumstances of Nikki's life. In multiple meetings to review and discuss interim narrative accounts, Nikki found the stories challenging and emotional with many of the words on the page speaking to the trauma she had experienced. At one point Nikki asked me, as we read, "*When do I get to stop telling these stories*?" Through this negotiation, we eventually came to letters as a form for our narrative accounts. These letters, mostly written to Nikki, were a way to share stories without plotting her life on a timeline. They also help demonstrate the closeness and trust at the center of our research relationship.

Renate & Kayden.

I met Renate the day before she delivered. A support worker, who I had met through my participant Nikki, had arranged for our conversation. When I arrived at the hospital to meet her she sat resting in bed, being monitored for the concern of a preterm delivery. Renate, petite and outgoing, did not handle bedrest well. While concerned for her son and diligent at following hospital orders, she vibrated with energy and excitement for her baby son to be born. Even with bedrest, Renate was a little more than halfway through her pregnancy when she delivered her handsome boy Kayden. For the first months of his life, she waited with that same energy at his bedside in the Neonatal Intensive Care Unit (NICU), as day by day he gained weight and strength. There were moments of fear and doubt that Kayden would not make it to his first birthday and through all of this Renate was hopeful, always present at his bedside. Kayden and Renate overcame difficult odds and now they live together in an apartment filled with toys. Each time I see Kayden, I am surprised with how strong he is and how much he has grown. The NICU will now always be a place that reminds me of Renate and Kayden. In writing Renate and Kayden's narrative account, letters were also the means by which we chose to share their stories. It helped locate the narrative account in relation to place, the hospital in particular, and also helped show the sense of waiting that was significant in the months that Renate spent at Kayden's bedside.

Marilynn & Jessica.

Meeting Marilynn for the first time was like catching up with an old friend. She almost bounced as she entered the room at the pregnancy outreach centre wearing an oversized black hoodie that hid her small frame and made her seem much tougher than her warm, easy, smile conveyed. She was pregnant with her 5th daughter when we met and it did not take long to find a comfortable rhythm to our visits. I was able to come along for doctor check-ups and run errands with Marilynn but most of our meaningful conversations happened at the end of these trips, sitting in my car outside her home. Sitting side by side was a chance for us to talk in private and share stories of disappointment but also determination. Marilynn had very little stability in her life growing up. Now, in her early thirties she was living in a house and caring for all of those around her in her life. In the year since I met Marilynn, I watched her welcome her fifth daughter into the world. I witnessed Marilynn's fight for custody of her older three girls and the happy news of the first pregnancy with a baby boy. Marilynn and I chose to record her narrative account as a story of growth to tell to her daughters and future son. She hopes that by sharing her experiences she can help mothers struggling with substance use and that a positive message of hope will help inspire others.

The narrative accounts of Nikki, Renate and Marilynn are all different. In the following section, each of their stories is shared separately to show their individual personalities and unique experiences. Each account begins with a prologue detailing the writing process and the iterative process of co-composing their narratives. The accounts do not include all the learnings made visible over the course of our extensive research processes, nor do they offer final conclusions. I return often to the extensive field notes, transcripts, memories, and ongoing conversations with Nikki, Renate, and Marilynn. It is impossible to share all the lessons and to write an ending for these lives still in the making. Instead, the learning is ongoing, lives are continuing to be lived and futures cannot be predicted by words on a page.

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Chapter 2: Narrative Accounts

This chapter is composed of three narrative accounts, with each narrative account focused on my experiences alongside one participant. Each narrative account was negotiated, to the extent possible, with each participant. It is important to understand that these texts only give a glimpse into the lives of the participants and my experiences alongside them. I learned so much more than I can ever express in words, and some of the experiences I become part of continue to be difficult to write. From the experiences shared with me, I know they are even harder to live. Writing the narrative accounts, we tried to show the gifts, strengths, and possibilities of each participant.

Nikki & Cora

Prologue

Where do I begin a story of a relationship that has lasted over three years? How do I make sure that others understand that the lives I have been part of and my own life happened much before I and we engaged in this research? How do I make visible that our lives will continue to unfold in multiple expected, and unexpected, ways. I continue to struggle with the challenge of putting the story of Nikki and Cora, and also our story, into words. This struggle was present from the beginning and it took a long time to find a rhythm of writing this narrative account, and to find a structure that would reflect who Nikki and Cora are, and who I am in the midst of their lives. Eventually we decided on a structure that had as its central form, letters and found poems. The narrative account is comprised of four letters. They are written as reflections on our research relationship and the stories Nikki has told me. Each letter is formed around a thread that became clear in the length of our ongoing research relationship. The letters contain dialogue taken directly from research transcripts; text is identified in italics. Separating each letter is a found poem created using Nikki's words.

Relationship

Dear Nikki,

I have sat down at my computer or a blank sheet of paper so many times over the last three years and tried to begin to tell the story of you, Cora, and me. Each time I attempt to find a beginning or starting place, I feel overwhelmed. I am stuck trying to translate our experiences into words and into a story. I do know that I will not be sharing our research work as a story with a beginning, climax, resolution, and heroes battling foes. Our relationship has never had a clear plot. It is also impossible to write a story since our relationship does not have an ending. The University and their ethics requirements, would tell us that we should resolve and wrap up our research relationship, but then again, our relationship and the words I write now feel so much like a beginning. Over the past few years, we spent time getting groceries and sitting in waiting rooms and, over time, we grew to be friends. This slow transition from researcher and participant to friends continues even now to evolve. This shift in our relationship further complicates our story and makes the idea of finding an obvious conclusion so difficult. I think so often about this notion of friendship and what you have taught me.

For the longest time, this lack of resolution stopped me from writing. I would sit at my computer and again feel overwhelmed. Months pass and it seems slowly that I am becoming comfortable enough to write to you. Perhaps it is a comfort in letting the lessons I learned become more transparent. It was as if I needed to grow into being at ease with our story, with yours, and perhaps my own.

When I started working as a nurse, I thought comfort was about having a set of skills and abilities. I thought that being able to start IVs, give medications and react in emergencies would make me confident. My time with you has made reflect and understand that comfort is less about action and is, rather, a state of rest. It is much more about feeling in place, at ease in an environment. Feeling comfortable in our relationship meant that we did not always have to talk but could just listen to the radio or enjoy a meal together. For us, as we navigated our research work, this comfort was and is dependent upon place. Sitting in a doctor's office or hospital waiting area can change who you I am. My own breaths may quicken, my shoulders and chest feel tight and it is impossible to relax. I remember times watching you in hospital clinics and remember when you sat bent forward, avoiding eye contact. How you shrank down into your chair, and, only as we left, did you stand taller and more confidently. Thinking back to our times together, the most comforting place, save for my bad driving, was in my car. Sitting side by side, we both found the space to breathe. Perhaps it was sitting side by side, looking forward to whatever road we were headed down. Not having to face one another changed our conversations, and allowed conversations between friends to happen.

I think back now, as I write to you, to the moment we were introduced at an Outreach program. A warm humid summer night in June, you walked down the stairs to introduce yourself, swaying slightly side to side with a pregnant belly; you quickly sized me up with a glance. As you tipped your chin back, scanning me up and down, I scrunched back in my chair nervously wondering what you thought of me. I was so thankful to have Paul, the outreach worker, beside us, with his easy sense of humor to help us both relax. My anxieties and discomfort lessened after the three of us laughed about stupid jokes and video clips. We quickly moved from light to dark though, when after only a few minutes together you told me of your son, who was born early on route to the hospital. I cannot imagine how terrifying that would be for you and for the paramedics, with all three of you in an ambulance hoping for more time. Your son was preterm, born weeks before the due date possibly (although this could be our judgement about you) because of your substance use and rushed to the neonatal intensive care unit when you arrived. When you told me this and I nodded silently, I thought of the ways that nurses, myself included, would have talked about you as a patient: “Substance use can cause sheering off the placenta…drug use causing neonatal withdrawals…” “34 year old, G6 P5; 32 weeks… risk factors include: current drug use, gestational diabetes: diet controlled… active abruption…” We would have talked about you in this fragmented sense, discussing the factors surrounding your delivery.

You told me about how you were sent home in bloodied clothes; given the same pants that you wore in the ambulance. You told me how the nurses refused to take a toy you wanted to leave for him. I never thought that you would be sent home before even seeing your son or having the chance to hold him in your arms. When you told me this I felt my face redden and I felt guilt I had not experienced, creep upon me. I thought the hospital where I worked was one of the better care centers. I hear, almost exclusively, positive feedback when I tell people about my job and the hospital where I work. I realized I would be hearing, in this research, stories about nurses and hospitals that I would not want to hear. In this moment, as you told me about being treated by the hospital as disposable, I felt nauseous. I did not know what to do with this story. I was frustrated. I think of your experience whenever I work at the hospital now. When I arrive to the labour and delivery unit to work a shift, I wonder about my patients and what they experience after they leave our care and as part of our care. I wonder now if they go home in dirty clothes or if they have anyone who will be there to help. These thoughts have changed what I do in my clinical work. While there is little time to ask hard questions, I now wonder about the patients and families I meet. I think about the lives that they will return to once discharged; what challenges they will face as they step out the automatic hospital doors. I wonder what they leave behind.

That day in outreach, when you told me your story, I knew we had to improve care but you were the first person who told me of the pain and hurt that these practices cause. I knew of women who had their infant apprehended but you were the first person how this felt. When you shared your experience, it again confirmed how badly we, in care, need to hear and to listen to your story. And I thought to myself how important it was to hear more. The thing that made me most uncomfortable was the worry that even after being so honest and open with me, that this would be our only interaction. That this story would be lost if we did not come together in the research.

Weeks later, as I drove to meet you again. I was so grateful that you were still interested in talking with me. As soon as I arrived at the Tim Hortons, I was again overwhelmed by feelings of guilt. I was late since I had been anxious driving on the busy roads and in parts of town with which I am unfamiliar. I felt terrible the restaurant was so crowded. The bustle of the customers coming and going made me anxious. I picked this spot because I wanted it to be casual and relaxed. Now I felt stupid that I had asked you to agree to such a serious and personal relationship in a loud and dirty fast food joint. You did not look nervous (were you?) and when you took the form, you signed your name with a casual ease that made me think this fear of not having the chance to spend time with you was all in my head.

I asked about health details, about your recent ultrasound and blood sugars and how big the baby was getting. Your response, again a casual reply but with a slight edge of annoyance, showed me quickly that you did not need another nurse. It did not matter to our very new relationship that I knew about gestational diabetes and high blood pressure. Your response reminded me of how little I share with many of my patients on the hospital floor. I am stuck sometimes after I inquire about the baby's name, gender, siblings, and cousins that I have nothing more to ask. I can explain my nursing care but much beyond those questions takes me from being a considerate nurse to one that is nosy, or overly involved, or one who comes across as nervous. I have become comfortable building my nursing relationships around knowing that at the end of my eight or even twelve-hour shift that I am finished with that connection. I know when I arrive to work, that I do not have time to chat with mothers and fathers about things beyond the four hospital walls. When I ran out of those questions with you, at a wobbly Tim Horton's table, I had no idea what to talk about. How was I supposed to connect with you beyond the fact that I was a nurse and at least knew something about pregnancy? Well, maybe I knew more about labour and delivery. After our first visit, I drove slowly home in the busy lanes of traffic, late for my own family dinner. I learned quickly, that if we were going to connect I needed to be different than the nurse I was on the hospital floor. I needed to be me.

It took time for that shift to happen, for us both to get comfortable in our roles as co-researchers. It took time spent walking through grocery store aisles, playing with Cora on your sofa in the basement suite, laughing as we enjoyed coffee and takeout at your kitchen table. And it took car rides, sitting side by side, driving to appointments and running errands. Somehow, it was sitting in the car, where we did not have to face one another that changed how we shared stories. I was no longer the researcher or nurse across the table, assessing, appraising, and evaluating each comment you made. Instead, sitting side by side, with the world in front of us laid out, meant that silences were a place to rest, and research interviews became conversation. It is challenging to share how these interactions were grounded in ethics in ways that I did not know was possible. Perhaps sitting side by side is another way to imagine relational responsibilities that position the researcher, not as an expert with a subject, but rather as co-creators of knowledge. Perhaps it was forward facing that let us shift our focus to the worlds we both inhabit. Safe in my car, being together opened spaces for some of our most challenging conversations.

One of these times, cozy and warm in my vehicle, we were stuck in traffic. As we sat, not moving on snow covered roads, we saw a jacked up truck drive past us. You joked about the type of guys who drove these trucks. That these were the type of guys you met when you were on the street. We sat then, surrounded by glass and steel and the world moving outside beyond us, and talked about relationships and hard stories. There were no strangers or people who might overhear and Cora slept in the back seat, lulled by the slow back and forth rocking of a traffic jam driving pattern.

We talked about sex work. We agreed that sex is such an uncomfortable thing to discuss. You shared that most programs focused on about resilience, strength, and positive changes; very rarely did anyone in these programs talk about the actual sex. There is little acknowledgment of the sex work itself, possibly because it often makes people uncomfortable. I know that it made me uncomfortable. You started sharing stories; stories of clients, people's kinks, and about the times you were scared. In this moment I realized, that we needed to talk about it. That never mentioning this topic did not change the fact that it was still a part of your past. I listened and thought how little I knew about this world of yours. You invited me, in this safe space where we blasted the heat and kept the seat warmers on full, to visit and revisit some of your hardest moments. The details did not feel as important as listening to you share these stories. They were not all difficult, some you shared in your typical witty sense of humor and I remember laughing while Cora slept. We laughed about how little people know, about how weird this world can be –

in many ways we laughed because in my warm slow little car we were both so far from the possibilities of this outside world creeping in.

With time, I learned to read your demeanor and tone. Thinking back to a winter's day in early February, I knew right away when I pulled up to the apartment that you were not doing well. You usually smile and roll your eyes joking about me being late, but instead with Cora bundled up in her car seat ready to go; you just looked down at the ground. Seeing you look so defeated just confirmed that something was going on. After I turned out of the parking lot, I opened my mouth to ask about the phone call from a few days earlier. I opened my mouth but said little. I did not know what to say. It was you who found the words and, as we pulled onto the main roads, you started to talk.

You called me just a few days earlier – anxious and crying about relapsing. You were almost a year sober when you used illegal substances again. I have read in many places people can relapse many times before they find sobriety but I do not think it would matter if I told you this. You held back tears on the phone telling me that after checking Cora into respite care, you met up with friends to party. You used again and now, afterwards, you realized that whatever high you experienced wasn't worth it. You were just so exhausted, so tired of everything, that you wanted to feel happy and just have that pressure gone for even a short while. When you hung up Nikki, I wanted to come over and give you a hug. I knew Cora was safe and that you still were able to care for her but I wondered whom else, beyond caseworkers and care providers, you had to talk to.

When I picked you up for errands that winter day, I knew you were in a bad place. As we drove, we talked about you using illegal substances again. You told me you knew this relapse was just that, a pause, in a long journey to sobriety. The substance use was not what scared you.

You told me as I nodded, sitting beside you in my small car, that you used the same syringes as a woman who you knew was HIV positive. Things had just gotten so bad that when you finally did need to use, there was no planning – you did not have supplies ready and a used needle did not seem like the worst option to choose when there was nothing else. I nodded again. Looking only forward at the lanes of traffic, I asked if you had sought medical support. I shared the names of services – but they were all programs with which you had connected already. You had already had an HIV and hepatitis test done and were now waiting for the results. You reached out to every agency that you could: respite care services, mobile testing services and your psychologist. I had nothing to offer you in the way of advice or suggestions; the labs had been drawn, the teaching done. While the burden of waiting for results was yours to carry, I was there. My expertise or my experience in nursing did not matter, and I could do nothing but be present. Together we would wait.

As we drove forward, your voice steadied, and you told both yourself and me that if it were positive you would manage. There would be no other option than to sit down and accept the negatives of a positive diagnosis. You told me that for years on the street, you had been in similar situations and never became infected. You told me that you worried more about housing and food and about Cora being apprehended, than an HIV diagnosis. *"I could manage HIV, sure it would be challenging and hard but what is one more burden to shoulder?"* I did not know what to say and instead nodded to what you were saying and turned towards the nearby shopping centre. We would finish our errands after we had sat down together and eaten something for lunch. In this moment, I sought out some action that felt normal and routine. I think about this now, how much comfort I find in sitting in a warm booth, talking about food, picking out a meal, and waiting for it to arrive is usually an experience that settles me. Were you even that hungry? I did not ask and instead I just pulled into the first restaurant parking lot that I saw.

Both of us had forgotten about Valentine's Day. As we walked into the Boston Pizza for lunch we were greeted with red and pink streamers pinned on the walls, and posters advertising heart-shaped pizzas for couples. I laughed when you asked me "*Are we ordering one of those?*" as we walked to the table. We both laughed about our joke –we had spent so much time together that celebrating seemed fitting. I see you more than many of my friends, and the consistency of our interactions, the stability and routine of our meetings, every few weeks, is something I have come to count on. I like that Cora recognizes my voice and that she turns her head to listen when I speak. We continue to negotiate who we are becoming alongside each other. Elements of friendship and care are becoming increasingly visible. You are more likely to share hard stories of your life. More than that, we have started to share silences between us.

We settled into our booth at the restaurant and I held Cora until she started to drool onto my jeans. I put her down beside me and she giggled for only a second before starting to cry. Her crying was my cue – I held her out in outstretched arms and you took her from me. You are so good with your daughter, and watching her settle almost instantly is one of my favourite memories. It makes me happy to remember her little chubby cheeks and watching Cora dampen your shirt with a kiss of spit, completely at ease in your embrace. I am thinking back now to jokes about heart-shaped pizza, to wiping Cora's spit off me and to your worries about one more burden to shoulder. I spent so much of that day silent. I wanted to let you know it was not for lack of care. I did not know what to say. All I could do was promise to stay and, at the very least, just be there.

As our relationship formed, I wondered about who I was to you and how we changed in relation to each place we traveled. Was I a support? A nurse? A researcher? A friend? What did people think when we were together running errands or waiting for appointments? What I did not consider was that I was lucky to be somebody to you and that you and Cora are somebodies to me. For this, I am so grateful. Thank you Nikki for bringing me with you, for introducing me to your life – both the joys and the struggles. The depth of our relationship feels, at times, overwhelming. Each time I start putting words to a page, we are in a different place and I remember a small detail, a feeling, and another story. However, in all of these memories, I always remember your sense of humor, your kindness, and your strength. As a researcher, I was not sure that you could overcome the struggles in the world around you. While I still worry about you and Cora, now as your friend, I know you well enough to know that even in the face of life's hardest challenges you persevere.

Always, Georgia

Making Friends

I’m not the person to reach out

It’s hard for me to express my feelings

Express emotions to certain people.

It’s just a trust issue

When I make friends

or I make whatever,

I make them for life,

It’s really hard

Seeing people come and go out of my life.

Waiting

Dear Nikki,

I think about you often when I wait. Standing in line, or sitting hoping to have my name called for an appointment, you and Cora come into my mind. When I am moving slowly in traffic on icy roads, the memories of our visits are often what I think about. I am reminded of the times that I was late to pick you up and you too must have stood, annoyed, waiting for me to arrive. How you never really complained, only joked with me when I pulled up, frantically apologizing for bad traffic or missing my alarm clock. On my way to meet you, I would sit in my car guilty and cursing bad traffic I could have avoided if I left on time. You were always so understanding and I should have been better for all those meetings, especially since I hate waiting. That is, I hate waiting alone; I never minded waiting with you.

I guess I'm thinking about this now because I am stuck in traffic today. I wish you were there sitting in my car. My toes are frozen and I see the cars beside me moving forward

Inch

By

Inch.

Barely crunching on the snow covered road feels like wasted time. If you and Cora had been with me in that barely moving traffic, we could have visited. We could keep an eye on Cora, sitting restrained in a car seat, and we could talk about the weather and life in general. Together, we could have made a waiting experience feel meaningful. It is a thought I came to as I reflected on the last few years. We spent so much of our time waiting together - for food hampers, for Christmas parcels, and for doctors' visits that I have been thinking often about the word "to wait".

I went back to its meaning and origins and the verb *wait*, from 1200 means slightly different things based on history. If you look at French origins, it can mean "to watch, be on guard for, to defend". Taken from Old High German, waiting means "to watch and be awake". In more modern connotations related to health care wait means "to wait (something) out" or the idea of enduring a hospital waiting room. While these meanings are more recent, they are still a few hundred years old. When we talk about waiting today, I think most people, myself included, do not realize how different the origins are for the word. I never thought about waiting in terms of wakefulness, endurance, and hostile defense, at least not until I waited with you. Every life is marked by hours and days of waiting but I realized, as our friendship grew, just how much privilege can shift this experience. When I wait in a line - I reach the front and I am listened to. Thinking about waiting today reminded me about the time we returned your stroller at Walmart. This same stroller we picked out together - spending at least an hour mulling over cost, reading reviews.

It was a decision that could not be entered into without careful consideration. You care more about your stroller when you have to push it everywhere; when it has to get you from transit center to center. It has to last the bus trips, the walks from agency to agency, and it has to fit the budget.

This was the stroller that broke.

A stroller is more likely to break when you have to push it through winter snowdrifts.

When we were waiting in line for a return and for a replacement part, the stroller stood in front of us with a tire barely staying on. When you made it to the front of the line, the sales attendant was short and terse in her replies. She had no idea how important this stroller was to you and Cora. While I tried not to intervene, the longer we spent waiting the more it felt like a positive resolution to this problem was slipping away. We were waiting in hostile defense. I spoke up only when I was truly angry, and left the store still frustrated that your complaint had almost been ignored. You, on the other hand, did not seem even the least bit surprised. There were other moments of waiting that stand out.

I remember the time I joined you for Cora's cardiac check-up. As a small infant, Cora often seemed drowsy and calm, which is how doctors realized, that she had a small hole in her heart. "Don't worry", they said. You were given instructions to keep caring for her and to watch to make sure she put on weight. "Just wait", they told you and look for the signs – either good or bad – to tell if she is healing.

How did it feel as you watched for her to heal?
What does that do to your own heart?

I thought about Cora's heart when I arrived at one of her hospital cardiac visits. I had walked over from my office at the university but you had taken multiple buses to get there. You were exhausted from transit and from a lack of sleep. Cora was sleeping fine but your back was causing intense pain that kept you from closing your eyes at night. I knew of your discomfort and the challenge you had getting to the hospital that day. As I sat beside you and Cora, I watched nurses move from room to room, assessing vital signs, and checking on patients, I wondered if you were told that you were doing a good job. Do the nurses acknowledge how hard you work to make it to the hospital, and that you are rarely, if ever, late? I doubt that many realize how you make it to each appointment; that you spend hours pushing a stroller through snow banks and waiting on buses to get to the hospital. It is only through our time together that I have started to think about each patient's travel, the time it takes to reach the hospital. I try to be kinder to the patients that apologize for bringing their children along for appointments. I know now, in a tangible way, that often they have brought them because there is no one to help. I know how much longer it takes to push strollers through snow banks and waiting for buses when you have children along.

I try to be more considerate of patients who cannot make the morning appointments. Some colleagues roll their eyes. It is hard not to get annoyed when you know that this changes how the rest of the day runs. It is so much busier when all the patients show up at the same time. Yet, when I find myself getting frustrated, I think of the bus schedule that runs infrequently that early in the morning. On that day, when I came for Cora's cardiac visit, I remember watching, and wondering about your nurses.

Did these nurses tell you they recognize how much you care?

Do they say that it was not your fault Cora was born with this condition?

I know you had others, family even, who looked at you as if it was your fault. I told you once that this happened to mothers who did not use substances but you shrugged it off; I am no cardiac expert. Maybe it was this reason that we did not talk much about Cora's heart. This silence was present in other ways. It shaped our conversations about Child Social Services. The thought that Child Social Services may intervene and take Cora was always present. Past memories of your other children being apprehended were always present. The day before Cora was born and the day before your labor was induced at the hospital you told me, voice trembling *"I guess my future is my hopes and dreams for this pregnancy is that I have a good birth… that I have a healthy baby and I get to bring her home*." I, too, was scared that Cora would be taken from your arms and your custody. Other care providers told me how difficult it was when you gave your other babies up for adoption. That with your two children, only a little older than Cora, just surviving became too difficult. When you knew that you were not in a place to care for your children, you took the step to choose a new family for the two. With Cora, the possibility that social services may intervene was terrifying. You spent much of the pregnancy trying to avoid substance use, restarting your life away from illegal substances. Now with Cora as a newborn, neither of us could do anything, we could only watch and see if social services made their decision. We did not talk much about their involvement.

Later in winter, as Cora grew older, fear of intervention faded. There were more pressing worries. The waiting never disappeared; it only shifted, still present in different ways. One day, leaving the stroller at home, we went to the food bank together. We waited, sipping on the coffee – yours with sugar and cream, mine with milk. This was not our first food pick up together. We had gone to Christmas agencies and the Salvation Army for their supplies, but this felt different. Perhaps the pace of the place, with volunteers always moving; those waiting always revolving. As soon as people got their boxes and bags of food, they rushed out into the cold air and to their bare cupboards at home. There they would count again all the items they were given.

1. Pasta
2. Pasta sauce
3. Tuna canned – in oil, not water
4. Jam
5. Peanut butter
6. Day-old pastries

I was thinking about that list when we got the call to your station. We quickly hurried to meet the volunteer bring the food and began loading up your donation into bags and boxes. As I was helping with your bags, a man a few tables down looked at me carrying bags to the car and returning for a second trip, when he yelled at you. "*Who's she?" "My support*" you answered. He slammed a box on the table at your answer. "*How do I get my own fucking support?!"*

I was shocked and kind of stood there stunned. You tipped your chin higher and turned your back as if you had only felt a slight breeze, ignoring his words. I remember thinking in that moment how cool you were. You brushed his response off as if it were nothing. I looked at you for how to act in that situation. Chin up, check. No eye contact, check. After our confrontation, one of the support staff asked to speak with me in a separate office. There was no mention of the outburst; he only wondered if I could help drive an old man home with his food parcel. He was frail with his bags of groceries piled precariously on his walker. The answer was an obvious yes. Even with Cora starting to fuss, I knew you would want me to offer the ride. You helped him load his things into the trunk of my car and when we settled, we headed back across town in a quiet car.

As we drove home, I thought again about the outburst at the food bank. While you had support, it unfortunately meant you had to wait for me. I was, more often than not, late.

While the act of waiting in lines or offices might have positioned us against a system and connected us, it still meant hours of waiting. There was always the fear that you may leave with less than when you started.

My experiences with you have made me attentive to the feelings that waiting brings. As my partner struggles with headaches and pain two years after a concussion, I feel angry. I am frustrated with the physicians telling me to wait, looking for the signs – good or bad, to tell if he is healing. As my mother faces a future of oncology assessments, multiple tests, and PET scans, these waiting experiences have not gotten any easier. While I am resigned to the impending dates, in many ways I think of these visits with an increased sense of uncertainty and apprehension. Each time blood work is drawn and I know we are waiting for results, it feels harder to breath, that I cannot relax until the waiting is over. These experiences have made me think more about waiting than I ever have before. I wait now with hostile intent and I think again about the fear of waiting and leaving with less than when you started.

I used to think that waiting was merely a feature of our health system; that waiting was an unfortunate but inevitable aspect of care. As budgets get tighter and wait times lengthen, I grow impatient wondering if this will ever improve. My frustration with waiting though is not without hope. During my time with you Nikki, I have started to recognize how waiting is dependent not only on place but also on who waits beside you. The time spent in a particular waiting room, on a plastic chair with outdated magazines nearby, was shifted by our relationship. This difficult and complicated experience changes when there is another person there to acknowledge the process.

I try to imagine how you can change waiting, how you can make the fear better. The only thing I can imagine is companionship. In our visits to clinics and hospitals, there was comfort in sitting side by side. When I wait alone, I feel like I have no control. I have no ability to change the situation, but waiting with you, we were no longer powerless. We had our conversations and, though unable to speed up the process, we had solidarity. We were watching together.

Always, Georgia

New Traditions

Not being able to parent my kids.

Having to leave them.

Leaving them just like that.

To me Christmas was just another day.

A lot of the times

I would be high on Christmas.

I would be really fucked up on Christmas.

I really didn't care about Christmas when I was out there.

But you know

It is something I can build with my daughter now.

That we can do together.

I don't know…

Christmas is going to be different this year.

Birthdays

Dear Nikki,

This year Cora turned three years old. I know that this year, the third of her life, is going to be exciting and full of change. She will outgrow toddler clothes, feel more confident than ever and stand strong on her feet. You will have to watch her even more carefully, since she is going to run everywhere. She has already started becoming her own person. Now more than ever, she will change from the memories I have of her as a baby, held softly in your loving arms.

When I think about Cora turning three, I wonder about changing milestones and the distance and time between them. Over the last few years, her birthday has been a time for us to celebrate and reconnect. It has been a constant in our relationship. These celebrations bring us together and each year she looks so different. The joy of these visits is marked though by the worry that one day, as she grows up, I may pass by and not recognize her face.

I hope our tradition continues, since it has been an immense joy to be part of her birthdays. While I was not there in the delivery room during her birth, we spoke only hours before about your excitement and fears. We sat across from one another in your apartment all ready for a newborn and talked about these worries. Everyone was worried about Cora's size, though in end you delivered her, over 10 pounds with nothing on board for pain. There was a more serious worry that Cora may not even get to come home from the hospital with you. A worry that you would lose her.

It has been three years since that time, and you two are still together. Even though the fear of losing Cora has lessened, I still feel it sometimes, when we drive to the food bank or when you share your frustrations about finances and the conditions of your home. To be honest, I try not to think about these worries and struggles. I try not to think about these fears since they sit heavy like stones in my stomach weighed by guilt that even in tough times, I will never face the same scrutiny for wanting and having a child. I face a very different world than you do, but I have learned so much from you. Watching you each year on Cora's birthday confirms this. I choose instead to remember happy moments we have shared; I reflect on how beautiful she was as a baby and remember back to the first time I met her.

When I arrived to the hospital, I was surprised that no one asked if I was allowed to be there. I have been to post-partum units many times; in my job, I am the nurse that brings new moms and babies over from the delivery suite. I introduce them to new nurses and sometimes family and friends. My visit to see you and Cora was the first time I had been to the unit when I was wearing regular clothes – no one knew or asked if I was a nurse. I walked in, uninterrupted, turning immediately into the first room on my right hand side. The curtains were pulled close for privacy and I remember slowly pushing them aside, just enough to enter the small cozy space. There were half eaten breakfasts of bland scones and milk cartons on the bedside table. The partitioned room was filled with the smell of tired sweat and of hospital disinfectant. At the edge of the bed, Cora lay resting in a bassinet. When I looked down in the small plastic bassinet, I saw a baby that was so new but already so loved.

You dressed her in one of the few onesies that fit (most didn't) and tucked the crib in close beside your bed so when she cried you could comfort her. I was scared to pick her up since she seemed so peaceful and happy and perfect. Even though I hold babies all the time as a nurse in labour and delivery, this felt different. I looked down on Cora's pink cheeks and tiny nose and I got worried. If I picked her up, I was committing to a relationship. I would be agreeing to birthdays, to not leaving like most caseworkers and supports. I only paused a moment with those feelings though since it took only seconds before you started teasing me, laughing, "*You're not* *going to break her Georgia*". I nodded and reached down to lift Cora out of that crib. I cradled Cora in my arms, gently supporting her neck. She did not cry and looked up at me with her eyes. I swayed back and forth, forgetting all my worries.

A little more than a year later, we found ourselves in a coffee shop to celebrate Cora's first birthday. I brought with me a purple stuffed rabbit – the super soft kind with weighted feet and floppy ears. Cora immediately started chewing on its foot when I handed her the toy. There were others joining for Cora's birthday celebration, but we had a chance to talk, just us, before they arrived. We spoke about all the changes in one another's lives before the others joined. I had just moved across the city and was finally settling into my new home place. You stayed silent for a few moments before telling me of your stresses and worries. You wanted to break your lease, but were worried about the money needed to put together a new deposit. There was stress about doctors' appointments and medical trips out of the city. The many medical appointments meant you had to re-enroll in a parenting program offered through one of the local inner-city agencies. This would be the third time attempting the whole course, and you were frustrated. Both of us became quiet. Cora remained strapped in her stroller, unaware of the palpable unease between you and I. Cora giggled as I made the toy rabbit dance on the table.

Things felt different when I drove to pick you both up on Cora's second birthday. Her present, a dress that took me hours to pick out, sat tucked in a pink bag beside me on the passenger seat. I messaged multiple times asking about Cora's size and even called while I wandered the aisles of a store. I pictured you rolling your eyes at me when I kept asking what to buy. I doubted you were truly annoyed. I tried to find a purple dress (we both know you care more about purple than she does) but I settled on a soft pale pink with gold polka dots and hearts.

It had a crinkled tulle skirt that I hoped would make her feel like a ballerina. As I sat in traffic, I wondered if it would fit. I wondered what you would think too.

I worried less about the outfit when I picked you and Cora up; there were much more pressing concerns about her fitting in the car seat. She started crying the minute I took her from your arms and put on the safety restraints. The straps pulled too tightly across her chest and barely clicked into the locks. I worried about pinching her as I tugged on the straps and was shocked at how much she had grown since the last time I picked you both up. I remembered when we shopped for that very car seat and how its higher price was a source of tension. When we stood looking over the tags and costs of all the available strollers and seats, you settled on this one – with its purple flowers. When we talked about the high price, I never thought about Cora growing out of it. Now, I struggled to fit her into it. When I heard the resounding, "click" that showed us that the straps were secure, I felt saddened. I realized then that today may be one of the last times you would be able to use this car seat and that soon you would be again standing in Walmart comparing prices and weighing costs as you picked out a bigger model.

Cora cried all the way over to breakfast because of the tight straps and because the sun shone too brightly in through the back window. I did not have a screen protector in the back seat; I did not think about how she would be taller now. She thrashed in her seat and I thought back to only two years earlier when she was a baby. The doctors worried about her heart being weak and the fact that she was so tired all the time. You were told to watch if she had enough strength to be active. I wish those doctors could have been at our breakfast yesterday. The minute I unstrapped her, Cora gave off a charge of energy. As we walked to the restaurant; we had to hold Cora back from running. When we arrived at the café, the same place where we celebrated her first birthday, she pushed through us at the front door blazing a trail ahead of her. The server looked at her in purple tights and a bright floral shirt and nodded in the direction of a cozy corner of the diner. I let out a sigh of relief. I have no experience with toddlers in coffee shops, but the chance to have a bit of privacy seemed like an absolute blessing.

Settling in at the table, we ordered our cups of coffee, and I turned my attention to Cora. She is wild but hilarious, pulling off her clothes and banging cutlery on the table. At first, I laughed at her mischief, until I realized how tired you were, and thought mostly about how calm you were. You gave her the small little containers of milk to play with. As I sat beside her, I was thinking about the constant risk that Cora might squeeze the containers too tightly in her little clammy palms and that milk would spray everywhere. I was wrong though, and, at least for a few moments, Cora sat engrossed in the task of stacking the cups into a tower or pyramid. No milk spilled and I felt guilty that I would have denied her that toy because I was anxious about strangers disapproving. Eventually though, after she slid under the table and tried to make friends with a toddler just down the row of tables from us we finally put her in a high chair so we could eat in a bit more peace.

You told me before Cora was even born that you wanted to raise her differently than how you grew up. *"So, I don't know, like what I want to do differently parenting is to like nurture my daughter and tell her I love her every day and give her a kiss and a hug, and you know make sure that's a routine, and for me, I wasn't told that a lot.*" I thought to myself, as I grew (I am sorry to say) annoyed with Cora after only a few minutes, how patient you are as a mother. More than that, I reflected upon the fact that you came to learn all of this about how to be a mother on your terms. How to be a mother all on your own.

Cora is a typical two-year-old in many ways, but she is also feisty and defiant. I wonder if I would be able to stay calm the way you can. I think of how you manage by yourself and how you hold yourself to this patience on a regular basis as a single mother. I wonder what you learned in all the parenting courses you had to start and retake over the years. Is it possible to learn kindness, patience, and resolve in a course at all?

As Cora turns three this year, I think back to these memories, of her in the bassinet, in the stroller and in her car seat. I am grateful that I could be there to watch her grow up. I think about how different you have become along the way. While I worry about walking by on the street not recognizing Cora's face, know that I am still bound my promise. The promise I made the moment I picked her up that first time and that you both will always be in my life, and I in yours. This promise will be carried in my memories and thoughts, and I look forward to the next birthday celebration.

Always, Georgia

Family

We didn’t have very strong family-like values.
It is not like I wanna be better than my family
It’s just I wanna build stronger family
For me and my daughter.

I want my daughter to be able to tell me things that I was not able to tell my own mother
I don’t wanna keep secrets
I don’t wanna keep all these terrible things inside.

Like having to numb pain through drugs and alcohol
I don’t want my daughter to start doing that or my sons or stuff like that.
I just don’t want them to do that.

If I stick with my morals and all that
I hope that she will confide in me
Love me enough that she won't keep secrets from me
Be warm enough to me that she’ll tell me things.

Home

Dear Nikki,

Reflecting back to my early visits with you, I am struck by the experience of entering your home. So much changed with time. At the beginning of our relationship, I remember the trepidation I experienced as I walked slowly across the threshold of your apartment. I gingerly placed my bag on the floor and slowly removed my shoes carefully before greeting you. I remember looking around, appraising the toys on the floor and the sink filled with dishes. Later, I saw this space differently. I started to notice the smell of lavender, recognizing the air fresheners placed around the room. I looked to see which new pictures hung on the fridge and walls. Over time, there was more ease with how I entered your apartment. I rushed in with excitement to see you and Cora, dropping, without worry, my bag and coat. I crossed the threshold of your home as a friend; no longer waiting for a welcome and a greeting. This same comfort was present in other ways. In our early visits, I remember perching on the edge of your sofas; sofas that I thought were too big for your apartment. Later, I flopped into them and I would lift Cora onto my lap for snuggles. In these moments, they were the perfect size for me to be able to place Cora next to me and change her diaper.

Now as I think about these shifts and the later ease with which I entered your home, I reflect on parallels that I experience in other worlds we were a part of. I am reminded by the joy I have in kicking off my shoes at my parents' house. How there is comfort in knowing I do not need someone to come greet me; I am already welcome. In some ways, my entrance needs no attention since I have never truly left. How I feel a physical sense of relief when I enter my own home at the end of my workday. These realizations made me wonder about what I take for granted in the meaning of home. It has helped me think of your experiences and I wonder now about what the impact of place has on a family. Over our research relationship, you experienced many moves and adjustments; new apartments, new buildings, new areas of town. How do you establish a home in these constant and evolving places?

When I visited at your new apartment, I began at the start. It took time to feel comfortable, and I was again careful and slow to enter your home, feeling the trepidation that had been there when we first started meeting. What was the reason for this change? Much of the furniture was the same and the room still carried a light lavender scent. Was it the place or the change itself that shifted my experience of your home? The idea of a comfortable home makes me wonder about what living so precariously for so many years actually means to a life. It also calls me to reflect on the early days in my life, and what you have told me about a childhood shaped by transitions.

I think back when we tried to sit down together to write a timeline of your family. We stopped almost as soon as we started. It was too difficult to travel your history from childhood forward; all the breaks and disruptions, the changes in your life were hard to overlook. I thought about how different my timeline looked compared to yours. My childhood was one of stability, while your youth was spent moving, readjusting, and trying repeatedly to establish a home. I think about when you told me about your grandmother and how that story, even with our different experiences of place, were so similar. My maternal grandmother was the centre of our family, the matriarch that kept us all close. As a child, I knew no better place in the world than with Omi. It helped me understand that times spent with your Kokum were memories of love and safety, even in the absence of financial security. You told me of your grandmother's struggles. How she was removed from her family, displaced and forced into a residential school at a young age. Her story was shaped years before your own. Looking across generations in your family, disruption has in many ways been the norm.

It is a disruption that makes me physically upset. It reminds me of the times when the peace you fought to establish in your own home was so quickly unsettled. I remember with anger the day when I picked you up on the other side of town. Angry, but not exactly surprised, that your apartment was “unexpectedly” experiencing a bed bug infestation. We took turns packing your suitcases and black plastic bags of linens, sheets, curtains, towels, and blankets into the trunk of my car. The bedbugs forced you from your apartment and into a hotel suite on the opposite side of town. I tried to not show how uncomfortable I was when we were packing up, since I know it hurts you to live in a place that is yet to feel like a home. To live in a building that doesn’t have hallways that smell of sour milk and stale sweat. That you hope to live in a building where you don’t worry about safety at all times, a building where you can make your house a home. In a home free of fear that someone may smash open your window, or watch you enter and exit with your daughter. As I drove across the city, you apologized to me for needing my help. I tried to brush it off. The thought of bedbugs and cockroaches makes me cringe, and I cannot imagine having to worry about being comfortable in my own home.

It is this thought that reminded me of the sense of security you fought for in your apartments. How holiday decorations took on a special meaning, and how important, the pictures and reminders of family were. I do not know if someone, a caseworker or care provider, would notice these items. They may only see the sink full of dishes or ask about what you are doing to fix an apartment wide infestation problem. They may overlook, as I did early on, the effort you placed in making your house a home.

I hope now that even with what feels like inevitable moves and adjustments that one day you will feel settled. I see you trying to challenge this history though, and I return to thoughts of your grandmother. Our conversations around home have made me appreciate Cora's name more than ever. You chose her name for its Cree meaning. You told me about challenging the history of having a culture taken away. Cora will never experience the same level of support with your Kokum that you did; but her name brings with it a hope for the future. A hope that the past moments of love will carry forward to the future and I hope that her name always holds this sense of belonging.

Always, Georgia

Girl on the Greyhound Bus

I was born into a home where everyone, mothers, aunts, grandmothers, great grandmothers, raised you. Talking about my childhood makes me remember all the shit that we went through - me and my brothers and sisters. It just brings up a lot of feelings for me. Not all the experiences were good but I at least I was raised by family.

We moved around a lot
I went to Valleyview back to live at my great grandma's. For two years. Kindergarten.
Then I moved to Edmonton with my mom. For about a year and a half. Grade 3
Wetaskiwin with my other grandma. Two years. Grade 4…. Grade 5
Then I moved back to my great grandma's. For about two to three years. Grade 6
Then back to Edmonton.
I just moved basically back and forth
I'd go there for a bit, come back, go back….
I transitioned a lot
I went back and forth,
I was the girl on the Greyhound bus
By myself
- *all the way.*

Renate & Kayden

Prologue

An antepartum unit on a hospital unit is a dedicated space for keeping expectant women healthy, and in many cases, pregnant. This unit, with an emphasis on observation and careful monitoring, is a familiar space for me. In my role as an obstetrical nurse, I have worked many shifts on an antepartum unit. Yet, working on antepartum still makes me anxious, especially when I care for patients who are early in their pregnancy. Things can change so quickly for many of these women, and while science has made incredible advances in neonatal care, there are major dangers for an infant born prematurely. My confidence has improved with time, but I still find myself relieved at the end of each day. I walk away from the unit exhausted from worrying that one of my patients might go into labor and am thankful to step away from their bedsides, knowing that they are still pregnant.

I carried this anxiety with me, when I walked on to the antepartum unit to meet Renate for the first time. I had heard about her through a caseworker, a woman I met through my first participant. She knew about my research and asked if I was interested in talking with other mothers. I was so grateful. She told me that she had known Renate for years and that she thought we would get along. That is all she could share about the woman I was going to meet in the hospital. As I held our lunch and walked quickly down the linoleum halls, I checked my phone multiple times to make sure I had the correct room number. When I finally made it to the room at the end of the hall, I remember double-checking that I was in the right place.

The room was like no hospital room I had ever seen before. It was bright, airy and spacious. It had a bed and a sofa bed, a flat screen TV mounted on the wall and a large window with light streaming through. Renate was sitting, tucked in the hospital bed, trying to stay pregnant; still months away from her due date. I remember feeling confused because Renate did not look like most patients. When I first saw her, I was not even sure she was pregnant. At only 25 weeks along, she was tiny, barely filled the single bed. Her blanket, a pink thin fabric lay rumpled around her small frame. She was sitting with her hands on her tiny belly, one that did not look big enough to hold an infant. Renate had short hair that curled out, making her seem younger, and brown eyes with thick eyelashes and a huge grin on her face from the moment I walked in the door.

Even though this was our first visit, we talked for hours over lunch. Renate was quick to share stories of her past and her family. She had an engaging warmth; she was quick to laugh. On this first visit, she teased me about my own stories. She told me of her love of cooking, not because she liked to eat, but because she liked to feed other people. She barely touched the food I brought since she was so busy talking. There were few pauses in our conversation except when she suddenly stopped mid-sentence to pull out her phone and show me pictures of her older sons. As I looked at the pixelated images on her phone, I felt happy and was excited to begin our research journey together. When I left our visit, I said a silent prayer that she did not go into labour. I thought of the research showing that most micro-prem or premature babies born before 26 weeks face extremely low odds of survival. Nevertheless, my faith in medicine made me hopeful that hospital care could help Renate's baby grow just a little longer. I wished that Renate would stay pregnant. But this was not the case. She delivered her beautiful, tiny, delicate boy, Kayden, the next day.

Kayden had a difficult start to life. Born weighing less than two pounds, he struggled to stay alive. In the days and weeks after his birth, Kayden's only job was to survive. Under the watchful supervision of nurses and specialists, Renate stayed at his bedside often and sometimes I joined her for visits. I arrived to the unit and Renate guided me to Kayden's space in the neo natal intensive care (NICU) and peeked into his incubator, often covered by a thick blanket to block light. A mess of monitors covered his tiny body. These wires, all relayed a change in temperature, heartbeat, or breathing pattern to the team of care providers. As these care providers stood watching his monitor, at the bedside of her son, I began to learn Renate's story.

With each ounce that Kayden gained, we became closer. In the weeks and months following his birth, I was fortunate to be alongside for the changes in both his and Renate's life. Messages, photos, and video updates from Renate punctuated this time spent alongside her. Returning to these messages, I am reminded of the fear that hovered above Kayden's incubator. There were moments that it did not seem like he would make it to another day. Times where his death was so imminent, I felt the need to talk about his future as an unlikely possibility. During this time, I witnessed a mother strengthened by love. It was in these moments that our relationship has grown, grounded by the experience of waiting at Kayden's bedside. Each time there was a concern, he had a team of care providers and he had a mother, utterly captivated with every positive change he made. Kayden was tiny, just like his petite mother Renate. He was also a fighter, just like his mother.

In her own life, Renate had faced abuse, trauma and loss. Her previous children were in different places, and now, at Kayden's bedside, she fought to be present with her littlest child. The past with her other children was hard to discuss and remember. The stability Renate had found at Kayden's bedside was not different from that she had with her older sons. There was a guilt and sadness that punctuated the conversations about her other boys. These emotions meant that when conversation was difficult we returned our focus to the present, to Kayden.

In the time since our first interaction, my anxiety with antepartum care and preterm infants has lessened only slightly. Working on the antepartum unit, and now when I think about

Renate and Kayden, I recognize the complexity of this experience. Moving forward in time, they are both doing so incredibly well. Kayden is now stumbling around on chubby legs and Renate has gone back to school. With this current reality, it is easy to forget the moments when they were scared about his lungs, as they monitored each mL of food intake, as the specialists assessed him. The joy that resonate from mother and son makes it almost easy to overlook moments when she felt like it was too much to handle and that she wanted to just slip away to use substances or drink to numb the worry. Kayden is too important and, in response, Renate continued to ask for, and receive, support from friends, agencies, and therapists. Their journey outside of the hospital also shows that challenges often shift; instead of fears of Kayden surviving through the night, worries center on the day-to-day life, on buying groceries, and on finding safe affordable housing.

Renate and Kayden taught me that things change quickly and over the course of this year, I gained an understanding of what faith might look like in the face of disruption. The hope Renate had in all the moments in the NICU was for a different future for Kayden. For this reason, Renate and Kayden's account is written as a letter to Kayden. This letter traces the early months of his life. Renate's words, visible are in italics font, as well as text messages shared back and forth during Kayden's stay in the hospital, form this narrative account. Renate and I hope that he can, one day, read this letter and look back to our story to understand what shaped his early days.

A Letter to Kayden

Dear Kayden,

I became friends with your mother during the first year of your life. Actually, I came to know you the day before you were born. It was a year your mother called her happiest year and yet, at times, it was her most challenging. You were born premature, tiny, and frail. The initial months of your life were spent watching you gain weight, gram by gram, in a secure incubator in the neonatal intensive care unit. There were periods during this year we did not think you would survive. I would receive a message from your mother about your declining health, or weak lungs and remember only being able to look down at the phone in my hands and worry. My connection to the health care system made me critically aware of how uncertain it was that you would live. I knew how frail the lungs of an infant born at 25 weeks could be. I knew that your immune system was weak and even the smallest infection could have dire consequences. In my work, we do not try to record the heartbeat of a baby less than 24 weeks old. Those babies do not live. You were only one week past the age when we tell parents not to intervene, to let nature take its course. My past few years of working on a labour and delivery unit, I had seen numerous deliveries of preterm infants with both positive and negative outcomes. The memories of the sad conclusions were the ones that stayed in my mind. These memories rushed back and I questioned if things really would all be all right; that you would live. When your mother called me scared and crying, she never doubted in the same way I did. Your mother always believed you would find the strength and toughness to stay alive.

In the early days of your life, I visited your mother and the time at your bedside was mostly spent looking into your small secure incubator. We watched you breathe under the supervision of a nurse, carefully observing your vital signs on a monitor above your bed. Your mother was so proud of the vital signs, so excited about your breathing pattern, your heart rhythm. It was so amazing to see how your heart made her so proud. I just watched your chest rise and fall, wondering if the monitors were recording properly.

When you were in the intensive care unit, your mom and I talked and I learned of your family. I heard stories of her perseverance, and how she overcame obstacle after obstacle. I heard how your mother was unable to care for your brothers and that Jordan, only a few years older than you, was no longer in her care. I heard her pain as she talked about missing him. She truly believes that she will, one day, bring you both together. I learned how she met your father and of their instant connection; of how life complicated their relationship in ways that put her safety at risk. The stories I heard were from one perspective, and, since this time, I have wondered often about how your father and brothers' presence, or lack of presence, would shape your future. I have struggled with how to write about the times before you were born, when I did not know your mother. Even with this difficulty, I think it is important now that you have grown to hear about her life even if you only hear pieces of this story.

While much of this letter traces your first year of life, it also offers so many hopes for your future. Your mom and I believe that one day, when you are older, healthy, and strong, you will read this letter. Having grown up in a safe and supportive home, you will sit with pages laid out in front of you and understand some of the moments that marked your first year of life. This letter is unable to capture all the memories, but it offers a glimpse into what this experience was like. It begins on the first day that I met your mother, when we talked about her past and her hopes. It shares what happened but also what we imagined could be. It ends with wonders about your future.

This letter reads often as a story, though it is not an easy narrative, with many moments of sadness and pain. It is a story that you should read only when you want to know the challenges as well as the joys that came with your first year of life. We hope these pages help you understand what the world was like and how many times we thought things could have gone very differently. Most of all we hope that this letter shows how your mother fought for you and that she loves you with her whole heart.

The first day I met you, you were less than 25 weeks old, still safe in your mother's womb. I was nervous visiting the hospital, anxious to meet your mother and to ask if she would take part in a research study. If she said yes, she would be agreeing to have me alongside for numerous conversations, hospital visits, and appointments. If she said no, I would begin looking for another participant, something I dreaded at this point in my work. Fortunately, a support worker and longtime friend had asked your mother if she would be open to participating in the study. While she knew ahead of time and invited me to visit, I still felt jittery and nervous.

When your mother welcomed me into the hospital room, gesturing me with one hand to sit down, the other still resting on her stomach, I remember feeling instantly at ease. She could tell I was anxious and I remember her quickness to laugh, asking me right away for the paper work to sign. There was a warmth to her tone of voice and she was so overjoyed to talk about you that all my worries melted away. She told me, as I pulled out the forms to participate in the study, "*I want this boy to hear our story one day. I want to share with others so they can see it is possible be the mother they want to be, just as I am doing now*".

I asked her how she was handling things, especially now with the fear of labour. She assured me that you recently measured just under 2 pounds on her last ultrasound. You were small but getting bigger. Apart from your tiny size, the thing that I remember most from that day was how happy your mother was. I had only met your mother for a few minutes, when she told me how much she loved you. She spoke, barely pausing to catch her breath, at a rapid pace; I scarcely got a word in edgewise. Now as I write her words, I am reminded by her excitement and her pride when she spoke of you.

This little boy is a miracle to me; he's changed my life 360.
The scare of getting rushed into the hospital bleeding, getting a surgery….

It's just, it feels everything's starting to come together now in my life and I'm back to
where I don't want to end it.

Your mom vibrated positive energy, hopeful excitement. However, even as we sat with your mother smiling ear-to-ear and telling me how joyful she was to have you in her life, there was a sense of fear present. She had been under observation for the past few days, with specialists and nurses caring for her, and you, around the clock. The doctors and nurses had her on bedrest, surgically managed what they could, and were watching carefully for signs of labor. She told me that all the staff were kind, and I could imagine that they would have a hard time not being considerate. Your mother, outgoing and warm, spoke to everyone in her enthusiastic verbal style. I still think about how easy it would be to overlook your mother's fear around opening up and trusting people when she was so visibly engaging. Before you were even born, your mother changed because of you.

...I've walked away from a whole bunch of people.
I cut the west out,
cut the downtown out,
I want a new area, a new start.
I mean everywhere I go I know people.
I used to steal drugs really hardcore.
I used to do drugs big time.
I mean and everywhere I go I run into somebody I know.
And like I mean they're actually, it's easy to fall back in.
And now I'm strong enough, I say no now.
I would never ever get back to, 'cause you know what I just seen too much,

I've lived too much,
my body's tired,
I'm tired
and I got this little thing
and I realize this is what I need is to have my family,
that's it.
That's all that matters.

I remember thinking of how different the experiences of pregnancy are for different mothers. They say it takes a village to raise a child. Instead of building a community, your mother and other women I knew through my research, had to do the opposite. They had to show that they were focused on motherhood. They had to start their lives again, in a new neighborhood, new community, and in many cases alone. When I think about your mother cutting out the west, the downtown, starting fresh, my mind traces back to the times when I was lonely in my life. Even with a supportive family, I remember feeling isolated during moments of change in my own life.

Your mother approached this task with a sense of optimism but I wondered to myself.

What does it take to build a community?

What does it mean to begin again?

Thinking back to my own moments of starting anew, I remembered how challenging and lonely this process could be alone, without a newborn baby in tow.

What would it be like for your mother, without a network to help her through these new starts? Your mother had your father, but I questioned what it was like trying to find housing as well as friends and supports all at the same time.

These worries, though, seemed like distant problems during our first visit. Your small size meant that your mother's only job was to rest. On the antepartum unit, she would be observed, monitored, and assessed daily to make sure that you were healthy. Instead of arranging housing or finances, both of great worry to your mom, your mother's only job was to stay pregnant.

I wondered often about how you could think only of your pregnancy when you do not have a safe place to go once you deliver? These thoughts weighed heavily on me while I chatted with your mother. I worried if talking about these concerns would add more stress – something I knew could be harmful to both you and your mother. Instead, I just leaned into her warmth and vivacious spirit, laughing over lunch and talking about happier things in life. I was shocked to look down checking my watch to realize that it had already been two hours since I walked into the room. Our very first visit ended with your father arriving to take your mother for a stroll in a wheelchair for some fresh air. I left that day feeling as if I already knew her, and by extension, you so well. We walked into the elevator together and when we reached the main floor, we parted. I headed to my car, and your mother and father turned the opposite direction. I thought to myself as I left that I was happy she was in such a good place, that she had a beautiful room, and that she was doing so well. I said a prayer to myself. I hope she stays pregnant as long as possible.

The next time I heard from your mother was just days after you were born. I was surprised to hear back from her so quickly; we had just had our first visit a day or two before. I never imagined that she would be calling to tell me that you had arrived.

I remember catching my breath when I heard that you were born.

"What? He is only 25 weeks!"

"How is he doing?"

"Is he going to live"? is all I thought.
You were too early
Too small - under two pounds (the ultrasound was wrong)
Not ready to live outside yet.

I did not quite believe it when your mother told me the news. Though your mother knew there was reason to worry, she was so excited. I wonder if the nurses told her that many babies do not survive when they are born at this age. In my work in labor and delivery, our hospital does not even care for babies this early; it is just too dangerous.

I remember standing in my office at the university, looking out to a grey November day, just hoping that you would live to the end of the week. Instead of joy, all I imagined was grief.

Your mother was so full of hope and excitement for the life she would provide for you. When I thought of you being born at 25 weeks, all I imagined was a heartbroken mother losing a preterm child. I felt sick to my stomach and remember the overwhelming worry that I had when I told her over the phone:

"I can't wait to meet him".

I came to visit shortly after getting the phone call that you were born. I drove to the hospital to meet you. I had been anxious to meet your mother the first time. As I waited in traffic, I felt that heavy weight in my stomach but for very different reasons. I carried that anxiety with me as I walked to the unit, unsure of where to go. I had been in the hospital many times but only to care for, and visit, adult patients. I had no idea where the neonatal intensive care unit (NICU) even was. Asking for directions made me feel again like a novice. As I headed in the right direction to the unit, I found that my confidence as a nurse began to fade slowly away. By the time, I made it to the front door of the NICU I felt overcome with nervousness. I waited at the front door, which was locked shut for security reasons, until your mother came around the corner to wave me into the unit.

I relaxed as soon as I saw her smile. I stayed mostly silent as your mother led me from the front doors of the NICU to your bedside, where your incubator stood. Babies were sleeping here, and not dressed in my scrubs or wearing a nursing badge, I like an interloper. Part of me was bracing myself for meeting you. Tucked in the corner of the large open space, with the shelf behind it full of stuffed toys and a recliner chair for your mother, was your incubator. Above your bed, a screen showed your heart and breathing pattern with a nurse standing only feet away watching for any changes. A whiteboard hung on the wall and had all the information about your care written on it and updated by the nurses daily. I looked around at all the objects in your space, and when I finally turned to you, I saw just how small you really were. You were so tiny, barely bigger than a hand, so fragile and delicate. However, even with your perfectly formed features, all I saw was a mass of monitors and cords.

Your mom thought differently. She leaned over the incubator and said, *“Doesn’t he look beautiful?”* I thought to myself how frail you were and that you looked like a small alien with little goggles covering your eyes, blocking out the light. *“*Yes he does*,”* I said.

I remember looking at your mother after I said this and seeing someone so in love with a person. She adored you with her whole heart. I struggled to imagine you as separate from the machines keeping you alive.

Days forward from this time were marked with updates of your growth. Your mother sent text messages, short windows into the world that she lived at your bedside. These messages, though sent in haste, were a way that connected us. Your mother, at your bedside watching and sending news, made me feel like I was there along for your journey.

A journey marked with both good and bad days.

10 mL every 2 hours.

Rough day yesterday.

He had to get a blood transfusion.

Low hemoglobin

Never been so scared.

I wondered what to say back to your mother as I read this.

How do you comfort someone when you think they should be worried?

When they should really be bracing for the worst?

I did not want to make her more frightened, but when I read that you needed yet another transfusion, I remember swearing out loud.

This was bad. This was really, really bad.

I waited a few days before I messaged back. Tentatively asking how things were.

How’s the little guy doing?

Staying strong.

15 mL every 2 hours.

He’s 1070 grams

They just extubated [2]*him*

He's doing awesome

Before and after he's 1360 grams

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[2] Kayden had been intubated with an artificial airway in his trachea to help with his breathing. In this text, Renate shared that they had extubated him, meaning that his breathing tube was removed.

Each message I received from your mother was a glimpse into her life. It was a gift to hear about each mL more that you could eat. Each day you grew was a source of pride. These small changes started to make your mother more confident, and everyone around began to notice. She took on the role of devoted mother the moment you were born. She also helped others in the NICU, donating breastmilk, and serving as a support for other terrified parents. When I think of your mother at your bedside, I am struck with how different the current situation was in comparison to the stories your mother shared of her past. Your mother grew up in a home without much support. She had a strained relationship with her mother, and with the extended family that raised her. Her childhood stories were narratives of neglect and some were of heart wrenching abuse. In all your mother's stories what was most striking to me was how she always fought to find love and be a source of support for others. I remember wondering when I saw her at your bedside, aware of each mL of breastmilk you were eating, knowing the names of each baby in each incubator, how she did this.

How does one shift from being unloved to a loving mother?
When do we accept life on this complicated journey of living?

While you were the baby, who came too early, it was in many ways the right time for your mother. She was finally entering a stage in her life where she had access to counselling and stable support in the form of the NICU family. It was at your bedside at the NICU where your mother found herself.

While your mother found her confidence in the hospital walls, I continued to feel anxious when I came to visit. Given my expertise as a nurse, I felt confident in the hospital but there was something so much more frightening about the NICU. The patients on this unit were too frail and too tiny. Your lungs and your risk for infection was a constant worry throughout your early months. When I arrived at the NICU, I waited at the front doors of the space. The two large doors remain locked until someone scanned me in. I remember standing there and watching as your mother let me in. She walked toward the entrance with arms open as if to welcome me into a high-end hotel. The receptionist usually did not bother asking who I was and instead just opened the doors once they saw her waltzing over with open arms. All the staff knew your mother. Your mother did not just walk, she sauntered. She did not ask how I was, as an offhand comment; she asked and then leaned in, thoughtful to hear my response. For someone who struggled with opening up and talking about her past, she was warm and inviting with all those around her. Receptionists, nurses, and even other parents always said hello, or at least gave a friendly nod as we walked past.

With your mother there to escort me, we walked to the sinks, where I often repeatedly washed my hands. I began, planning to count in my head the suggested time necessary to wash my hands well, but often forgetting where I was in the count because I was feeling so much anxiety. As your mother gained confidence in the NICU, I lost mine. I did not feel useful or helpful in this space and worried I would be the person who introduced some germ that just was too strong for you to fight. With this worry heavy on my mind, I washed my hands again. From the sinks, we headed to your incubator. Your mother always took me on different routes, past the beds where she knew the parents or by the nurses she wanted me to meet. We strolled by others' pods, and she said hello to the nurses and sometimes to the parents. The longer that you both were in the hospital the more comfortable she was on the unit. She showed me the fridge where all her breast milk was stored (much of it was donated to other babies in need). I was always two steps behind, nodding quick greetings before increasing my pace to catch up to your mom. Though it was not far from the entrance, it always took longer than I expected to finally make it to your bed. Once there, I leaned in to peak at your tiny hands and little body. Sometimes I lifted the fabric cover to see just how big you had grown. After our check to see all your changes, your mother and I headed to a different part of the hospital to find a quiet place to talk. Your mother always asked me to visit, and while it was a gift seeing you grow bigger and stronger than my previous visit, I never felt comfortable.

During your entire hospital stay, your mother was always nearby. She stayed in supportive housing in the hospital, shuffling between your bedside and hers when she could not keep her eyes open any longer. She had options of staying at different respite care centers, ones with bigger rooms and furniture that was more comfortable, but she did not move. Instead, this space was a blessing – so close that she could walk over to be at your bedside. She knew the nursing staff and doctors and they knew her.

I was happy to know your mother had a place to stay but it felt strange walking through the hospital, past patient units and communal spaces, up stairwells and across pedways to the parents' room. The parent lodging was in a part of the hospital that seemed forgotten, tucked out of sight with furniture and decorations that had not changed in decades. The space never felt like a home; there was too much beige and anxious emptiness to it. The space had a tense energy. Once, as we sat eating lunch together in the common area of this space, another woman exited, walking towards the elevators, bent over with hunched heavy shoulders. Your mother recognized her instantly and leaned over gently to tell me, "*Her little one didn't make it.*"

In this space, joy and sadness were close bedfellows. This, not quite a home not quite a hospital, was where your mother lived. It let her be nearby your unit, and it was a safe place for when things became tense and difficult with your father.

I saw him only once, your father. On the first day I met your mother, he arrived to visit just as I was leaving. I remember as we took the elevator down, your dad pushing your mom's wheelchair, heading for some fresh air and a cigarette. He was polite and excited about your birth but this one moment was easy to forget when I later saw bruises on your mother. When I heard about her fear, I was thankful there were security and support staff keeping both of you from harm's way.

On one of our later visits your mother was upset, distressed about how bad things had gotten in the relationship with your father. She told me about how embarrassed, she was and when we sat across from each other, I wanted to tell her things would be all right in the end. I know she wanted you to have a father but things were so complicated. Saying things would be fine was not an honest answer. Instead, I only nodded when I heard about Child Social Services being called. As they became involved, I wondered what they thought of your mother. She welcomed the help from Child Social Services and I wondered how this changed what they thought of your mother. Did this make her, in their eyes, a more devoted mother?

Your father left the country.

Your mother was at your bedside when this happened.

He crashed last night and we had to put the tube back in

At the U of A

Had a blood transfusion today

1477 grams

I remember one visit with vivid detail. I had stopped by the unit to pick your mother up for lunch. We wanted to leave your bedside to eat some cafeteria food and have a chance to talk. Our routine was for your mother to meet me at the NICU doors. At this point, we had worked on the routine well enough. I had my jewelry in my pocket; rings can carry germs. I had my jacket off and stuffed into my bag. It was easier to wash my hands without pushing up my sleeves. The unit clerks did not recognize me but let the doors open as soon as your mother came down the hall. It was obvious to them that I was there to visit her. I nodded a thank you to them as I walked to the sinks and washed my hands before heading to the pods, the space on the unit where the incubators were set up.

When I approached your incubator, still tucked in the back corner, I noticed your blanket cover was gone. Usually there was a cover on top of your incubator keeping the light away from your fragile skin and eyes. You still wore an eye mask and there were many cords keeping track of your vital signs. It was one of the few times I had truly seen your tiny form. Your mother stood beside me as I looked over you, appraising the smallest detail on your miniature form.

She asked me excitedly then, "*Do you want to touch him*?" I stumbled on my answer. While comfortable in the routine we had established, the thought of your fragile skin and weak lungs made me nervous. "I don't know…." She encouraged me regardless of my trepidation. Finally, I opened the small circular door to the incubator and ever so gently stroked your back with my index finger. "WHAT ARE YOU DOING?" I startled back, quickly taking my hand out of the incubator and away from you. A small woman, your nurse, with dark hair grazing her shoulders and her hands on her hips, scolded me for breaking the rules. She turned to your mother, as if to ignore me, stating how fragile you were and that only parents and family were allowed to touch the infants. "Do you want to make the baby sick?" I flushed immediately and apologized multiple times. I was not going to mention that I was a nurse. I just wanted to fade away, anxious and uncomfortable at getting in trouble. Your mom was unfazed by the comment. She nodded when the nurse told her the rules, agreeing with her but at the same time telling her "*She is practically family*". The nurse shook her head and said again, "Just wait until he is bigger and stronger."

I practically pulled your mother away from your bed after this, "C'mon let's go get lunch". I wanted so badly to be anywhere else, away from the steely gaze of the nurse who had never seen my careful handwashing routine or met me during my many previous visits. Eventually, we laughed about the experience, and your mother she still teases me about it. We laugh about how red my cheeks flamed. We bonded over my nervousness, but later, I thought more about the nurse's statement and your mother's response. When your mother said I was "practically family", it was a personal moment for both of us. It had been a gift for me to be alongside to see your growth. It also mattered to your mother that another person saw her as the mother she hoped to become.

I wondered at that time, as I do now, about the rules for family.
Do you get to decide who and what you consider family?
Ultimately, though, it should have been your mother's choice.

It also made me reflect on the tone and the words that nurses use to speak to patients. It was the first time I had been on the other side of the interaction – I was no expert, I did not even know the rules of who could touch the baby, and I was made to feel so small in that moment that all the confidence of our careful routine was disrupted. I never considered how quickly we could tear down the confidence of patients or families. I learned that I wanted the nurse to know that I too cared about you. I wanted to make a good impression with a person in charge of care.

Back at the Royal Alex Hospital

Lungs have fluid

Not doing well

I remember shortly after this message, talking to your mother on the phone. You were struggling with pneumonia at this point, and your mother was terrified. She was upset when she called me, and I wrote about it afterward, still unsure of what to do. I reread what I wrote that day and still feel like I have no answers.

> When you called me crying I didn't know what to say. As I sat wrapped in a blanket in my chilly house, I knew that you were phoning me from a room in the hospital with no curtains, paintings, or fixings of a home. We were in such different places but your sadness and a telephone line connected both of us. Kayden was not doing well – you had told nurses that something was wrong. Something was wrong since they intubated him again just after New Year's but what I didn't say, as I nodded on the other end of the phone line, was that this isn't because of something anyone did. It wasn't your fault that he came so early, that you maybe gave him pneumonia, that the reason he is struggling so badly is you. It wasn't the nurses' fault for watching a difficult breathing pattern. I have been in similar situations where you have to sit and hold out – hoping that things get better or worse, that they get so bad that you are justified in intervening.
>
> Field Notes Jan 6, 2017

Getting better

My lil fighter

We had to put the breathing tube back in

Too much is happening to text.

Over the weeks and days that you were gaining strength, I started noticing your mom become more independent and outgoing. She was always a force to be reckoned with. The sense of purpose that came from being your mother was only reinforced with time. One day I came during the middle of the day for a casual lunch. Carrying in sandwiches and a Dr. Pepper for your mother, we sat in the supportive housing wing of the hospital. We were supposed to talk about you and your mother's story. Instead, your mom spent most of the time trying to help a young couple from rural Alberta who were struggling to find housing and support. She was a firecracker of energy, frustrated for them and an expert in navigating the system.

I just handed her my phone.

She started dialing numbers off by heart.

She reached out to agencies and support workers, savvy as always, to try to help another couple. There was unfortunately little either of us could do to help this young family in the long term, but, as I watched their faces, they were just amazed at the energy and determination of your mother. Their problem were too complicated to solve over sandwiches, but your mother managed to get them temporary housing with one community agency. After, as the couple sat still stunned at the prospect of having a place to stay, your mother ran to her own room. She rushed out holding a pile of clothes, and she gave the girl a new dress, one of hers she did not need. The look of joy this young woman had on her face when she went to change into this new dress was striking.

This moment is one of my favorite memories of your mother. You were still so fragile to touch and I wondered if she took on the role of support with those around her to make up for it.

Your mother was there to help navigate the system, yet it too made me think about when she talked about losing custody of your brother, and how different things could be.

Maybe she was making up for past times when she could not be there for your brother. Remembering her words: "*I had all the supports. I just ignored them all 'cause I gave up on myself."*

Another time, one of the few where we left the hospital, we went for lunch, not far from the building. It was during one of the many times we waited, worried about if you would make it through the next few days. It seemed like a good idea to be somewhere else. As we sat at the table, your mother shared with me her story of growing up. She shared stories about your brothers, some of whom you might one day meet. She told me about the abandonment she faced from family.

"I would die to have my mom come back in my life but you know what ... I just feel like I just gotta be a better mom than she was ever to me and that's what I'm doin'"

She spoke of the abuse she experienced from a young age. She told me about your brother, how she decided to give up custody to family when she knew she was not able to care for him safely.

"I was so shame ridden
and I kept everythin' on my own which I shouldn'ta took it all on my own
because I really didn't do that bad that much .. .. but the same reason I just gave up on
myself and that's the first time I've ever gave up on myself.
So I didn't use any resources
but no, when I had enough
and enough's enough

and I got pregnant with Kayden and I just decided…

This was…

…time, this is it so and if you see that little boy,

you know.”

Later as your mother worked to bring her life together, she told me how deeply she missed your brother. We went back to our meals, and I felt nauseous as I tried to imagine her losing you, and I just shook my head. She would shatter.

There was one moment in your early days when I was scared not for you but for your mother. Your health was so fragile and holding hope all the time was exhausting. Texts from your mother slowed, and I wondered what was going on. A support worker that had known your mother contacted me worried, waiting to hear back as well about where she was. In the end, it was less than 48 hours that she left your bedside. However, it was the longest stretch of time she was away from your incubator and she had left to use substances. I remember when she called me crying. I felt like I was disappointing her as her voice, raspy from tears, told me she just felt overwhelmed. It had been too much. I comforted her saying that this road to recovery is not a straight line. That I was just glad she was safe and then I asked, "What's next?" Your mother paused, catching her breath. She told me that she reached out to Child Social Services, "*I asked for more support. I told them I made a mistake. They are going to help*."

I can only imagine how frightening this must have been for your mother. In the weeks leading up to this moment, there was a constant fear that you would leave this world too early. Now disclosing substance use to Social Services, there was an added fear that you would be taken away too early. Social Services had options with your case. You were still in the hospital care; you would still need much more time to grow. Your mother had time to get more support in this time. She started seeing a psychologist, finding ways to get through the sense of overwhelming pressure. Throughout this process, a part of me was thankful that you came early. I thought of how difficult these past few months had been but even still was glad that by being in the hospital it gave your mother time and the ability to access supports, all while you were connected to cables, cords, and monitors.

He’s over 5 pounds now.

He's doing awesome

I loved getting these messages.

They were usually brief. Punctuated with a burst of photographs, pictures of you lying on your mother's chest. But the joy in the short texts held so much joy in their news.

Started breast-feeding this morning.

We go home on March 3rd.

When I heard that you both had a date to go home, I reflected on the many moments when it felt like you would never leave the hospital. The times when the silence on the other end of your mother's phone line made me scared that you would not survive the night. When you were finally discharged, you had been in the hospital for around four months. These months were filled with more anguish, fear, and hope than some people experience in a lifetime. It felt like there should be a clear and simple path when leaving the acute care setting. However, worries shifted from you making it through the night, to worries about what supports your mother would have outside of the hospital.

Your mother had formed a community at the hospital. She knew all the nurses, donated breast milk to the mothers that did not have any, and she was present. All the time, she was visible and engaged at your bedside. She was an expert, an experienced mother who had positive messages to share; you were still alive and stronger than ever. I wonder at times if you were my son, if I could have stayed at your bedside the way your mother did? I question what strength is needed to stay day in and day out at your bedside watching the monitors constantly. I wonder about the many families who find it too difficult. Marriages break in the NICU, families shift and re-form. There were some things, perhaps, which made it easier for your mother. She was naturally warm and open. Would the nurses have been as supportive had she not been? Did they really know her?

"No. No… I'm just open with people I like… I'm a very closed off person. I used to walk my baby there ... yeah like I'm one of those people… you know, like I'm not afraid to show him off but to let people close to me or know where I was at or know anything about me, it takes a lot and if it's a friend somebody like I'm close to, I must know now."

She was always present at your bedside. Would they have thought of her as your amazing mother if she had other children or life outside of the care to look after? I wondered often what qualities made her the ideal mother in the NICU, and what these would look like when she left the hospital. I imagined:

Now she would have to be like all the other mothers.

Now she would have to be like all the other mothers, all on her own.

The transition out of intensive care was filled with both challenges and positive moments. You left the hospital still requiring oxygen and needing careful monitoring. The apartment where you and your mother were placed was quickly decorated with her loving style. She filled the space with toys for you, but it was quickly clear that the quality of air was poor. The unit was not safe. I remember hearing updates from your mother, the perseverance she had at your bedside shifted to finding a new, nontoxic, home. The daily fight took on a different meaning. Dealing with housing workers, moving between buildings, and getting you to a safe apartment became the focus of your mother.

I wonder now as this year has come together about what your future looks like. Your mother has been an amazing parent. There are times when the pain starts to come in and past problems creep into the edges of her life. In these moments, it shades things dark and makes hope look less likely.

When I imagine you reading this letter, I picture you grown up, with your fiery red hair tufted up as it does now. I imagine you as an older boy with your mother working hard as a nurse and I stop in to visit – finding time between when you are busy with sports, or theatre. Probably theatre since you need a designated space to speak up and find your voice. Getting a word in edge wise with your firecracker mother is tricky. When you read this letter, you will know that things could have gone differently and you will recognize that life is not a straight line.

Marilynn & Her Girls

Prologue

When Marilynn and I spoke about her narrative account, she wanted it told as a story for her girls. She wanted them to know that becoming their mother, at least the mother she wanted to be for them, was an ongoing process. She wanted them to know that she was sorry and ashamed it was taking so long to be a mother, but that she was trying. When she told me about her disappointments, Marilynn looked away, avoiding eye contact. Yet, she continued to share stories. At one point she stated that as difficult as it was, maybe someone could learn something from her experiences. Marilynn's narrative account is comprised of narratives of our visits, a story tracing Marilynn's past, and found poems about each of Marilynn's girls. Throughout the account, Marilynn's voice comes through quotations from recorded transcripts, made visible by italic font. The final pages of this account are found poems, which are her words about each of her daughters.

Introductions

Marilynn was the last participant I met in my doctoral research. For months, I struggled with a fear that I would not find a third participant; that I would not connect with a mother who wanted to share her story. I waited at drop-in agencies hoping I would meet an interested mother, but week after week, there was no one. I reached out to care providers asking if they knew any women who might be interested. Many women wanted to share their stories but they did not fit the strict parameters outlined in the research grant; in most cases, their children were too old. Instead, I could only listen to their narratives of their experiences with care and motherhood and then apologize that they could not participate in the study. I found these conversations incredibly difficult, stating to someone as they recalled with vivid detail the stories of their children's births, "it's been too long". I found myself dreading going to the outreach agencies, knowing that the sense of disappointment weighed on me when I left at the end of the day, still no closer to engaging with another participant.

During one visit, a support worker asked in an angry tone, "Why do we keep researching the same thing?" I listened as she shared, upset and frustrated, that the Indigenous women who accessed the program continued to have terrible experiences with care. That they continued to face racism, stigma, and discrimination from care providers. She questioned me on why we keep "researching" when we already know how terrible many women's experiences are in care. A doubt washed over me when she questioned me and I felt my cheeks flushed with embarrassment. I believed this work mattered, but, at the same time, I could not even find a third participant. This uncertainty caused my answer to come out mumbled and nervous. I said that sharing stories in narrative inquiry was different from most research approaches; that I believed we could make a difference. I left outreach that day without having met anyone and an even greater sense of worry.

A week later, when I returned again to outreach, my lack of confidence and uncertainty remained. However, during that visit, the staff told me they were expecting a pregnant client to stop by and suggested to me that she might be interested in the research project.

Coming Alongside

They told me you were bubbly and outgoing and I found myself trying to calm a spark of excitement lit by even this general description. When you walked in the room, the caseworker that had suggested I reach out to you nodded in your direction, signaling that I should introduce myself. I remember looking at you and noticing you wore an oversized men's sweatshirt that seemed to hang on your small frame. I remember thinking that you looked like you were the opposite of warm and outgoing, but when I introduced myself a smile lit up your face.

I asked if you were having a boy or a girl, and with that question, you placed your hands gently on your pregnant belly, and told me that you were having a girl. You told me smiling that her name would be Hazel. At six months pregnant, things were going well. Both you and Hazel were healthy. We talked about labour pains and what contractions were considered "real". I sat back in my chair and listened after you told me stories of your other daughters. It seemed that you could have kept talking for hours but shortly after starting to talk, you stood up to walk to the bus. You needed to get home. Before you left out the door, I gave you my number. I left outreach that day, feeling for the first time in months, hopeful that this research would continue. I had met Hazel, I had met you, and it was going to be all right.

After our first interaction though, life found its way of complicating things. You lost my phone number, and with no cell phone or way to reach me, life's chaos postponed our conversations. During this time, I continued to return to outreach, hoping that a mother would want to share her story. It was in the same room, weeks later, where we met for the second time. You smiled when you walked into the room, this time wearing a different oversized sweater, and I almost jumped off my chair. We agreed that day we would have a conversation in person, and we agreed on the date and time and place.

It was not long after this second meeting that we met for our planned first visit. We were going to eat lunch and have a conversation but beyond those plans nothing was arranged. Worrying about losing contact again and the feeling of failure that came with this loss, I said I would pick you up, and we planned a date. It was a chilly day, and as I drove to the other side of town, I felt both anxious and relieved. I pulled up to the address you gave me, a big two story home. As I looked over the heritage features of your rental property, I double-checked the address, surprised that this was your place. I had expected to pick you up from a run down, walk up apartment. I wondered now what that says about how I understood poverty – what were my expectations? Your house could have used a new coat of paint, but I could have driven by it many times and never noticed. I wonder if I only recognize things as a problem when they are visible, a building with a crumbling wall or a pile of garbage in the front yard? Who educated my eyes?

As I sat in my car, the front door opened and I saw your familiar figure. Again, dressed in an oversized hoodie, I watched as you shuffled your feet on the slick pavement, careful not to fall. I remember thinking, “Where is your coat?” It reminded me of a saying my grandmother always used in the winter. She said, “Only the poor and the stupid freeze” before bundling us to go outside. I wondered if these were the early stories that were, knowingly or unknowingly, implanted in me about poverty. With that thought, I guiltily reached for the knob on my car dash to turn the heat up. As the warm air filled the space around me, you opened the car door and slid into the seat next to me. "*Hi*!" you said beaming, as you put the seat belt on. I quickly brushed aside the questions I had about poverty, asking instead, "Where should we go for lunch?"

We chose a Vietnamese place only a few minutes' walk from your rental property, but with the snow and ice on the ground, we drove the short distance. We got out of the car and quickly made our way into the restaurant. I chose a table by the window, but with the corners of the glass covered in condensation, there was little to see outside. Facing each other, I said, before we ordered food, "If at the end of this meal, you don't like me or don't want to do the study it is completely fine, but you can decide over lunch." You nodded, but when I glanced up from the menu I saw you somewhat overwhelmed by choices. I wondered if your indecision was a question of food or about taking part in the study.

When I saw how nervous you looked, I told you, "Get what you want." Nodding again, but still looking unsure, I asked, "Do you want coffee or tea?" You told me, "*I've never had Vietnamese coffee before*." "Order it!" I said, and you finally started to relax, smiling. Food helped make both of us more comfortable; it made me less anxious about the pressure of having you join as a participant and it made our visit feel less formal. I ordered green onion cakes to share, and when they arrived to the table, they were so hot they burnt the tips of our fingers. Laughing over our shared pain and impatience, we blew on the food until it cooled. I waited for the main course to arrive before asking again about the study. You looked up from your lunch, nodded and told me you trusted me. I felt a wave of relief come over me and found myself again, as I did in outreach, leaning back in my chair and ready to just listen. You told me in rapid succession, several stories of your childhood. You mentioned your mother, stepfather, brothers, and cousins. You told me about your girls and the fathers of your daughters, and you told me about Hazel. This last topic made your cheeks flush, and I could sense your joy and excitement as you mentioned your weight gain and expected date to bring Hazel into this world. She and her older sister shared a father, and he was as excited as you were about the upcoming birth. The speed with which you told about your experiences left hardly any space for me to ask a question. I barely had time to reflect on what you had just said, as you switched quickly between stories of when you first became homeless and slept by the Greyhound Bus terminal and stories of recent visits with your daughters where you played in the parks. I remember one story you shared was of a time when you had nowhere to go and you were falling asleep on a city bus. The bus driver did not wake you for an hour. With your eyes closed and head resting against the window, you traversed the city until it was time for the driver to head back to the terminal. The driver did finally wake you. You laughed when you told me about the look of worry on his face and your fear of being on the opposite side of town. I wondered about how tired you must have been to sleep so soundly on the bus.

I calculated the time you likely spent on the bus, the hours of sleeping on a stiff backed chair. I felt sad for the bus driver when he had to wake you up.

I wondered if anyone noticed you?

Did anyone on that bus that day wonder why you were all alone?

I thought back to where I was at that same time. I was a student then, spending much of my time in transit. I could have been on that bus that day. Would I have gently shaken your shoulder to ask, “Where are you going?” Would I have moved seats and turned my gaze to the window? I know that even now, the answer is the latter. Thinking about how young you must have been at that time. I felt a sense of sadness that, at your age, no one was missing you, and I wondered about how lonely that must have been. Immediately after you shared this memory, you started talking again about the last visit you had at the park with your daughters and how much they love the swings.

There was hardly a pause between your stories. The speed at which you switched between these memories made me wonder about the idea of temporality, how time impacts experience. Many of your stories blended with the present. The ways you told the stories, they all felt as if they had just occurred. I was confused as you jumped around in time. Yet, I quickly stopped trying to figure out the dates and years of these stories and listened, instead, for the emotions, which connected the stories. As you shared stories, which spoke to me of trauma and sadness, it was clear linear time did not really matter. The world you lived in now was still shaped by those moments when you were alone or lost. Similarly, the joy you spoke of your daughters seemed to fill the space between us, and I smiled hearing about their personalities and temperaments.

This lack of grounding was present in time as well as place. Your childhood and youth were marked by disruptions. You told me that you moved often as a child, going between your mother, grandparents, aunts, and cousins' homes. I tried to follow as you talked about your family - you could always tell when I was getting lost as you laughed and paused. These small silences were not uncomfortable. Instead, they signaled a growing sense of comfort and ease with one another.

At some times, you paused between difficult stories. We shifted focus when this happened and talked about food, people passing by outside the restaurant, or we found something to laugh over. I don't recall these as moments of distraction; they were usually small jokes or a detail in a story that helped us to refocus and not feel overwhelmed by despair. The jokes always positioned us together as a team and the opportunity to laugh, and the ability to be playful was one that allowed us to be together with ease (Lugones, 1987). Looking back now, I am reminded by how many of the more difficult stories were book ended with humor.

At the end of our visit, I remember looking at my watch and finding that I had completely lost track of time. There was no sense of fatigue; rather it was as if I had been visiting a friend. It was with this feeling that I remember giving you a hug at the end of our visit. It was in this embrace that I noticed how physically small you were in the oversized hoodie. It felt like the size of the sweater hid your vulnerability. I thought back to the stories you told me about being lost and alone, and even more than before, I wished you had a coat. Something that could bundle and keep you warm from the harsh world. It was a thought I carried when I watched you shuffle away from my car towards your front door. For the first time in weeks, I felt relieved – I was so happy to have met you and to learn alongside you. I drove home, across town, not worried about connecting to another participant. I had met you, and I already felt I had begun to know about you and your daughters.

A few days later, we met again for another visit, but this day had a particular purpose. We picked up food, hot coffees, and sandwiches, before arriving at a crowded waiting room for a scheduled prenatal appointment. It was the first time I had been in that space and was surprised to see so many women waiting for the doctor. There must have been about 50 women there, some were accompanied by friends, others had grandmothers taking turns to cuddle older siblings. Your usual doctor was away at the time so, after checking in with the front desk, we sat, and you told me you hoped that the new physician was kind. As we sat drinking our coffees, I looked around the space. There were chairs surrounding the periphery of the room with rows of seating in the middle of the space. There were women who fussed in chairs, months into their pregnancy or close to delivering, unable to find a position comfortable on the hard backed seats. The room hummed with noise, and as we sat there, I wondered about the other mothers.

What would their deliveries hold?

Would they have vaginal deliveries or cesarean sections?

Would they ask for an epidural?

Would their baby be ok?

Would their experience in care be shaped by frustration or joy?

Did they experience fear or hope? Or both?

Did any of them worry about being asked about substance use?

Did any of them worry about not taking their children home?

These questions raced through my mind, and after looking around the room, I turned back to you and noticed again how much smaller you seemed in the seat beside me. You were so different from the Marilynn I witnessed only minutes earlier, laughing in my vehicle. I wondered about your previous deliveries, how you always came to the clinic alone. I thought about how much harder that would have been when you were even younger. How had the doctors treated you then? Most of all, I wondered what you were thinking in that moment. Did you have any worries?

These questions kept running through my head as you were called to the front desk. From there, a nurse led us to a small space, where she weighed you and took your blood pressure. She finished her measurements, and you stayed silent as she wrote the blood pressure in her notes. “What was it?” I asked as she was about to leave. She stumbled over her answer, seemingly surprised to be asked and directed her answer not at you, but rather to me. You continued to stay silent. She led us to a smaller clinic room, and as you set yourself on the edge of the bed, the paper covering the exam table crinkled and tore. You still seemed small and scared, and we barely spoke as we readied for the doctor to come into the room. When he entered the room, I recognized that he was familiar to me. He was a physician I knew from my experiences, as a nurse but he barely noticed me. I wondered if he had looked in my direction, would he have known my face? Would he have recognized me, if I wore mint green hospital scrubs and not my own clothes? I said nothing as I watched him listen closely to Hazel's heartbeat. I remember smiling when I heard the steady gallop that my ears equate to a healthy fetus. You waited for him to say that everything was all right. He made a slight gesture that indicated all was well. Your posture relaxed, and I remember smiling at that small moment of happiness.

Though the visit felt short and rushed, the doctor still took the time to reprimand you for missing your last appointment. He spoke in a warm, kind, tone. He talked about how missing your appointments was a risk to your health and the baby's health and restated the importance of attending all your visits. You laughed and said, "*I know…"* Before leaving the room, he stated again, you have to come to your visits. Again, you said "*I know…"* avoiding eye contact. He checked off some paperwork, told you to make your next appointment with the receptionist, and casually left the room. As I sat in my chair off to the side, I wondered about the care I had just witnessed. Your physician was not rude; his tone was not short or terse. However, in the interaction, there were no questions and no time for a response.

He could have asked so many things in that moment. How were your other girls doing? Is there anything you are worried about for this delivery? How have you been feeling lately? How is your stress? Why did you miss your last appointment? Instead, the doctor just left the room and I sat there, looking up at you on the bed.

As the door behind him closed, I asked just one of those many questions. “Why did you miss your last appointment?” Still looking down, you told me you had come into the clinic for the appointment. In fact, you had waited all afternoon, but the doctors were too busy to see you. Sent home after hearing this news, you were not able to return the next day. You used up your bus tickets, and no one was available to look after your other daughter. I nodded and felt anger. Sometimes care providers were far from caring; they never explained what was going on; they never asked questions.

But as I felt my anger, I turned inward and wondered about my own practice as a nurse. How many times had I entered the room and left without ever asking about the world of patients beyond the hospital walls? I rarely thought about the structure of the hospital unit I worked on and the ways it did not support mothers with children. There are no books, no toys, and no private space for waiting. The unit is busy, and partially because of this, we often provide care without explaining the reasons. When we left the appointment that day, walking past the women in the waiting room, I thought back to Hazel’s heartbeat. Its steady rhythm had its own hopeful speed. She had no idea she would soon enter a world that was used to rushing people through. It made me consider what would determine her pace in life. Would she find ways to not be swept up and swept away? Would people find the time to ask her questions and find the time to listen to whatever answers she wanted to share? Picturing Hazel into the future prodded me to imagine forward. I imagined days, years forward when Hazel was older. I hoped that one day, when she was having her own children, you would be one of those grandmothers in the waiting room. That you would be a Kokum who came to appointments, who helped care for the other children. I hoped that one day you would visit a waiting room like this and be there to support your daughter.

When we left that visit, I felt frustrated by a care system that knew so little about your life and at the same time, overwhelmed by my own lack of control. There was little I could do to shift this space, and it made me disheartened seeing how quiet you became in a clinic. I worried about your delivery and hoped that whoever looks after you then, will recognize the fear that your past carries forward into the now. It also made me want to do something to refocus on the present, so rather than drive you directly home, we stopped for groceries at the store. I knew that this was at least a small way to show support. Most of the time you struggled carrying grocery bags of food home, or you paid for a taxi to drive you to your front door. While the appointment was marked by waiting and silence, this time in the store felt different.

The space was noisy and bustling, with music playing and the bright lights marking aisles of food. We moved quickly and effortlessly around the store. We spent minutes in the baking section, as you wanted to make a cheesecake for your partner. The cake was for your partner's birthday and a visit from the girls, so we checked prices of baking supplies against recipes on my phone. We finally settled on a strawberry cheesecake and loaded the basket with all the ingredients necessary. We talked about the prices of the food, but the money you saved on bus fare and lunch today helped cover most of the cost for the dessert. I smiled when you told me this; we had somehow found sweetness at the end of a difficult afternoon.

Not all of our visits centered on appointments or errands. There were times when we met for conversations. On one of these visits, I picked you up at your front door, and we headed to an Italian restaurant for a snack. It was a beautiful day with a bright sky with few clouds. On this day, we bonded over shared frustrations over city drivers. As we drove across town, we were almost clipped by another car that swerved into our lane. When we finally made it to our destination, the restaurant was full with other customers. I turned to you asking, "Do you think it's too loud for a visit?" You said, "*What did you say? It's too loud!"* Your response sent us into peals of laughter and, still giggling, we turned on our heels and without pause, walked back to my car. We chose not to wait. I drove a little farther to a different coffee shop a few minutes away. I watched you tense up again when we walked into the café, and I asked if you had ever had their coffee. You shook your head, "*Their drinks are too pricy*". When you said this I realized how much I take the luxury of paying for a coffee for granted. I thought back to the first meeting with Nikki and how I felt guilty that we met in a Tim Hortons. Now I wished we could leave this space to something that made you feel comfortable. I quickly focused on making you more relaxed and asked what kind of drinks do you like in general. "*Sweet*" you told me, laughing. "They can do that here," I replied, smiling and ordering you a large white chocolate mocha. I had a drip coffee.

After finding a space tucked in the corner we cradled our hot coffee in our hands and settled into the worn out leather chairs. It was then that I watched you put sugar in your coffee. I counted as you took five packages and tipped each one into an already sweetened latte. I calculated the fine white grains slowly pouring from the paper package into the cup. I wanted to tell you that you were already sweet enough after the first two packages. I wanted to ask: "Do you think that much sugar is a good thing?" but I stopped myself from saying anything. Who was I to tell you what to do? I was not there to care for you as a nurse. Speaking up also felt like it would disrupt the special treat the drinks felt like. I wondered about my desire to interject. Helping you and the unborn child felt like a completely natural reaction. I now wonder if this was a natural reaction or one I learned while being a nurse, or had learned as a woman or as someone who likes dark, sugar free coffee. I thought back to the expectations we have for many women and their health and wellness, particularly during pregnancy. The fact I was worried about your sugar intake meant that I missed moments together with you in the coffee shop. While I was counting the teaspoons of sugar in your drink, I neglected a portion of a story about your childhood. A story where you told me that about age eight you took on the responsibilities of cleaning and cooking for your brothers. My focus on providing the right advice meant that I stopped just listening to you and learning about who you were as a person.

This realization came later though, when I reflected on our visit. In the coffee shop, I did not realize I was missing parts of your story. It made me think of so many aspects of my care as a nurse. I thought of all my work with checklists and charting where I only asked the questions I needed answers to, rather than listening to what the patient was telling me. It made me think back to our doctor’s visit together when the doctor was so focused on telling you not to miss another appointment that he barely noticed how anxious you looked. In that moment in the coffee shop though, I only nodded as you started telling me details of your summer.

During that visit, you shared with me that you were saving up for the girls’ summer visit. They would be in town during the peak of summer heat, just in time for visits to the carnival and spray parks. You told me the estimated cost and how much you had to save for all the trips you planned for them. Every part was considered: ticket price, taxi price, food price. You also shared with me that you often struggled as they most often came so unprepared. You had started to notice that your older daughters were coming for visits in clothes that were too small or marked with holes. You told me about your worries, how you spent so much of your time while they were back in your care talking with them about brushing their teeth. You bought them new toothbrushes, new socks, and new clothing. However, when they returned a few weeks later, they came with empty bags. I watched, as you shared your frustrations, that the family you asked to care for your children while you got your life together, were not caring in the way you hoped.

You felt it was like watching your own childhood again from a distance. As you struggled to regain custody of the girls, the social system seemed to remember only your mistakes and not the daily circumstances of your daughters. I thought about your past and what you had shared about your substance use. You had used substances during at least some of your pregnancy with most of your daughters, but this time with Hazel you had stopped your use completely.

When you told me about your budget and the details of your spending, I wondered if it was a way to distance yourself from that past. Each dollar budgeted was a reminder that the money was going to your daughters, not to substance or alcohol use. I thought of this, and I was reminded of your struggle in gaining custody of your daughters.

How do you show that you have changed?

How do you prove that this time history would be different?

What happens when no one believes you can make a change?

Maybe this was the reason we talked so often about money. As you told me about each expense and itemized cost, I questioned whether you thought I was evaluating your spending. Maybe you were just used to others appraising your worth as a mother. I remember thinking of comments colleagues made about mothers who live in poverty, “If you can’t afford birth control you can’t afford a kid”. How often do we consider income as a measure of how much you love and care for your child?

It reminded me of the story you told about strangers on the bus shaking their heads when you got on board with a stroller. How they refused to move, and how their eyes looked at you with judgment. You felt that they looked at you as if you were irresponsible for having children.

I spent much of our time that day in the coffee shop wondering about the circumstances around your life, rather than about you.

How much sugar is too much for pregnant women?

Would you have enough money to pay rent?

What was left for groceries at the end of the month?

How long would it be before the lawyers got back to you about court dates?

Would social services come assess to Hazel after she was born?

With question after question racing through my mind, I struggled to focus and listen to you talk. Only an hour before we had been laughing and sharing a connection, now sitting across from you, I felt uncomfortable. It was a feeling that reminded me of time spent in clinics and care settings. In this coffee shop, I became a nurse estimating amounts of glucose and a caseworker evaluating your finances and budget. I focused more on the circumstances around your life, than on you. As we sat sipping our coffees, the stories you told me were merely a way to diagnose symptoms and problems that needed to be fixed. This perspective separated me from you, and I found myself positioned as an outsider analyzing your life. Unable to disrupt this tendency, I had no ability to travel to your world.

Reflecting on that visit together in the coffee shop, I realized how easy it is to shift away from relational ways of knowing. I had taken for granted the relationship we had formed and did not consider that the choice to come alongside would require ongoing attentiveness. It was an understanding that has helped me think more about who I am as a nurse, as a researcher, as a friend, and as a person in relation.

When we finished our coffees, we quickly stood and headed back to my car. The stiffness in the coffee shop gave way and a relaxed ease, which I had come to know in our interactions, returned. Driving together became a chance for us to reconnect. In the car, space opened up for stories that were not easy to share. We both agreed that we felt better in my vehicle, that it felt like it was our own world. Perhaps the privacy connected us. You told me, "*You don't have to worry about other people talking… or looking*".

It was while driving that I imagined what you were like as a child. You told me that when you asked your mother if she ever loved you, she answered "*no*". She told you that *you were a mistake*; she always found you annoying as a child and now as an adult too. I imagined you as a small girl with dark hair and the same bright eyes you have now. When you told me, *I was on honor rolls at every school I went to. I was always at the top of the class or I tried to be at the top of the class. Just to prove to them that I could do this, that I'm a good kid. Can you approve of me somehow?* I pictured you with your head down, working in school. It was an image that reminded me of the moment I noticed how small you were in the doctor's office for your prenatal appointment. How in that clinic, you kept your head down; how you said nothing.

I pictured you caring for your brothers and thought about how lonely it must have been. How much harder that became when your father passed away at a young age; when your stepfather threw out the present, a stuffed teddy bear, you received after your dad's funeral. How you told me, you felt you truly had no adult watching out for you. These were the pictures in my mind as I dropped you off at your front porch.

As our visits together continued, my car was a continual place of safety. It was the only place where we talked about trauma or abuse. It was also the place when you seemed to radiate positivity and talking without pauses or taking even the shortest of breaths. We ran errands and sat in the car in front of your house at the end of our visits, just talking and enjoying each other's company. It served as a place to reconnect, and one later visit, when you had a sitter for Hazel and Brook, we drove together for a visit just to catch up. During these visits, we would not go in a particular direction; instead, I would drive with the flow of traffic. The steady pace of the cars beside us helped keep our conversation going. While driving down residential roads that day, I learned you were about to move into a bigger home in anticipation of having your older daughters visit more often. As you shared this exciting news, you also talked about the steps required for this transition, all the packing and cleaning. You already looked after grocery shopping, bills, cooking, and housework. More than that though, you cared for your partner, your brother, friends, and, most of all, your girls. It reminded me of my own mother, looking after my sisters and me. In our family, she was the central force that kept everyone close, and I have many memories of aunts, uncles, friends, and family coming to our house for visits and dinners.

As we kept talking, it was clear there were challenges that you carried that are so very different from most household duties. As we headed down quiet city streets, you told me of recent news, that your brother was ill and struggling with mental health problems. He had issues with paranoia in the past, and now, more recently; these issues had begun to surface again.

"Your brother's been admitted to the psychiatric hospital?"

You paused, exhaling slowly.

"*Well only after it got really bad.*"

I shook my head as you told me this. I remember asking about the logistics and how you are managing. You told me about waiting for the bus to take you to the hospital, the work that it took to get items for your brother, including a phone, money for snacks, and items to make the hospital more like a home. I remember you worried that your brother was being taken advantage of with friends borrowing money and that you had no way to help. I listened as you told me that you had been your brother's support since childhood, and even now, felt that no one recognized when you knew how to calm him down, or help him when he was scared. You frowned when you told me about calling the hospital and feeling ignored. "*As one of the people that knows him best, it is hard to talk to nurses that don't consider you as someone with knowledge, or aware of anything that had been going on*."

On top of this, there were the usual concerns of groceries and day-to-day costs. It is in these moments that I wondered about your supports.

Who was there to help with the girls? Who helped with the cleaning and the cooking? Who helped with the running of the home?

Did your daughters notice that their uncle was not at home?

I did not have to ask many of these questions. I let you talk about all the work you had been doing and watched as you turned your head to look out the window. In that moment, our small world, my warm car, gave us both the space to talk. Our meandering drive was so different from the daily struggle to cope with your brother and the care system. Disrupting this quiet peace with questions felt wrong. I let you speak while I kept driving. I could do little to fix your brother's problems, and I felt frustrated that these struggles were beyond my expertise. I felt saddened that, as you told me of these things, I had nothing to offer you.

It was one of our more difficult visits. Much of our time together that day was marked by silence. I believe this silence developed out of our inability to change the circumstances surrounding your brother's care. It served as a contrast to all the work you had done to change your situation, to fight to regain custody of your girls, to become a different mother. There was nothing you could do for your brother except be present. To care and to love him, and visit the hospital with his favorite candy. When you told me this, I said I was glad he had so much support, but you stayed silent. I understood, from my own work as a nurse, that sometimes simply being present was harder than trying to fix a problem. The times when all you can do is sit with someone and be a witness to sadness or grief or frustration can feel like you are giving up. Sometimes you have a feeling as you have nothing to offer. It was a thought that made my chest tighten, when I watched you walk up the steps to your front door. Seeing you so tired and worried that visit made me glad that we had found time that day to talk. I was grateful that we shared those silences together, and I wondered if you were too.

I think back to the many times I sat in my car outside your house, looking over the chipped blue paint and watching for your front door to open. I never got out of my car. Instead, I turned up the heat or put your seat warmer on, but I did not come to your door. You came out of your house, smiled and waved before climbing into my car. I thought about how we sat in my vehicle at the end of our visits and talked. I still never came inside. Only after we had a routine and a rhythm did this changed. Sitting in my car at the end of our visit, you suggested that for the next visit I should come to your place. I smiled when you said this. I had been coming to your home for months and this offer felt special. I had never asked to come inside.

After months of our visits, I finally entered your home. I remember standing on the porch waiting for you to answer the door and feeling as if I was about to enter a different world. I was reminded about how anxious I was that first visit. I was nervous walking in your entranceway, slipping off my shoes, and hanging my coat. You showed me your kitchen and your dining room. Sharing your excitement that one day, you spoke of being able to have meals as a whole family. When we turned into the living room, I saw Brook playing in her playpen and saw Hazel sleeping, swaddled in a blanket.

I brought food that day, but when I indicated that I would bring things, you told me not to worry about the drinks. You would make the coffee. As you poured me a cup, I thought about how many times in nursing school we were told to not accept food from patients, even during home visits. As I sipped my drink, I looked at your smiling face and nodded when you said that you were happy that you could get me a coffee this time. I thought about our past visits, how I was always covering the costs and that food always had the ability to put us both at ease. Today, as I sipped coffee from one of your favorite mugs, I sensed that it was important for you to offer me coffee.

Later after we had eaten our sandwiches, and I held Hazel in my arms, you tipped your head inquisitively. You told me that you could not believe that Brook was not upset. You told me that she always cries nonstop when a caseworker comes into the home. I thought about this statement and wondered how you felt when a caseworker came into your home. Did you become small, like you did in doctor's visits? Were you seem anxious or sad as you did when you told me of your childhood; when you asked your parents "*Can you approve of me somehow*?"

As I looked down at your beautiful, beaming daughter. I thought of the visits we had shared since I first met you in outreach and about how many times I listened without asking questions or without trying to give advice. How I had come to realize that asking questions did not always bring us closer and instead, staying attentive sometimes meant only being present. I thought about the trust we built over these visits. I reflected on how different my role was from the roles of caseworkers, who came into your home to assess your ability to parent. I can hardly imagine how frightening it must be to know that they have checklists and appraisals.

As you returned with my second cup of coffee, I turned to you and gave an answer to your statement on why Brook was not upset. I said, “Maybe the difference was that I was invited.” For a few minutes after I said this, we sat in silence, a comfortable silence.

How to Build a House in a Storm

At the beginning of our research work, Marilynn was looking after her youngest daughter and pregnant with her fifth girl. Her older three daughters were in the care of family friends. They were now the family Marilynn was fighting to have her children legally returned. During our time together, I was witness to Marilynn's ongoing fight to regain custody of her three oldest girls. While Marilynn faced numerous challenges around housing and financial support, she did not waver in her commitment to her daughters. It was a different experience than she had growing up; describing how her mother told her numerous times she was not wanted or loved. This was not the experience Marilynn wanted for her daughters.

I was alongside as she prepared and celebrated during the visits where they could all spend time together as a family. Shopping for groceries and deciding the menus served at birthday celebrations was significant. I came for medical appointments. In Marilynn's legal journey, I offered no assistance. She had a lawyer who was helpful in moving the legal work forward, but the fight for custody was arduous and emotional. We talked about the process, how so much of the time was spent waiting for updates, for progress.

In the time I was alongside Marilynn as a researcher, I watched her look after her girls, fight for custody, and try to build a home that fit her ever-growing family. Marilynn told me about her childhood and how home was a place marked by a lack of love. She mentioned, in a soft tone, that her mother told her as an adult, "*I hate you. I wish I never had you. You're a regret. You should give up on all your kids and everything like that. Give up on Jamie. Give up on this baby. Give up on the older kids and everything like that. Go back being homeless and do your drugs*." From an early age, she remembered looking after her younger twin brothers. At the age of five, it was her responsibility to supervise her brothers. By age eight, she was serving as a parent to the twins and looking after the housework. If she or her brothers misbehaved, she was often sent to her room, forced to sit alone for hours as a punishment. It was at this time she remembers that she stopped playing with toys. It was a moment in the third grade when she remembers asking herself:

"What is the point of having a doll?

What is the point of having a toy if you never learned how to play?"

There was abuse in the home at the hands of older relatives and the school offered little respite. Her experiences of abuse meant later in life, as a mother to her daughters, she had to relearn how to touch and interact with her own children – how to show care in a way she never learned in her family. She spoke of learning how to discipline her children. "*I put them out on timeout with their age limits. Now, listen to mommy when she says no. We are going to put you in time out for two minutes. I love you and everything, but just sit here, and mommy is going to sit here watching you. I never had that positivity and negativity at the same time. I want to break that cycle."*

There was little solace outside the home. Marilynn learned only later, after years of struggling in school, about her diagnoses of FASD, ADHD, and ADD among others. Learning these names helped her recognize her challenges with education were not her fault. Back as a youth though, she just left education entirely. Seeking love elsewhere, she had her first partner at a young age and became a mother at 17. She spoke kindly of all the fathers of her girls. Each man had been a partner Marilynn loved, and while they all cared, each struggled to provide support to her and the children.

Her first partner was overjoyed with the pregnancy of Robin, and he encouraged her to start a family. Yet, this change was too difficult for him when it happened, and he left shortly after the birth of his daughter. The other fathers are involved in the care of their daughters, but their own struggles with substance use and family trauma impacted their relationships with Marilynn. Marilynn told me that during the first year with her newest partner she flinched and felt scared every time he touched her. When he asked her why she was still scared even though he had never hit her, she stated: *"It's just reactions, really bad reactions."* This was a realization that Marilynn had come to through counselling and support. It was this realization that started to reshape her future. After this realization, she started talking about the things that bothered her and began to establish boundaries and rules with her home and with her family.

Marilynn made a decision to not welcome family into her home. It was a difficult decision for her. Sharing her house with cousins, brothers, and friends meant her home became a place of disruption, with people coming and going. It took time, but Marilynn has found ways to build a family on her terms. She put rules in place in relation to her own mother. She now only calls her mother by her first name. Taking back the name 'mother' was a milestone for Marilynn. Marilynn has decided that her mother did not earn or deserve the title 'mother'.

Marilynn has started to say at least one kind thing to herself every morning as she looks in the mirror. She has struggled to make this small change; nevertheless, stating these affirmations makes a difference and it is starting to shift how she sees herself. It is an attempt to distance herself from her childhood and to build a different future for her children. She tried to establish this same distance with her past, in particular, her substance use. Since she was young, Marilynn found substances helped, or at the very least, numbed her pain. Now as she fights for custody of her older daughters, she does not allow substances or alcohol outside of marijuana in her house. She fought to stop using all substances, except marijuana. Marilynn is comfortable disclosing substance use. When she was using substances while pregnant with Brook, she told her nurses:

"I was using while pregnant
not knowing that I was pregnant,
and then realizing that
and then quitting, and then just smoking a lot of weed.
That's all you should find in my system is weed.
Sorry it's not like the weed that you get from online from the doctors,
it might be laced,
but I've just been smoking weed."

Most striking in all of our visits and the stories Marilynn told me of her childhood was her intense lack of love. In her current life, I witnessed the opposite. She told me how she wanted her daughters to always feel loved, even when she struggled with substance use and poverty. Asking for support in the face of these struggles, Marilynn mentioned how it got easier with support and help from agencies and care workers, but that life often had its own way of messing things up.

"It was hard, like doing that all over again once you had everything
there, you were starting to get that picture perfect
and then when the walls were coming up,
just before the roof would come down too,
everything was like hi,
it's called life,
we've come to demolish your awesome things

that you're accomplishing right now,
see you next time,
maybe you can get it right next time.

Next time comes around again,
same thing,
and then it's like shit,
back to square one
trying to do this all by myself"

When I asked Marilynn what she hopes the girls will get from her sharing her story, she tells me that they understand how hard she tries. It surprised me that she wanted to share something that from the outside seems so obvious. Marilynn never stopped trying. She was always working towards a different future, even when she did not know what this looked like. In the face of a life that knocks down walls and places barriers, she was always positive. I thought of all the many times when I had nothing to offer as she explained her struggles. None of her challenges, especially around poverty and moving forward from her history of trauma, had easy solutions. Instead, her hopefulness reminded me of her small frame underneath her oversized hoodies. How she often carried the burdens of the past and the present without support or a community to help her move forward. It was a quality, at the beginning of this research, that made me want to wrap my arms around her and block some of the world's difficulties. Now, as I see her strength and resolve at facing these problems, I wish she did not always have to work so hard and that one-day things would get easier.

I just want them know that I was trying

That I am still fighting to get them those things that they want.

I know that I will change

but I'll never change on loving them.

That no matter what's going on in life

As long as you have that love

It could go through anything that you wanna get through

We can accomplish anything.

That's what I tell my kids

Whenever they come over for visits.

They tell me that they try doing something, but they can't

I got mad

I was like, why you say you can't - When you can.

Robin

February 18th, 2011.

5:55 in the morning.

7 lbs and 12 oz

20 inches long.

When I had her, I couldn't cry.
I thought I was crying but here I wasn't actually crying.
But I was like, I am crying though on the inside.

It was amazing.
And breastfeeding was hard with her though.
But we got the hang of it. I did it for a few months.

Watching her grow and becoming this little wonderful woman

It's amazing.
Especially in how loveable she is.
I would read to her and talk to her kind of like an adult.

She understands way more than she should
but, I'm really proud of her a lot.

She loves her sisters a lot,

she loves me a lot.

She understands where I'm coming from, which is amazing for someone of that age.

Robin's first birthday party was hilarious.

I got cake everywhere.

I cleaned the whole kitchen, the whole dining room, the whole table and everything.

And because I didn't have a high chair, we decided to sit on the floor.

We took the legs off tables and put the table on the floor too.

We put the cake on the table and I was like, happy birthday my girl, go to town.

She smashed the cake and then she picked up two handfuls and she was walking at this time, she was walking at 9 months.

She came up to me and just caked me in the face, and it got in my hair.

I was covered in cake.

Her dress was no longer a dress…. It was a cake.

She had cake in her hair

She was just having fun.

It was just me, Robin's dad, and a cousin and a friend that came.

Not even my own mother.
And she lived right next door to me.

But she had fun.

And then on her 2nd birthday,
She was excited to share her birthday cake with her sister
She was amazing with that.

She was such an amazing sister with each of her sisters.

Jamie

November 26, 2012

12:12 in the afternoon.

7 lbs and 11oz

21.5 inches long.

She was a little personality.
A little hectic person.
It was crazy.
She came out real fast and easy.

That was another one that changed me.
I wanted to cry too but I wasn't crying.
And it's so weird because like, with all my babies, even though I wanted to cry, I couldn't cry.

She had like this personality and attitude already.

And when she was 3 months, oh my God, that's where her attitude started.
3 months and going up 'til now, and it's been like a little road trip with her.

She wasn't so caring as Robin.
She just wanted to beat me up.
And she would, she would bite me.

That's something I never experienced with Robin, was the biting.

Jamie would bite me.
And she'd beat up her sister.
I watched her beat her sister up, I had to pull them apart.
And then once I started cooking again, I go to look over, she's beating up on her sister again.
I was like oh my God, it's supposed to be the other way around.
Oldest is supposed to beat up on the second. No. This is not happening.

I was like OK, maybe I could let her out while I finish cooking.
And then I let her out. No. She went right after her sister

I actually literally had to stop cooking my noodles on the stove and start microwaving it because it was faster microwaving it than the stove.

She was such a mommy's girl.
It was so cute.
I couldn't do nothing.
I couldn't go out for a smoke.
I couldn't do nothing at all.
And every time, she would find me if I was in the washroom because I'll put her down and then she'll start crying Mom, Mom, Mom, and then I hear like smack, smack, smack.

Callie

January 14, 2014

9:20 at night

9 lbs and 11 oz.

21.5 inches long

It was just me at the hospital.
Nobody else there beside the nurses.
She comes out 9:20 at night.

They were scared that she was diabetic.
Because she started shaking when she got out.
And they were asking me what was wrong and anything,
I was like well, you guys were telling me not to have any caffeine during, so I had Pepsi.
That was pretty high with caffeine.

And they said that I wasn't diabetic,
they checked her blood sugars and it turned out that she could be borderline diabetic, if I didn't change the way I was eating when I was breastfeeding her.
So I went healthy for about 3 months when I was breastfeeding her.
Got her checked out again.
They said that she would be in the clear unless if she has a change in eating pattern when she gets older. And other than that, she was an OK baby.

She was quiet.

But she was the baldest kid ever.

She looked like a boy.
Everyone thought she was a boy.
Oh my God.
She would be wearing a pink dress and a little pink bow in her hair
And they're like how old is your little baby boy.
It's a girl.

How old is this other little boy.
That's a girl.

Callie, she was so cheeky. Like, even when I was breastfeeding.
She is cheeky. Even when I would breastfeed her and she would like, pretend to be sleeping.
She'll spit out all that milk. Like, she would look like she threw up.
And she'll have like this big smile on her face. .. . . . Everyone's sleeping but you.

And then, as she was growing up, she never changed.
She was still that little cheekiness monster

Dear Robin, Jamie and Callie,

When your mother told me each of your birthdates and your weights, I realized how much I have come to think of you as a unit. Together, you three sisters are in my mind, the "big girls". It is a term that I think of fondly; it was the term used to describe my older sister, my cousin, and myself. However, as loving as that term is to me, it is a distinction that I hope shifts. I hope that one day when we meet in person; I will hear your voices and watch you play with your younger siblings. That I can see with my eyes the differences between the three of you.

Until now though, I have only heard about moments of your life. I have seen your photos, blurry pictures of you laughing and playing and I have seen how hard your mother fights for custody. My last visit, with your mother I learned that she was moving from the blue house on the corner. She had found a place that was big enough for all of you to be there together, that there was enough space for beds and room to play. It was a future I am excited for you all to share.

There are moments that I worry about your childhoods. I wonder about the toll that all this moving has on you. I think about how restless you all must get before the three-hour drive to see your mother and sisters; or how hard it must be driving away from the city. I worry when your mother tells me that Robin has started to remind her of when she looked after her brothers. That Robin works so hard, that your mother has to say stop, "*Go have play time, mommy's got this, go be a kid, go play.*" I worry when your mother tells me about you not having clothes or shoes that fit.

In all of these worries though, when your mom tells me in rapid fire your weights, your heights, and your personalities, I never question how much you are loved. I hope that this story and your mother's words show to you that there never was, and never is, a question of how much she cares. I hope that those are feelings you carry with you always, and I hope to one day meet you in person.

Always, Georgia

Brook

March 28th, 2016.
11:47 in the morning
7 lbs 11 oz
18 inches long

She was 7 lbs 11 oz
Like her older sister.

Crying at the same time.
And when Seth said "hi, baby"
She just went quiet and went over there and looked at him in the direction that she heard his voice.
And she went quiet.
She was like, I know that voice.
She just zoned in on her dad.

She's such a daddy's girl.
When Seth was working away.
Or when he went back home to do anything.
He had to do this funeral at one time.
And then when we broke up that time and then got back together.

When he was away I gave Brook her favorite shirt of her dad's and she just went to bed right after that.
For her to actually sleep.
She just had to have that smell of her daddy.

She loves her sister when she first met her sister.
She gave her sister a hug.
She bopped her on the nose and gave her a kiss.

And then when she first met her older sisters, she was jealous and kinda upset.
She was realizing the transition of having her sisters around, she can't get enough of her sisters.
She actually cries now when her sisters leave.

Every time, she's starting to talk more, she is quite the character.

Dear Brook,

I never saw you interact with your father, but I heard stories of your connection. I heard how when he was away, you cried and cried for hours, with your mother not knowing what to do. It was only after she found a shirt of his and swaddled you in it that you fell asleep. While I never saw you with your father, I did see you and your mom.

In the stories I heard from your mother, you had a distinct personality. I heard about how if you were ever upset, your mother could turn on the movie *Nightmare Before Christmas* and you would watch, wide-eyed and smile. I laughed when she told me this, the movie is not exactly a typical show for a toddler, but it was one of my own personal favorites. “She clearly has great taste,” I said to your mother, laughing. When I met you in person, you were independent, playing intently with your toys in the playpen. I only saw you looking over occasionally to make sure your mother was still there. Your small little glances to your mother were a sign of your trust. It signaled just how close you both are. I hope that this is a connection that will continue to grow.

Always, Georgia

Hazel

March 20th, 2017

3:47 in the morning.

8 lbs and 6 oz

I wanted to cry again, but I couldn't cry.

She's just a cutie.

She just came out with a lot of hair.

She was amazing.

She even has the little personality already, for being 10 months.
Little monster.
She's biting people.
So I got like another baby Jamie.
And she's all about the mom too.

Dear Hazel,

I have come to know so much about your older sisters but the connection that I have with you feels different. The moments shared with your mother, before you were born, connected us in different ways. I think back now to the doctor's visit when I heard your steady heartbeat; and I watched a relieved smile spread across your mother's face. It was a gift to be alongside you and your mother and to witness your mother's radiant joy when we talked about your coming birth.

I heard of the future your mother dreamed for you and your sisters, and I watched her work tirelessly to make her home one that was safe and loving. I was frustrated many times, as I watched her struggle to make ends meet, struggle with paying bills, and struggle to regain custody of your siblings. In all of this, I witnessed many times, how she put her hand on her belly and beamed. I witnessed how hopeful and excited she was that things would be better for you.

It is a hope that I carry now. I think about the futures of the babies that I see in my own nursing practice. I wonder if they will change the world one day, as you have. You changed your mother's world, as she waited for your delivery. You helped her keep fighting, and you gave her joy. Meeting you in person and seeing your beautiful face with your dark hair and dark eyes, made me recognize why your mother had such a strong sense of conviction.

I believe, as she does, that things will be different one day; that life will be better.

Always, Georgia

Marilynn and her Girls

Marilynn found joy in the pregnancy with Hazel that was not possible with her older daughters. She was finally in a place, both physically and mentally, where she could care for herself, as well as others. Her older girls were not in her custody, and during our year together, Marilynn spent much of her time contacting lawyers and social services. She believed, as she moved forward, planning holidays and celebrations, that one day they would all be together. It was easy to come alongside Marilynn. She welcomed the support and told me many times that she was finally ready to ask for help when she needed it. During our visits, this help was most often just friendship.

It was amazing to watch them grow together.

It was amazing to watch Marilynn become the mother she always wished she could be.

Chapter 3: Waiting as performative and relational

Waiting as performative and relational:

A narrative inquiry study into the experiences of women who use substances

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Abstract

Waiting in care is not a neutral activity; it is filled with expectations marked by cultural and social norms. Drawing on a narrative inquiry study focused on the experiences of three women who disclosed illegal substance use during their pregnancy or early postnatal period, we inquired into two participants' experiences of waiting. Over a three-year time span, I often accompanied the women to appointments, or places they were seeking services, where waiting was a common expectation and practice. During the time I spent alongside the women, I became increasingly attentive to the complexities of waiting. In this paper, I look at the performativity of waiting and the political and social implications of waiting in order to explore the subtleties and overlooked consequences of waiting.

Waiting [is] the great vocation of the dispossessed. Gordon (1)

I had not slept well the night before my shift and was anxious about making a good impression. Thankfully my fatigue disappeared when I arrived on the hospital unit for the start of my last clinical placement as an undergraduate student in a four-year nursing program. The nerves that turned my stomach into knots were exhilarating. After four years of being a student, I could imagine myself being a nurse on this labour and delivery unit. Everyone, including me, wore matching mint green scrubs. Wearing the green uniform and running shoes made me feel like an athlete on a team. It seemed only natural that together we would attend to the experience of birth in matching outfits. Together, this team – our team - was ready.

My partner nurse showed me the unit, teaching me where supplies were and how the rooms were set up. We walked through halls and inspected empty rooms, waiting for a patient to arrive. It took only a short time before we admitted a woman in active labour to one of the obstetrical rooms. I looked around carefully, examining the space. The delivery room was large. A relatively open space, there was room for the bed, a reclining chair, an infant resuscitation machine as well as storage for supplies and materials. The lights were dimmed and, in certain moments, I almost forgot I was in a building marked by humming florescent fixtures and pastel paints. Yet, this is not what I remember most. In this large room filled with equipment and hospital staff, what I remember was the sense of fear and frustration from the care providers, and the lack of connection they had with the soon-to-be parents.

Our patient, a young mother was admitted in active labour. Observing from my place on the side, I noticed a palpable level of stress in the room. At first, I was unsure what contributed to this. I recognized that care providers asked questions with a frustrated tone to their voice – something was not as it should be, at least not how I had imagined it. Their answers to the patient's queries were terse. They seemed annoyed. With time, I pieced the story together and learned their irritation was mostly due to suspected illegal substance use. There was a suspicion that the patient had used illegal substances while admitted in the hospital. This was of particular concern as the need for surgery grew. Surveillance and monitoring of the fetal heartbeat made it clear that both infant and mother needed an intervention. As a care team in matching outfits, we stood watching and waiting, anticipating the slowing of the fetal heartbeat. With each dip in the heartbeat, the increasing stress of the care team, especially the anesthesiologist, was evident.

With the steady sounds of the monitors serving as a metronome to pace, the questions became more and more urgent. The anesthesiologist raised his voice, asking repeatedly what illegal substances the patient had just consumed. I noticed that with each question, the patient retreated into herself, avoided eye contact, and refused to answer the questions. "Why doesn't she just tell us?" I wondered silently. The team, our team, was not accustomed to waiting for answers.

Waiting in many circumstances is the act of anticipating the unknown; waiting for something to happen. The verb ‘wait’ is defined as “to allow time to go by, especially while staying in one place without doing very much, until someone comes, until something that you are expecting happens, or until you can do something” (2). Yet, while this definition states that waiting is ‘without doing very much’, waiting is not inconsequential. In the health-care context, many view waiting as an inevitable aspect of care (3); and as my experience shows, waiting holds power and creates anxiety.

When I return to memories of waiting for the young mother in the delivery room to answer the anesthesiologist’s repeated questions, I am challenged by the recognition of the negative implications of this experience[3]. The care team’s experience, including mine as a student nurse, was part of the interaction. I remember thinking how difficult this patient had been, how we, the care team, had constructed her as difficult because of her silence. Her silence and refusal to cooperate, particularly by answering questions, had been an affront to the work and roles of the care providers who were part of the team. The experience, as I first experienced it, centered largely on the care team, standing at the bedside, waiting for this mother to tell the truth. In that moment of waiting for an answer, I thought, “*Why doesn’t she just tell us what she used?*”. I did not consider that the only answer we would have valued was one particular truth; one embedded in our assumptions about her and her partners substance use. We waited for a confirmation of our thoughts and judgments, a confirmation that she had used illegal substances. In this sense, waiting for her answer was silencing, since it was not a question filled with possibilities. I wonder if the choice to remain silent was the only option she could control. That she made us wait was a way for her to exercise at least some power in a setting and situation that

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[3] “I” throughout this paper will refer to Georgia Dewart, as this work draws directly from her doctoral research.

offered her little autonomy or permission to express herself. Given time and an environment not filled with a team of frustrated care providers in matching outfits, would her, and our, experience of waiting have been different?

Looking back now, I see that on my first day as a nurse in obstetrical care, I failed to recognize how we shifted the patient's experience, how we created a sense of waiting that foreclosed the possibility to build relationships. I vividly remember that I did not care about her discomfort and fear as I waited for the answer that confirmed her illegal substance use, as I waited for a compliant and good patient, and as I waited for the time that she would transfer out of our care. Years later, this experience lives in my body and frequently awakens me and confronts me with the interplay of power that is present in this encounter, present in the moments of waiting, and present in the absence of relational care.

These questions about the experiences of waiting have carried into my graduate work. In my doctoral research, a narrative inquiry into the experiences of three women who disclosed illegal substance use during their pregnancy or early postnatal period, I heard numerous stories about the uncertainty of waiting for care. My observations of doctors' visits and clinic appointments provided me with insights into and wonders about experiences of waiting. These interactions called forth more questions about control, gender, silence, and discrimination as well as who patients and care providers are in moments of waiting.

In this paper, I draw on Caine and Estefan's (4) work on waiting alongside research participants, while I explore waiting in the context of care. Considering waiting as a relational process, I draw attention to particular forces that shape the experience of waiting. I inquire into the experiences of two participants, Marilynn and Renate, alongside Butler's (5,6) concept of performativity. It is through my inquiry that I begin to see that waiting is not a neutral act and that care providers need to remain attentive to the relational nature of waiting. Waiting is a socially located performative act – an act that calls forth responsibilities. When waiting is understood as a relational process, care providers can address the interplay of power, gender, and ethics embedded in the experience of waiting.

Background

While waiting is present in many aspects of everyday life, there is a recent move to study the experience of waiting within the context of care. Much research on waiting focuses on macro-level factors, including time spent on wait lists, wait times for surgery, or methods to improve the waiting process. In the majority of studies, waiting is framed with a particular focus on processes and environment (3,7,8). The relational nature of waiting appears to be underexplored. Considering that many populations already face stigma and discrimination in access to health care (9-11), it is necessary to explore the experiences of waiting for individuals who are marginalized.

Women who use substances during pregnancy

One population that faces serious and persistent marginalization are women who disclose illegal substance use during their pregnancy. Recent Canadian estimates on the percentage of women who use illegal substances during pregnancy are placed at around 1% (12). Women, who use illegal substances during pregnancy, face significant stigma and discrimination and are considered by many to be a source of harm to their unborn child. While substance use carries risks for the fetus and mother, attention on substance use often overshadows social factors such as poverty, discrimination, and racism, which complicate access to care and maternal health (9, 13,14). Negative attitudes from care providers remain a significant concern for individuals who disclose substance use (15). Stigmatizing and negative attitudes have real life implications, including increased fear and apprehension in accessing services, and higher rates of leaving care (9,16,17)

Narrative Inquiry

Narrative inquiry is both a methodology and a way of understanding experience. It is a methodology that draws on both relational ethics and philosophical traditions of Dewey's theory of experience. Experience, within a Deweyan view, is a source of knowledge (18,19). In narrative inquiry, this understanding of Dewey's theory, led to the recognition of narrative with a three dimensional space comprised of: sociality, temporality, and place (18,20). Understanding experience in this framework begins from a place of relational ethics. Relational ethics guides narrative inquiry, directing the development of collaborative research practices where inquirers and participants are seen as co-composers of knowledge (18,20). In this paper, drawing on Butler's (6,21) work which is not often taken up in relation with narrative inquiry, I reflect on how different forces shape waiting in the context of care for two participants, Renate and Marilynn.

Performativity and Waiting

Butler's concept of performativity is instrumental in the understanding of gender and sexuality. Grounded in constructivist and post-structural philosophy, Butler's work explores how gendered identity, rather than being an intrinsic quality, develops through socially located performance: the repetition of gendered acts. Butler's (6) theoretical work expands on earlier literary theory, specifically Austin's (22) work around performative language. Austin's (22) literary theory explored how language not only describes context and experience but also shapes and determine outcomes. In this way, for Austin (22) language is performative in that it has the tangible ability to shape the world by naming, declaring, or determining future results. Butler goes further, arguing that performativity is not only a function of language, but that an individual's gender and associated traits are achieved and conditioned through repeated performances. Butler draws a distinction between performativity and performance, which is a conscious theatrical act. Butler joins individual agency and socially dictated norms, defining performativity as acts that are practiced routinely to the point of appearing natural (23). For Butler (21) "[g]ender reality is performative which means, quite simply, that it is real only to the extent that it is performed." (p527). Within her work on performativity, she also explores how societal norms and expectations dictate gender. "The more mundane reproduction of gendered identity takes place through the various ways in which bodies are acted in relationship to the deeply entrenched or sedimented expectations of gendered existence" (21 p524). Performativity requires engagement from those performing and from others within the performance space.

While Butler's theory on performativity challenges heterosexual norms, specifically male or female gender tropes, there are individuals who expand on her work beyond topics of gender and sexuality. "Butler's concept of performativity opens up interesting avenues for the exploration of identities and identification, not only in the areas of race and gender" (24 p421). Butler's theory draws attention to the larger social influences on individual behavior, and her work can be helpful in understanding the normative expectations that frame the waiting experience. Specifically, normative structures influence how both the ideal patient and the ideal mother is performed in the act of waiting for health care. These normative expectations are both socially influenced and mediated by power. Waiting in this context is not a solitary endeavor; rather there is an engagement in both the individual performative act and those that interact with this experience. In the context of care, this means that performative acts serve to either compliment or challenge actions of care providers. The recognition of the interpersonal nature of those engaged in performative acts offers a lens through which to view relational contexts. In this way, waiting can be understood in relational ways.

Performativity and narrative inquiry

There are tensions in applying Butler's theory of performativity (6) to a narrative inquiry study. Butler's work considers experience and identity through post-structural and constructivist lenses, whereas narrative inquirers "understand experience as a narratively composed phenomenon" (18 p16), nested in larger social and institutional narratives and a relational ontology. Yet, re-telling the stories of patients and care providers while reflecting on Butler's concept of performativity can be an important step to understanding the experience of waiting. There are, however, important considerations for narrative inquirers in such an endeavor.

Butler's work, is grounded in post-structural theory, and as such, is focused on analyzing, deconstructing and understanding discourses specifically around language. Post-structuralism, in many ways, is a methodology of dissection, whittling down analysis into smaller frames. Narrative inquirers understand participants' experiences as evolving and continuously changing; temporal stories in which the past, present, and future all hold sway, where place and person play central roles (18). Clandinin and Rosiek (26) discussed the similarities and differences between post-structuralism and narrative inquiry, they described, how post-structuralists view participant's experiences not as a source of knowledge but as a beginning place to analyze and understand social forces shaping experience. They said, "Narrative inquiry, by way of contrast, begins with a pragmatic ontology that treats lived experience as both the beginning and ending points of inquiry" (26 p24). Butler's concept of performativity is in conflict with narrative inquiry's ontological grounding. Engaging with Butler's work in narrative inquiry risks analyzing participants' stories of experience separate from place and temporality. It also challenges ontological commitments that ground narrative inquiries in relational responsibilities.

Addressing the concerns of using Butler's theory of performativity as an analytical tool and disregarding relational responsibilities, it is useful to consider performativity in relation to participant narratives in a more generative sense. Performativity may provide a means to explore possibilities in narratives and helps us to consider what goes unsaid or unnoticed in the experiences of coming alongside participants. Alertness to the conditioned, institutional forces, which shape waiting, is a necessary step in returning not only to a relational view of waiting, but also has potential to disrupt processes that are discriminatory and unjust. Looking at the experiences of Marilynn and Renate, when naming waiting as performative, helps consider the implications of waiting and the ways in which waiting is socially located.

Stories of Experiences of Waiting

Renate

> *Renate sat for days at Kayden's bedside. Born prematurely, Kayden's incubator sat in the corner of the Neonatal Intensive Care Unit (NICU) as he was monitored and assessed. The NICU was an open unit with little privacy, where Renate spent most of her time in the open during Kayden's stay. She pumped breast milk for him daily, and during her time on the unit I witnessed a cooperative relationship between Renate and the nurses. They provided constant updates on Kayden's vital signs and wrote daily on a whiteboard sign with new details of his growth. Renate was always present, living in the lodging accessible for parents with children in the hospital. During one of my visits, Renate, overjoyed with Kayden's improvement, encouraged me to reach out and physically touch her son. I opened the small circular door to the incubator and ever so gently stroked Kayden's back with my index finger.*
>
> *"WHAT ARE YOU DOING?"*
>
> *I was startled, quickly taking my hand out of the incubator and away from Kayden. Kayden's nurse, a small woman, with dark hair grazing her shoulders and her hands on her hips scolded me for breaking the rules. She turned to Renate, ignoring me, to state how fragile Kayden was and that only parents and family were allowed to touch the infants. She, referring to me, needed to wait to do so. It was a short interaction; my crimson cheeks burned with embarrassment longer than my hand had been in contact*

> *with Kayden's soft skin. Renate challenged her statement quietly, with a casual comment "She's practically family."*

Renate was a mother to only boys; her older sons were currently in the care of family, because of her struggles with substance use. Her pregnancy with Kayden was different; Renate was focused on building a home with him, one in which she did not want to use substances. During the months Kayden spent in the NICU, as he grew under the safety of a plastic incubator, Renate waited at his bedside. She lived in the supportive housing connected to the hospital to be available around the clock to Kayden. This proximity made Renate's waiting visible. She was acknowledged by the nurses when she arrived in the morning, when she was at the bedside, and when she left at the end of the day. Her day was filled with hours of observable waiting. Renate's visible waiting was a means by which she was seen as a loving and caring mother. My inability to wait to touch Kayden was interpreted differently; my percieved inability to wait had challenged the rules of the NICU.

When Renate encouraged me to touch her son, she showed the confidence she gained from waiting at his bedside. It was an opportunity to build a connection between her son and me, and it was her decision. Later, when I asked Renate about that moment, if she was aware of the rules that only immediate family could touch the infants, she responded, "*You're practically family*." When, the nurse corrected my actions, instructing Renate and me that only family could touch Kayden, there was the assumption of who belongs, or at least is recognized as, immediate family. At this point in Kayden's care however, Renate was parenting alone.

In this experience, there was an expectation of active waiting, to be present at the bedside and involved in Kayden's care; however, there were limits to the rewards that were permitted for waiting in this way. Returning to Butler's theory, the performative nature of waiting in this context involved multiple normative values. In Renate's experience, two normative values were that women who use illegal substances are a risk to their own children, and that "family" is still defined by heterocentric expectations of nuclear families. Renate went against the recommended waiting time and allowed me to touch her son, which challenged these norms.

When Renate encouraged me to touch Kayden, she was challenging a normative ideal. Her challenge to the normative "ideal" mother was to allow me to touch her son. If Renate performed as the "ideal" mother, she would have waited quietly and avoided disrupting unit norms and rules. The nurse's involvement and her role in limiting my engagement in Kayden's care revealed how disruptive performances beget negative consequences. The performative nature of waiting in this context required and reinforced set normative values. Renate did not participate in the performance of waiting in a way that was expected. As such, her deviation from the performance of "good mother" started to show normative values that were filling the waiting space.

Marilynn

> *Marilynn was a young mother of only girls. When I came alongside her in our research, she was fighting for custody of her three oldest daughters while still looking after a young toddler and being pregnant with her fifth child. Marilynn had a warm and relaxed demeanor but one I saw quickly shift to shy and reserved when confronted with authority. Weeks before her daughter was born, I came with Marilynn to a prenatal appointment. We picked up some food before arriving at a crowded clinic. As I looked around the space at the 40 or so women waiting to be assessed, I turned to Marilynn and noticed how much smaller she seemed in the seat beside me. She was so different from the woman I had seen only minutes earlier, laughing in my vehicle. It was a realization that carried forward from clinic waiting room to the clinic exam room. With Marilynn sitting on the edge of the bed, crinkling the paper cover on the table, we barely spoke as we readied for the doctor to come in. When he entered, I recognized his face, he was a physician I knew from my work as a nurse. I watched as he listened closely to the infant's heartbeat and I smiled at the steady gallop that my ears knew signaled a healthy fetus. Marilynn waited for his nod to indicate that everything was all right. Though the visit felt short and rushed, the doctor in a warm tone took the time to reprimand Marilynn for missing the last appointment. She laughed and said, "I know…" Again, he talked about how missing appointments was a risk to her health and the baby's health, and restated the importance of attending all the visits.*

> *As we left the room, I wondered about the care I had just witnessed. The physician was neither rude, nor was his tone short or terse. However, in the interaction, there were no questions from Marilynn, no time for a response beyond what he hoped to hear. I asked Marilynn once the door behind him closed, "Why did you miss your last appointment?" Marilynn told me she had waited all afternoon, but the doctors were too busy to see her. She was not able to return the next day, as she had no bus tickets left and no one was available to look after her daughter. "I wanted to come," she said.*

In my time alongside Marilynn, I came to know her as the family matriarch. Even with a history of complex trauma, including intergenerational experiences with residential schools and an unsettled childhood, she joyfully took on the role of the organizer of family gatherings. Her home was the center for meals, celebrations, and visiting relatives. Yet, in her interactions with the health care system, Marilynn's autonomy and power were minimal. In our hospital visit, the conversation was a one-sided interaction with the care provider. Instead of asking Marilynn any questions, the obstetrician made statements about her choice not to wait. By not asking about her life and circumstance, he relayed a judgement of Marilynn as a mother who does not wait for her prenatal appointment, as a mother who does not care.

Without knowing Marilynn, the obstetrician was free to exercise the privilege to disregard who she is as a person and as a mother. Marilynn was already an expert in waiting. The fight to regain custody was marked by weeks of waiting for calls and emails between lawyers to be answered. She waited for city buses, and she waited every month for the support that she needed to help not only her immediate, but also her extended, family's needs. In performing his role as obstetrician to an Indigenous mother, the physician never asked her about the reasons she did not wait. Was it because he already had an idea formulated about how, and why, Marilynn waits in the first place?

There were other moments of waiting embedded in the care interactions, as in the time Marilynn waited for the nod from the doctor as a signal that her baby was healthy. There was a silence between his finding a heartbeat and the casual gesture to show that the infant was fine. While the moment - measured in time - was short, the implications for Marilynn in that moment were significant. Marilynn's fight for custody for her other children, filled this moment of waiting with worry and anticipation. In this moment of waiting, there was no acknowledgement of the impact waiting had on Marilynn, or on the relationship. It was the first time I understood why Marilynn changed who she was so suddenly when she entered a health care setting. In these moments, alongside Marilynn, I see waiting is temporal, social, and situated. Thinking about waiting alongside Butler's ideas helps explore how people perform waiting, and how that performance constructs how waiting can be known and experienced.

Waiting is Relational

In the context of care, there is often little acknowledgement of the relational nature of waiting and Butler's concept of performativity allows us to see this as a generative process. Considering waiting as performative also requires us to see waiting as an extension of language. While waiting does not always involve directly speaking, the physicality and its visible nature, means that even silent waiting takes on a communicative role.

In the context of care, the social nature of this communication can influence the evaluation and treatment of patients. Waiting is not neutral. Both Renate and Marilynn's experiences were shaped by assumptions and judgments related to their waiting. These assumptions were made by those in health care who held power and control. Across all narratives shared in this paper, clinicians, both physician and nurse, are positioned as experts. This expertise leads to the idea that care providers should not be made to wait. Not only did they enact expertise, their own performance of waiting determined whether Renate and Marilynn could be known as caring mothers. While Renate was unable to carry Kayden to term, waiting in the

NICU provided a way to demonstrate that she cared about him. Renate's performance of waiting can be seen as an extension of showing care. Had she not performed waiting each day, it may have become a signal for clinicians of: risk, impatience, and possible harm. Marilynn's missed appointment was interpreted as not caring by the obstetrician. As he performed his own practice around waiting, he in turn, was shaped to see Marilynn as not a caring mother.

Within the hospital or care context, waiting is shaped by institutional structures and normative expectations. Waiting (or not waiting) in ways that disrupt these processes, signals impatience, risk, and serves as confirmation of unsuitability as a mother. The belief that a caring mother should and must wait, also serves another function – to sustain the legitimacy of clinicians as arbiters of identity. In my story of the patient in labour, the care team's experience in the waiting context contributed to the perception that she was not a caring mother. The team's frustrations that she made them wait, and my own questions surrounding "*Why doesn't she just tell us what she used*?" again confirmed the judgement about her identity as a mother. Returning to Renate and Marilynn's experiences, care providers engagement in their care occurred when the normative expectations around waiting were challenged. How we perceive patients and how we act in the moments of waiting becomes a significant conduit of care. This conduit of care reflects our judgements, which intentionally or unintentionally shape who patients are and are becoming. In many ways it shapes their identities, their 'stories to live-by' (18,19).

Butler does not directly address motherhood in her writing on performativity. However, her ideas have been taken up with attentiveness to the complexities of motherhood (27). Performative waiting does not reveal the moral deliberations of good motherhood. However, the performance of waiting is visible in the public sense and can reveal some aspects of parenting as it conceals others. For many women, pregnancy and the biological ability to carry a child to term is itself a unique period of waiting. Waiting during this time is a visible and public process. In this context, social expectations on waiting for answers about illegal substance use, waiting for appointments, and waiting to engage others in care, are connected to social norms. Renate, Marilynn, and I all participated in the reproduction of gendered expectations. In spaces where the impact of motherhood influences care, specifically care areas such as a labour and delivery unit, a prenatal waiting room and a NICU, the importance of performativity cannot be overlooked. Once visible to the care system, expectations of motherhood, femininity, and gender can shift how waiting is performed.

Conclusion

While the performativity of waiting draws our attention to the importance and impact of waiting, it is in the moments where we can see the spaces of waiting as relational encounters that we can see the possibilities to create dialogue and conversations that recognize the importance of time, place, and social contexts in the lives of others. Waiting takes on various forms in the health care system, waiting is a relational process influenced by factors such as place, gender, and power. It is important to acknowledge the impact that waiting has in the lives of mothers. Acknowledging that waiting shifts when seeing waiting in relationship, in the context of time, place, and society is a necessary observation to make in a health care system that relies on the cover story that “everyone waits”, as if waiting was a “without doing very much” (2).

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Chapter 4: Lugones' metaphor of 'world traveling' in narrative inquiry

Lugones' metaphor of 'world traveling' in narrative inquiry

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Abstract

The metaphor of 'world travelling' (Lugones, 1987) has been taken up by researchers engaged in narrative inquiry. This metaphor provides a reference point throughout the research process for navigating relational processes. In this paper, we unpack how the metaphor of 'world travelling' shapes the writing of research texts in narrative inquiry (Clandinin, 2013) and the meaning making inherent in shared texts. We draw on a narrative inquiry focused on the experiences of men who are homeless in Japan, as well as a narrative inquiry focused on precariously housed women who are pregnant or engaged with early parenting and who use illicit substances. As we work with Lugones' (2003) ideas, we see it is critical to engage in a collaborative process that is marked by a playful exchange of ideas and that pushes us to identify connections with others. At the same time, we work to create meaning, we need to challenge racial, social, political, and economic boundaries and social differences in ways that allow researchers and participants to locate themselves in relation to others. Engaging in this manner shows openness to multiple ways of sense making and creating texts where expectations are broken. Representation requires the development of texts where we can "exercise double vision" (Lugones, 2003), and "create and cement relational identities" (Lugones, 2006). These spaces of openness and multiplicity are always in motion and are marked by a sense of 'dwelling' (Caine, 2007), 'world travelling', and 'playfulness' (Lugones, 1987).

Introduction

Lugones' (1987) conceptual metaphor of ‘world travelling’ has been considered by many as a way to understand another individual, culture, or community. In developing this concept, Lugones (2003) distances herself from other theorists’ conceptions of travel. Instead, her concept, grounded in her experiences as a Latina female, is centered on “locating the multiple self in space, conceiving of space itself as multiple, intersecting, co-temporaneous realities” (p. 16). Initially, Lugones (1987) explores the concept of ‘travel’ from a personal lens, in reflections on her relationship with her mother. In later work, she (Lugones, 2003) expands on her notion of travel when she discusses the implications of these concepts in relation to political theories, agency, and oppression. Moving from “I → we” (p. 7) she takes initial reflective work about her relationship with her mother further by examining in depth the experiences of marginalized communities, in particular, Latina women in an Angla centered world. Lugones (2003) defines her work on ‘world travelling’ and other concepts in *Pilgrimages/Peregrinajes* as “theoretico-practical in every respect” (p.ix).

Acknowledging the risk of appropriating Lugones’ metaphor, narrative inquirers have taken up her work. While Lugones’ (1987; 2003) writing centers on the theoretical and practical notions of ‘world travelling’, narrative inquirers have moved the concept of ‘world travelling’ to research and to a particular way to understand experience. Narrative inquiry as phenomena under study and as research methodology focuses on understanding experience (Clandinin & Connelly, 2000, Clandinin, 2013) with relational ethics as a central concern (Clandinin, Caine & Lessard, 2018).

Lugones’ metaphor of ‘world travelling’ and its conditions of ‘loving perception’ and ‘playfulness’, provides a reference point throughout the complex relational research process from entering the field, to composing field texts and to co-composing and composing interim and final research texts. The metaphor of ‘world’ travelling helps situate the relational work within an inquiry and provides language to help understand representation in the composition of interim and final research texts.

In this paper, we make visible the use of Lugones’ metaphor in the living of and representing of narrative inquiry studies. We draw on two narrative inquiry studies in which participants are homeless or precariously housed. Hiroko Kubota’s study is situated in Japan with older men who were homeless. By returning to her work in the field alongside a participant named Yoshi, we call attention to ‘world-travelling’ in the relational work while in the field, particularly in the negotiation over time of their relationship. Georgia Dewart’s study is situated in Canada and focuses on her work alongside Nikki, a young mother who is precariously housed. Georgia shows how their negotiation of the research relationship, marked by ‘world travelling’, continues during the development of interim research texts. We explore three aspects of Lugones’ metaphor of ‘world travelling’: ‘worlds’, ‘playfulness’, and ‘loving perception’. Our aim is to advance narrative inquiry as a methodology and phenomenon under study, by explicitly making our uptake of these concepts visible.

‘World Travelling’ and Narrative Inquiry

As a feminist philosopher, Lugones (1987, 2003) introduces the conceptual metaphor of ‘world travelling’ to explain the process of understanding and learning about difference. She (2003) states, “I affirm this practice as a skillful, creative, rich, enriching, and given certain circumstances, loving way of being and living” (p. 77). Lugones (2003) does not provide a fixed definition for what she defines as ‘world’, “because I think the term is suggestive and I do not want to close the suggestiveness of it too soon” (p. 87). She outlines some characteristics of the concept noting that size is not a requirement for a ‘world’. A ‘world’ can be whole societies or just made up of only a small number of individuals (Lugones, 1987). She states, “for something to be a “world” in my sense, it has to be inhabited by some flesh and blood people” (p. 87). For Lugones, the requirement for living inhabitants means that a utopia is not to be considered a ‘world’. While some inhabitants must be alive, others may be imaginary or deceased or those who have only traveled to this particular ‘world’. Individuals can be present in multiple ‘worlds’, and their ability to travel between these ‘worlds’ is dependent on context, setting, shared history, shared language and understanding of the social norms; “a “world” may be an incomplete visionary non-utopian construction of life or it may be a traditional construction of life” (Lugones, 1987, p.10).

While much of Lugones’ writing on ‘world travelling’ centers on the experiences of women of color, ‘world travelling’ describes the experience of outsiders to the mainstream, and of their adjustment to the ‘world’ around them. For women of color, ‘world travelling’ is not so much an option as a necessity and part of daily life (Lugones, 2003). Lugones (1987) is “offering a description of experience” (p. 11).

The choice of Lugones’ term ‘travelling’ remains central in the individual act of resistance and a recognition of oppression. The term ‘travelling’ connotes privilege and leisure, as well as displacement of others; Lugones (2003) chose this term to actively resist this discourse. For her, “[t]he shift from being one person to being a different person is what I call travelling” (Lugones, 2003, p. 89). Lugones (2003) points out, that for women of color, ‘travelling’ is not a pleasurable or leisurely experience. For those who view ‘travelling’ as enjoyment may be challenged when the term is used to forefront privilege and power. Lugones recognizes the possibility that those within the mainstream can ‘world travel’ as an act of resistance. Lugones notes that ‘playfulness’ and ‘loving perception’ are two conditions that must be present in order to ‘world travel’.

Playfulness

For Lugones, a sense of ‘playfulness’ offers the vulnerability necessary for travel. However, playfulness has two aspects: ‘agnostic playfulness’ and ‘loving playfulness’. ‘Agnostic playfulness’ is marked by a sense of superiority and competence that prevents individuals from ‘world travelling’ and “leads those who attempt to travel to another “world” with this attitude to failure” (Lugones, 1987, p. 16). Alternatively, ‘loving playfulness’ is characterized by a sense of possibility as it is, in part, “an openness to being a fool, which is a combination of not worrying about competence, not being self-important, not taking norms as sacred and finding ambiguity and double edges as a source of wisdom and delight” (Lugones, 1987, p. 17). ‘Playfulness’ is a central aspect of being able to connect to others, which may be tied to the ‘worlds’ construction or who an individual is in this space (Lugones). Whether an individual is ‘playful’ is related to the individual’s ability to be ‘at ease’. Lugones outlines the following conditions, which allow someone to be ‘at ease’ in a particular ‘world’: a shared history; shared language; human connections; and agreement with the particular norms of the ‘world’ (Lugones, 2003). For Lugones, it is important to consider the relationship between being at ease in a ‘world’ and the ability to be ‘playful’. Lugones is clear that lack of ease does not directly affect ‘playfulness’, noting “lack of playfulness is not symptomatic of lack of ease but lack of health. I am not a healthy being in the “worlds” that construct me as un-playful” (p. 93). Lugones defines a ‘playful’ attitude as openness to possibilities, including the possibility to disrupt particular contexts that are oppressive or provide power to a particular group.

‘Loving Perception’

While Lugones focuses on the exploration of loving others, it is important to explore the opposite of loving others. The development of the concept of ‘loving perception’ has been shaped by both Lugones’ failure to not love her mother and white/Angla lack of love towards women of color. Lack of ‘loving perception’ is a result of ‘arrogant perception’, that is, viewing others with a dismissive and oppressive gaze. “Many times White/Angla women want us out of their field of vision. Their lack of concern is a harmful failure of love that leaves me independent from them in a way similar to the way in which, once I ceased to be my mother’s parasite, she became, though not independent from all others, certainly independent from me” (Lugones, 1987, p. 7). Building on the work of Frye, Lugones sees ‘arrogant perceptions’ and ‘loving perceptions’ as two opposing ways of perceiving the world. In exploring the failure of recognition that many women of color experience from white/Angla communities, she writes “I am interested here in those many cases in which white/Angla women do one or more of the following to women of color: they ignore us, ostracize us, render us invisible, stereotype us, leave us completely alone, interpret us as a crazy. All of this while we are in their midst” (p. 83).

While Lugones’ uses her theoretical work to frame politics and her personal life, it is possible to explore her metaphor within the context of research. The risks of ‘arrogant perceptions’ are significant in research, as research often positions individuals as the ‘other’ or as a ‘subject’ for study. Narrative inquirers have taken up Lugones’ writings to more explicitly develop research processes that create possibilities to ‘world travel’. In narrative inquiry, ‘world travelling’ is not a process in the abstract, rather it is a process that calls us to question who we are and are becoming as people in relation (Clandinin & Connelly, 2000).

Narrative Inquiry

Narrative inquiry, as conceptualized by Clandinin and Connelly (2000) is both a research methodology and a way to understand human experience (Clandinin, 2013). Taken up by researchers across disciplines, including nursing and education, narrative inquiry explores individual experience as a source of knowledge. A narrative inquirer seeks to understand not only personal and unique experiences but also how individual storied experiences are constituted and enacted within larger social, historical, and institutional narratives across time and place (Clandinin, Murphy, Huber & Orr, 2009; Clandinin & Rosiek; 2007). Prediction and generalizability are not the focus of narrative inquiry, nor is the need for objective understanding (Pinnegar & Daynes, 2007). Instead, narrative inquiry "is a way of honoring lived experience as a source of important knowledge and understanding" (Clandinin, 2013, p.17).

Drawing on pragmatist philosophies, narrative inquiry works from Dewey's theory of experience and his criteria for experience: continuity and interaction (Clandinin & Connelly, 2000). Dewey's criteria are reflected in the three dimensional aspects of experience, comprised of: temporality, sociality, and place. *Temporality*, thinking of narrative as evolving over time, encourages a reflection on experience over time, attending forward and backward as the experience unfolds. *Sociality* focuses attention inward and outward, that is, outward to the social events inward to the emotions, aesthetic reactions and moral sense of each person. The dimension of *place* turns attention to the physical landscape of individual researcher and research participants as experiences unfold over time. Clandinin and Connelly (2000) highlight that narrative inquirers must attend to all three dimensions simultaneous. Furthermore, they highlight that narrative inquiry is the study of the experience of researcher and participant over time. These dimensions of narrative inquiry are important to being able to use Lugones' conceptual metaphor.

In understanding experience narratively, temporality, sociality and place can be further developed through attentiveness to the concept of ‘world travelling’. One aspect of thinking narratively is an inquirer’s commitment to coming alongside participants. In narrative inquiry, this process occurs early in the research work, as researchers negotiate relationships in the field, and as they negotiate the relational space in an inquiry (Clandinin, 2013). As researchers come alongside participants in a narrative inquiry study, they are entering into the worlds that are co-compose with participants, worlds where temporality, sociality, and place matter. Clandinin (2013) acknowledges that researchers are always entering in the midst of each participant’s life, the researcher’s life, and their ongoing relationship. “Coming alongside in the midst” (Clandinin, 2013, p. 34) names the ways temporality, sociality, and place are within experience, and it calls each researcher to be attentive to their own worlds, the worlds of each participant, and the world that they and the participant are beginning to co-compose.

Within each study, researchers acknowledge that “each person [researcher and participant] is composing a life shaped by the contexts, times and relationship within they are enfolded” (Clandinin, Caine, & Lessard, 2018, p. 19). Thinking narratively, it is not possible, for narrative inquirers to disregard the evolving nature of individual experience, or to fix or tie a narrative to a particular category (Clandinin, Caine & Lessard, 2018). Narrative inquiry forefronts the person and the relational between researcher and participants throughout the research process. “These ontological commitments with their related responsibilities become a way of living in the world. As we attend to our ontological responsibilities, we are attending to the lives, the experiences, of those with whom we live in relation. Our commitments are not first and foremost to the inquiry puzzle but to the lives of the people involved” (Clandinin et al., 2015, p. 23). Within this view relational ethics is at the heart of a narrative inquiry (Clandinin & Connelly, 2000).

Lugones' also offers a perspective within which to view the world, as she provides a guide to relational ways to interact with others. By naming 'worlds', she provides a conceptual way to reflect on individual experiences but also on how social context, privilege, and power shape who we are amidst multiple and diverse circumstances. Lugones' focus on the multiplicity of worlds that we each inhabit further supports Clandinin, Caine, and Lessard's (2018) argument that individual experience cannot, and should not, be reduced to single stories. A single story is impossible when each person exists in multiple 'worlds', can move between 'worlds' and can co-compose new worlds. 'World travelling' is also a way to understand the multiplicity of experience and acknowledges the uncertainty in narratives of experience.

In the following section, using field notes from one study (Kubota, 2017) and interim research texts from another (Dewart, in process), we illustrate the ways Lugones' work offers conceptual understandings to narrative inquirers in all phases of a narrative inquiry. Hiroko Kubota's illustrates the ways Lugones' concept is used in thinking with participants in the field. The metaphor of 'world travelling' assists in understanding the development of a research relationship between her and Yoshi, a research participant. Georgia Dewart focuses on making visible the concept 'world travelling' in relation to composing interim research texts, a part of the analysis and representation of narrative inquiry. She highlights the importance that Lugones' work holds in representing the relational and social conditions that shape experience.

'World Travelling' in the Field

Narrative inquirers have taken up Lugones' concept of world travelling as they navigate and negotiate the relational space, the field, of an inquiry. Hiroko's doctoral research, a narrative inquiry situated in Japan, brought her alongside three men, who face significant social stigma because they are homeless. In Japan, the number of people who are visibly homeless has decreased by almost a quarter within the last fifteen years (Ministry of Health, Labour, and Welfare, 2016). However, the issue of precarious housing conditions, unemployment, and poverty do not seem to be resolved; rather they have been growing into more complex issues which are hidden from the public's attention and public discourses. Voices of people who are homeless in Japan are often represented in narrow socio-political terms and not in diverse personal terms.

Yoshi and Hiroko

One participant in Hiroko's study was called Yoshi, a 65-year-old man who has been homeless for more than ten years. Despite many uncertainties and anxieties in initiating a relationship, Yoshi dared to take part in the research and engaged in a series of conversations with Hiroko over a period of three months. Negotiating multiple explicit and implicit conflicts Hiroko and Yoshi slowly built a relationship within which they were both able to find and live who they are. Underpinned by trust in their relationship, they created a space where lived and imagined stories became possible. Returning to her memories Hiroko writes:

I used to take a train every day as I went to school in Japan, from Grade 7 up until University, where I spent my childhood and young adulthood. I am at ease in train stations. Connecting via subway lines and other major railways is familiar to me. Returning to this train station during my doctoral research called forth a nostalgic feeling and situated me within this familiar landscape, which seems not to have changed even though it has been several years since I moved away from Japan. Yet, this time, when I returned to the train station, I came as a researcher interested in the lives of people who were homeless. One evening I spotted Yoshi at *this train station. In the moment of seeing him, my familiar landscape suddenly changed. Catching sight of him in the distance, I was uncertain about whether I could talk to him, there, at that moment. I felt my willingness to talk to him and yet, I also felt my hesitation. As I walked closer I saw that he looked weary and downcast, his body curled tightly, his head tucked into his chest, as if he was trying to merge his body into the landscape. He looked different from how I had come to know him in our conversations, in a small meeting room next to a support center.*

Together, Yoshi and I had built a relationship in the quiet meeting room, where we gathered around a table and engaged in telling, retelling, and reliving stories. In our conversations, Yoshi was not characterized by homelessness, but shared the multiplicity of his life stories with me ... stories of his childhood when he lived in extreme poverty, but creatively crafted toys to play outside. In our relationship, Yoshi was not made small and anonymous. He was the one who took care of us and enriched our relationship with compassion. In our later conversations, he always brought me a bottle of tea or shared a slice of bread with me. In our meeting room, his worn-out winter jacket did not reflect his exhaustion, but a swollen pocket in his winter jacket was where he hid a surprise gift for me. In such ways, we co-created the world while we were co-composing stories of us and our relationship. Within our relationship we made visible the multiplicity of who we are and are becoming through playfully locating ourselves.

Back at the train station, seeing Yoshi only a few meters ahead, I looked down at his shrunken shoulders covered by a worn-out winter jacket that was too large for his build. As I looked at his tired body, I was more intensely confronted with a consideration of who I wanted to be in our relationship and also of my close world with Yoshi, a world we shaped together, a *world in relation to other worlds of which we are part. Watching Yoshi in these seconds where I recognized him at the train station, I quickly tried to assemble my thoughts to imagine possible implications of my action. Could I approach him? Am I trying to talk to him for myself or am I doing this for Yoshi? Wondering whether I could tap on his shoulder then and talk to him, I was afraid if I was going to connect our protected 'world' with the noises of the insecure 'world' constructed by dominant narratives that might carelessly marginalize his body and disregard his voice. When Yoshi lifted up his head, I wondered what kind of experiences he would have to encounter within this unexpected colliding of the 'worlds' we both inhabited as individuals.*

On the verge of two different worlds, I tried to see both of us from within his eyes, from within his 'worlds' (Lugones, 1987). I wondered if this part of him, situated in the train station, was what he would agree to show me in our relational world. Also, I felt disoriented between "a double image" (Lugones, 1987, p. 14) of myself: the one who used to be at ease in the mainstream world at the train station, and the other one who intimately dwells in a relationship with Yoshi. If these two worlds were going to be merged, does it make him vulnerable in our relationship? Are these worlds compatible? Or does one world assimilate the other? I felt I was clueless, as if my questions only clouded my vision, rather than giving me any insights. In a fleeting moment, I thought it was not what he agreed to show me. I thought it might be better to turn away before he saw me. I worried that we would no longer look forward to our next meeting, a meeting in the agreed-upon meeting room where we had co-composed a 'world'. With having no clear answer, I found myself absorbed into the busy crowd and passing by Yoshi, while my thoughts were still lingering around him.

It is impossible to return to the train station, but Hiroko's account of her experience with Yoshi offers an opportunity to learn about 'world travelling' in the field. Initially we can see how the metaphor of 'world travelling' is important when Hiroko is attending to place, one dimension of the three dimensions of narrative inquiry. The resonances between this dimension of narrative inquiry and Lugones' metaphor are significant. In narrative inquiry an individual's experience cannot be separated from the places in which their experiences occur; experiences are always situated in time, place and relationships. Narrative inquirers turn to Lugones' metaphor of 'world' to frame a more complex understanding of place. Worlds exist in a physical sense, that is, they are tangible places and not utopian ideals. For Lugones, one lives in a world with flesh and blood people, such as the world that Hiroko inhabits at the train station.

Hiroko was at ease at the train station; people, sounds, and the atmosphere continued to sustain her in this 'world'. Yet, when she encounters Yoshi in the train station, she begins to understand that Yoshi's 'world' in the train station is different than hers. Recognizing the multiplicity of 'worlds' and that one place can be different 'worlds' for those who inhabit it highlights the situatedness and complexity of experience.

Acknowledging the plurality of 'worlds' and people situated in them, however, does not allow one to 'travel'. Hiroko and Yoshi had worked, over time, to co-compose a 'world' they could both inhabit, a 'world' where they both felt at ease and where they could both be 'playful' in Lugones' sense. Their relational 'world' encountered a potential difficult disruption for Hiroko when she saw Yoshi in a train station – a time and place where their 'worlds' could have collided. It was Hiroko who, using the concept of 'world travel', confronted the possible disruption and acted by not approaching Yoshi.

“Those of us who are ‘world’-travelers have the distinct experience of being different in different ‘worlds’” (Lugones, 1987, p.48). We are, each of us, multiple. Lugones’ metaphor also acknowledges that we each live in multiple situations. By recognizing pluralities within who we are and are becoming, ‘travelling’ to another’s ‘worlds could elucidate one’s presence to others in relational ways. Lugones’ metaphor of ‘world travelling’ names the spaces in which many marginalized communities are located. In doing so, she makes visible, ‘worlds’ formed through colonization, inequities, and discrimination. From an emancipatory perspective, it is important to recognize the value of the perspectives and experiences of people who live in ‘worlds’ that may be overlooked or made invisible. Learning from Yoshi and Hiroko’s relationship, we recognize the importance of attending to the social conditions, social injustices, and disparities. It is through ‘world travelling’ that we learn about multiplicity and respect, through loving each other (Lugones, 1987).

In the relational space, co-composed through ‘world travelling’, we can become attentive to who others, and we, are in the places in which we live. To do so, however, requires a move from ‘arrogant perceptions’ to ‘loving perceptions’ (Lugones, 2003). Hiroko’s decision to not disrupt the ‘world’ that she and Yoshi had co-composed was an ethical choice, one guided by ‘loving perceptions’. Greeting Yoshi in the ‘world’ of the train station could shift the relational world of their research. In the ‘world’ where Yoshi was made vulnerable and marginalized, Hiroko was unsure who she would be in his eyes and how he would see himself when their ‘worlds’ collided. She was also not sure if it would interrupt their relationship. Ultimately, in the recognition of the different ‘worlds’ they lived within, Hiroko made the decision not to greet Yoshi.

What we hope we have made visible is the importance of thinking with Lugones' concept of 'world travelling' while we work in the field composing and co-composing field texts as narrative inquirers. However, 'world travelling' is also important to co-composing interim research texts as we work to represent our work first with participants and subsequently to larger audiences.

World Travelling in Co-Composing Interim Research Texts

The relational process within a narrative inquiry does not end once a researcher leaves the field and shifts their focus to co-composing interim research texts with participants. The progression from being immersed in the field to writing interim and then final research texts is a process with political and social implications. Lugones' metaphor helps frame this complex transition. In Hiroko's writing, thinking with Lugones' metaphor carries forward into the interim and final research texts. However, reading her interim and final research texts does not show all aspects of the representational processes. To illustrate this process further, we turn to Georgia's doctoral research.

Georgia's narrative inquiry explored the experiences of three women with young children, homeless or precariously housed who disclosed illicit substance use. Like Hiroko's work with men who are homeless, Georgia's participants lived within dominant social and institutional narratives that resulted in significant social scrutiny and stigma. The rates of substance misuse and mental illness remain significantly higher for women in precarious housing situations compared to those in the general population (Bassuk, Buckner, Perloff & Bassuk., 1998; Torchalla, Strehlau, Li & Krausz, 2011). Stigma rooted in dominant narratives in which substance use is a choice and sign of immoral and bad mothering (Boyd, 2015) significantly shapes their health and wellbeing.

Georgia came alongside three families all facing complex challenges in relation to care. In this paper, we pull forward the experiences of Nikki, a young mother in her mid-thirties. In order to illuminate the ways that Lugones' metaphor of 'world travelling' is taken up in co-composition and in representation, we draw on Nikki and Georgia's relationship. Providing three examples of writing, we explore the impact of Lugones' metaphor of 'world travelling' in relation to co-composing interim research texts[4]. We begin with a fragment of an early draft of one narrative account, an interim research text.

We sit in Nikki's basement apartment across from one another with Cora who, cheerful and bubbling over new vowel sounds, sits in a high chair between us. Cora, who was a big baby, is now growing into a beautiful little girl. She smacks the tray in front of her with her small palms before reaching for crackers. Her bright eyes track between Nikki and me but always return to her mother and nodding as Nikki feeds little dollops of yogurt to her between distractions.

The one-bedroom apartment is cozy but seems too small for all of Cora's toys and the worn leather sofas take up most of the living room. The sink is filled with dishes and there is little counter space for cooking and even just storage. The apartment carries a slight smell of mildew and sour milk and Nikki puts out air fresheners with lavender to help. There are photos on the fridge. On the wall behind me hangs a chart for behaviour and chores written for Nikki's son.

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[4] Narrative inquiry differentiates the stages of writing in a research relationship. Interim research texts vary in form but are negotiated texts with research participants that make visible the experiences of researcher and participants. These texts are carefully co-composed with attentiveness to the three dimensional narrative inquiry space. These texts are later developed to final research texts, which are shared more broadly and show the resonant threads across all narrative accounts in a study. Frequently parts of, or all of, the interim research texts are included in final research texts.

She has not taken it down yet, even though he is with his adoptive parents. Its place serves as a reminder that not all of the family is present.

It is not ideal – but messiness aside, this is a home. It is in this space that Nikki and I begin to talk about the past, when Nikki was younger. She told me "I really wanted to finish school and do a bunch of things but just life happens and you know I became a teenage mom. I tried to raise my son to the best of my ability…. I didn't have parenting skills. My mom didn't teach me any of that". As I sat across from Nikki watching her feed and comfort Cora I never thought about her lacking skills or knowledge. The homemade chore poster made for her young son hung unfinished – as if she was expecting to have him come back and finish his assigned tasks. He now lives with his adoptive family a short way outside the city. Nikki stated that she wanted him to have a family and life she would not be able to provide for him. That she wanted there to be a mother and father – that children are always better when there are two parents. She felt that while alone she was not good enough. (Early Draft of a Narrative Account – January 2016)

Georgia shared this fragment of the narrative account with her supervisor, shortly after it was written. She remembers the experience of sharing the account and her experience of receiving a response.

I remember the first time I wrote a portion of my narrative account. I was so proud of myself. I handed my work to my supervisor, thinking the work was rich with detail. I believed that I had explained the apartment and the experience of sitting at Nikki's kitchen table in wonderful clarity. My supervisor handed the account back to me and told me gently that she wondered if I had forgotten to consider my relationship with Nikki, and who I was, within that context. She responded that the description had not provided any space to come alongside Nikki *and me in order to understand the unfolding experiences we were both undergoing. She wondered if I had approached my writing of the narrative account as an 'expert', as someone who was studying an 'other' and, in doing so, had positioned myself as outside the study. My impartial detailed observations seemed to distance me from Nikki and her daughter.*

I did not try to re-write the interim research text for ages; I struggled with how to create a narrative account differently from the detailed and rich descriptions that were so often emphasized in our qualitative methodology classes. Yet, when I finally re-read the account, I saw that, in an effort to be competent and clear in my observations, I took on an agonistic sense of playfulness (Lugones, 1987). I missed my own thoughts and feelings, the sadness I felt when I saw Nikki's lack of confidence and when I saw the pictures of her son. I had missed Nikki's sense of humor as well as the comfort I thought she had in our connection. I had approached writing with a predetermined sense of purpose; a self-importance that meant I failed to make visible our relationship and the 'world' we had built together over many months. By writing my observations rather than experiences, I was unable to articulate the determination and love present between Nikki, Cora and I. Nor was I able to contemplate the complications that even the best parenting faces in light of poverty, discrimination, and solitude. (Field Notes, October 12, 2017)

In Georgia's reflective and reflexive field notes brought forward as she was awakened by her supervisor's response, she makes visible the importance of continuing to co-compose with the three dimensional inquiry space, with attentiveness to place, sociality and time. However, her attention is on Nikki and Cora as 'others' and of narrative inquiry's purpose to study the experience of the researcher and participants in relation. It is Lugones' metaphor of 'world travelling' that awakens her to the need for making visible the co-composed world that she and Nikki shared.

Slowly Georgia gained new insights into how she could work with Lugones' metaphor of 'world travelling' to guide the co-composing of the interim research texts, the narrative accounts. She continued to face challenges:

I struggled to put down on paper my feelings about my experience with Nikki. I sensed that when we were together in the field, things shifted for her. I had a sense that when I was alongside Nikki, as we walked through grocery store aisles, Nikki was no longer watched and often times she received better services, because I was there. I too noticed that doctors and nurses spoke softer and more kindly when I was beside her. At the same time, strangers' glances when we went for coffee or meals met my eyes as if to say "why are you spending time with her". I wondered often about the reason for these shifts or the sense of judgment: Is it because of the privilege my skin colour affords? In the health-care context, is it because I am a professional nurse? Was my presence enough that individuals could finally, as Lugones (1987) states, identify with, and "perceive through loving eyes" (p.5)?

Yet, what I wrestle with most, is putting down the shift in how things felt. I struggle to put these small but important side-glances, faster service, gentler tone into words. Having co-composed our own 'world' and knowing Nikki in a loving way, how do I write on the difference? How do I find a way to talk about this without Nikki feeling less then? How do I represent the experiences outside of our 'world' where Nikki is again ignored, rendered invisible, stereotyped or left completely alone (Lugones, 1987)?

(Field Notes, May 1, 2018)

In narrative inquiry, the shift from being in the field to co-composing interim research texts is a complex process. Narrative inquirers start their relational work in the field, entering lives in the midst of participants' lives and in the midst of their own lives (Clandinin, 2013). During this time, field texts are developed in multiple ways including observations, photographs, artifacts, music, and conversations (Clandinin, 2013). These often co-composed field texts are reflective of the ongoing relationship of researcher and participants. However, as researchers move out of the field and begin to co-compose interim research texts they continue to work within the three-dimensional narrative inquiry space. These interim texts, most often thought of as narrative accounts, are co-compositions. Sometimes they are drafted by researchers and negotiated with participants. Other times they are co-composed by joint writing or joint representations (Caine, 2002).

Georgia and Nikki lived alongside each other for many months, with numerous visits spent running errands, waiting in hospitals, and engaged in conversations. As Georgia worked to co-compose an interim research text, a narrative account with Nikki, Lugones' metaphor of 'world travelling' helped them represent their experiences with 'loving perceptions' and with continuing attention to their experiences that when they were together. As narrative inquirers, we do not assert that our work can provide answers or conclusions; instead, the focus is on understanding the individual's experience grounded in temporality, sociality, and place. The three dimensional space, particularly the temporal dimension reminds inquirers to understand that experience is always "in the midst" (Clandinin, 2013, p. 34). As they co-composed the narrative account, Georgia continued to also attend to the sociality dimension, which highlighted the larger social, cultural, and institutional narratives which shaped the particulars of Nikki's experiences. The interim account acknowledges how place, be it shopping centers or care centers, shifts experiences. Place was also visible in the places where Georgia and Nikki met, such as stores and hospitals, as well as the places where they lived as doctoral student/nurse and young mother. Place acknowledges the impact of poverty and racism in Nikki's daily life and in Georgia's daily life helping them to frame their experiences in larger social contexts.

Lugones' metaphor reminds inquirers to attend to the importance of attending to worlds as co-composed. As Georgia continued to work with Nikki on the narrative account, she learned to leave spaces to represent her uncertainties and lack of clear answers. These spaces serve as a way to reflect on these issues, to leave open possibilities that things could be otherwise. These representational choices demonstrate that inquiries, and lives, continue to move forward beyond these interim texts.

Continually returning to Lugones' metaphor also influenced the decisions Nikki and Georgia made on which aspects of their experience to share in the interim research text and eventually in the final research texts. Recognition of 'arrogant perceptions' helped them consider what to put in and what to leave out in the narrative account. Given the stigma surrounding substance use during pregnancy and as a young mother, writing about Nikki's challenges could emphasize negative opinions on her mothering abilities and provide reinforcement to the larger deficit social narratives. Georgia, however, wanted to find ways to represent the ways that others had responded to Nikki when they were together in the field. Georgia noticed that others did not recognize or acknowledge Nikki. This lack of recognition was, in Georgia's eyes, an expression of "arrogant perception". In the narrative account, Georgia worked to create ways to acknowledge how this arrogant perception was tied to an outsiders' inability to relate to Nikki and imagine themselves in her 'world'. Georgia turned to Lugones (1987) for help in representing these 'arrogant perceptions'. Lugones states, "[t]here is a complex failure of love in the failure to identify with another woman, the failure to see oneself in other women who are quite different from oneself" (p. 7). In the narrative account, Georgia sought ways in which purposeful representations of her experience with Nikki could encourage readers to imaginatively travel to their co-composed world to evoke times when they may have arrogantly perceived someone undergoing similar experiences. Questions emerged of how one calls the reader into a text, to come alongside Nikki and Georgia with 'loving perception'. As Andrews (2018) argued: we cannot not imagine an other's experience but must work to travel to different 'worlds'. It is not enough to erase or silence the experiences of others.

Representing the multiple 'worlds' that researcher and participants inhabit is challenging; yet, perhaps more challenging is representing the shifts participants and researchers experience in their relationship. Lugones (1987) states, "the shift from being one person to being a different person is what I call 'travel' (p.11). As an inquirer moves from the field to co-composing interim research texts, it is important to be wakeful to who we are in the research texts. As Georgia wrote, she learned to shift the tone and perspective of her writing. Lugones (1987) states, "I am suggesting disloyalty to arrogant perceivers, including the arrogant perceiver in ourselves, and to their constructions of women" (p.18). Just as Lugones (1987) explores her own failure to love her mother, co-composing narrative accounts asks us to engage in self-facing, in reflexive processes in order to confront their own tendencies and inability to love. As Georgia engaged in these processes, she learned to make herself vulnerable in the writing and to highlight her experiences in multiple 'worlds'. This openness in writing, that is, in creating a narrative account that is invites readers to world travel to participants' experiences provides a different way to 'world travel'.

Georgia's experience of learning to co-compose interim research texts was an emotional one, partially due to Georgia's lack of 'playfulness' in writing. Lugones (1987) argues that when one is playful in a 'world' one is "not fixed in a particular construction of ourselves, which is part of saying that we are open to self-construction" (p. 16). In order to be lovingly playful, Georgia was required to first recognize, and then shift, her focus on competence and understandings of being an expert, symptoms of 'agnostic playfulness', to 'loving playfulness'. Shifting the emphasis away from competence required that Georgia's experience become visible in the writing. Georgia needed to show that she was part of a 'world' that was both playful and healthy. Nikki had to be visible as a co-composer of the world she and Georgia were constructing. Part of being playful and healthy meant finding ways in which Nikki's experiences, particularly the trauma and injustices she had experienced, were represented in ways that created, rather than foreclosed, a sense of possibility. Together they negotiated writing letters rather than creating a chronologically unfolding account. The letters written by Georgia to Nikki, include questions directed to Nikki, acknowledging that, as a co-researcher, Georgia continues to wonder and reflect on their experiences.

Now as I think about shift and the later ease at which I entered your home and I reflect on parallels that I experience in other worlds. I am reminded by the joy I have in kicking off my shoes at my parents' house. How there is comfort in knowing I do not need someone to come greet me; I am already welcome. In some ways, my entrance needs no attention since I have never truly left. How I feel a physical sense of relief when I enter my own home at the end of my workday. These realizations have made me wonder about what we take for granted in the meaning of home. It has helped me think of your experiences and I wonder now about what the impact of place has on a family. Over our research relationship, you experienced many moves *and adjustments. New apartments, new buildings, new areas of town. How do you establish a home in this constant and evolving changing of place?*

(Excerpt – Nikki’s Narrative Account)

The relationship is always at the forefront of interim research texts and intertwined with questions about representation. In narrative inquiry, response communities, comprised of peers, supervisors and research participants, are integral in the self-facing work that is a necessary part of the relational process. These response communities, rather than offer vacuous praise (Lessard, Caine & Clandinin, 2018), challenge researchers to question their assumptions, understandings and perceptions around experience. While it was difficult for Georgia to receive initial response from her supervisor who asked her to reconsider who she was in the initial narrative account, it was that response that opened the possibility for Georgia to consider how Lugones’ metaphor of ‘world travelling’ might help her co-compose research texts.

Implications and Final Research Texts

Navigating relationships within research is neither an easy nor a straightforward process. Narrative inquirers turn to Lugones’ writing because of the value it holds in reflecting on the research process through an ethical, political, and representational lens. While Lugones’ work offers a starting place for ethical research and relational work, risks are still present in the use of the metaphor ‘world travelling’. Metaphors present the possibility of misinterpretation. In the case of ‘world travelling’, misinterpretation can have real consequences given that in narrative inquiry, ‘world travelling’ is not merely a rhetorical device. Instead, Lugones’ work has served as a guide to shaping the relational research process within narrative inquiry. It is an embodied metaphor. This complexity leads to further concerns of over simplification of the term and the use without the conditions of ‘playfulness’ or ‘loving perceptions’. Moreover, the final stage of the writing process in narrative inquiry involves the transition from interim to final research texts. These final texts must reflect the experiences of researchers and participants, at the same time, they need to be “embedded within social, cultural, familial, linguistic and institutional narratives” (Clandinin, 2013, p. 207). Recognizing that final research texts carry forward into different and imagined ‘worlds’, a continued reflection on ‘world travelling’ in relation to the research process, with particular focus on final research texts, is necessary, but goes beyond the scope of this paper.

Conclusion

Lugones’ metaphor of ‘world travelling’ challenges readers to attend to the difficult issues of living alongside participants in narrative inquiry throughout the research process, from living in the field to co-composing and composing field texts and in co-composing interim and final research texts. Lugones’ work reminds inquirers to name the complex and layered ‘worlds’ that each individual can inhabit. In the work of narrative inquiry, imagining oneself in various ‘worlds’ requires that one think of one’s own life narratively. This shift in perspective allows for a more deliberate understanding of an individual in relation to others. The process requires an acknowledgement of the temporal, social, and spatial conditions, which you experience in different ‘worlds’. In Hiroko’s work, ‘world travelling’ shifted how she interacted with Yoshi. Her attentiveness to the ‘worlds’ they co-composed guided her decision to not greet him in the train station. Lugones’ metaphor provided a way to understand the ethical commitments that continue after a research relationship is formed. This ongoing relational work is also taken up in the writing of interim research texts.

In both of these examples, Lugones’ metaphor is taken up in different ways; her work helps articulate the complexity of the living and representation of researcher and participants’ experience in a narrative inquiry. The idea of ‘world travelling’ provides a metaphor to name both the actual and imagined political, racial, and social inequities amidst the multiple colliding ‘worlds’ between researchers and participants and among people in relation. This metaphor strengthens the work of narrative inquiry, a relational research methodology, as we think with others and our own experiences.

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Chapter 5: (Re)considering Harm Reduction

(Re)considering harm reduction: A recognition of an individual life and gender

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Journal: Harm Reduction

Abstract

Background: Harm reduction is both a philosophy and approach, which seeks to reduce the harms an individual experiences from the use of both legal and illegal substances. In recent years, harm reduction has gained increasing support as an ethical approach to previous prohibitionist drug policy and for its focus on a reduction of cost and mitigation of risk. Yet, a focus on fiscal value of harm reduction overlooks an individual life and its complexity; in particular, there is a lack of recognition on how gender intersects with harm reduction.

Objectives: Recognizing the need for responsive gender sensitive harm reduction services, this narrative inquiry aimed to better understand the experiences of women who use illicit substances during pregnancy and the early parenting period (defined as the first 2 years following birth).

Methods: This narrative inquiry study centered on the experiences of three women in a large Western Canadian urban center from 2015 to 2017. This work focuses on the experiences of one participant, Nikki, to explore her life in relation to care and harm. Building on extensive field notes, recorded transcripts of conversations and observations, this work returns to Nikki's story.

Importance: By returning to Nikki's experience, we suggest a more nuanced exploration of harm reduction is necessary. This work contributes to the future development of harm reduction services and challenges the emphasis on outcome driven programs rather than comprehensive services.

*Keywords***.** Mothering. Harm reduction. Substance us. Pregnancy. Women.

Introduction

Nikki and I shared many conversations in the living room of her basement suite[5]. She had decorated her room with new curtains covering her windows and despite the lavender air fresheners in the outlets, her apartment still carried with it a stale mildew smell. Each season the space would change and in my visits around Christmas, she managed to tuck a big tree in the corner with twinkling lights and homemade ornaments on the branches. On one of these visits, we sat eating lunch and talked in-between the moments where we entertained her newborn daughter Cora. Nikki was in her early thirties, tall, and with an expansive personality. She was quick to tease me. It had been months since we first met, and only now, was I learning about the details of her childhood and family. Sitting together, I asked about care providers and case support workers' understanding of her life. Nikki scoffed at me when I asked her this question. She told me then, in her characteristic no nonsense tone:

> *Oh no. I don't think they care about history, they just care about what's going on right now, 'cause we're probably just a statistic right.*

I frowned but nodded when Nikki told me. I reflected on my experience as a registered nurse and the times I treated my patients without understanding the larger social and historical context of their lives. I know that there were times I had made assumptions about the person and the family, sitting in front of me; quick to lose sight of who it was they were. It was this recognition, a sense of not knowing the people I cared for, that made me return to graduate education. My doctoral research, a narrative inquiry study, brought me alongside the lives of three women, each pregnant, transitioning into motherhood and the birth of their newborn children in different ways. All the women had a history with illicit substance use in pregnancy.

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[5] This work is part of a narrative inquiry study, within a Canadian Institute for Health Research funded project. This article will focus on one particular research relationship.

Nikki was the first participant to join this research, and our time together as co-researchers highlighted some of the unique challenges in access to services within a large Western Canadian urban city. Focusing solely on Nikki and her daughter Cora – in this paper, I will explore how harm, risk and access to services are shaped. Ultimately, this work seeks to advance the philosophy and practice of harm reduction.

Background on Harm Reduction

Arising as a response to the socially mediated inequity that faces those who use illicit substances, harm reduction is considered both a philosophy and a practice (International Harm Reduction Association [IHRA], 2018; Pauly, 2008). Given harm reduction's complexity, a singular definition of the philosophy is inadequate. One common understanding of the term is that harm reduction aims to improve the quality of life and reduce the negative impacts high-risk activities have on an individual's and a community's health (Marlatt, Larimer, & Witkiewitz, 2012). One high-risk activity, illicit substance use, refers to the consumption of substances that are controlled and regulated under Canada's federal drug laws and statutes (Canadian Nurses Association [CNA], 2017). People who use illicit substances commonly face social exclusion, stigmatization, and difficulties accessing care (Pauly, 2008); they too experience discrimination, stigma, and overall poorer mental and physical health (Ahern, Struber & Galea, 2007). Illicit substance use places individuals in positions of increased risk and likelihood of harm. In addition to the physiological impact of substance use, the factors that affect the lives of those who use illicit substances are commonly rooted in social isolation and structural discrimination.

The support for harm reduction has grown since its initial development, yet, this approach to care is a highly politicized subset of health delivery. Supporters of harm reduction argue that one key strength of harm reduction is its value free stance on illicit substance use

(Keane, 2003). However, interpretation and moral appraisal of harm may differ significantly between individuals (Valverdre, 1998) – in fact rarely are individuals who use illicit substances asked what they consider to be harmful in their lives.

In an era of evidenced-based medicine, harm reduction has gained support by improving patient outcomes and reducing health and social care costs. The high cost of lifetime care related to HIV and other blood borne pathogens and the relative low cost of many harm reduction programs have led proponents for harm reduction, to highlight the ability to reduce treatment costs and government expenditures when integrating harm reduction (Wilson, Donalda, Shattocka, Wilson & Fraser-Hurt, 2015; Kwon et al., 2012). Numerous reviews have shown the positive benefit of needle-syringe programs (NSPs) and safe injection sites (Wilson et al., 2015). Even with the growing need and acknowledgment of evidence supporting harm reductions services and research demonstrating its fiscal value, many communities remain underserved. In particular, women sensitive and family centred care remains lacking and the need for policy changes and gender sensitivity programs is dire (Pinkham & Malinowska-Sempruch, 2008).

Gender and Harm Reduction

While illicit substance use remains more common for men, women, as well as women with children, face additional challenges related to gender in combination with their substance use (Rhodes & Hendich, 2010). Treatment programs for addiction have predominantly focused on males (Ettore, 2004; Murphy & Rosenbaum, 1999). Women typically have lower access to care and socioeconomic stability, a disadvantage often magnified by substance use (Tuchman, 2010). Women continue to face stigma when accessing services and the negative perception of substance use is particularly evident when pregnancy and children are involved. The social value of women – including those who consume illicit substances - remains highly associated with reproductive capabilities (Boyd, 2015).

Pregnancy and the possibility of motherhood change the social perception of substance use; during pregnancy women are considered as possible sources of harm for their unborn fetus (Boyd, 2015; Campbell, 1999; Ettorre, 2004). Women face additional stigma based on the notion that substance use is seen as immoral and indicative of bad mothering. "Women who use illicit drugs do not fit the hegemonic model of a 'good mother'" (Banwell & Bammer, 2006, p.506); instead, they are seen to lose control both over their physical characteristics and their perceived ability to manage and organize a traditional family household (Benoit et al., 2014). While stigma and the social perception of substance use remain high for many women, their ability to access services, impacted by poverty, lack of childcare, and negative care provider attitudes, among other, further complicates this issue.

Research into existing programs and support have outlined the dearth in programs for women, in particular, those with children. The majority of available programs do not provide flexible delivery of services or account for the need for childcare in order to accommodate larger numbers or women who serve as primary family caregivers (Banwell & Bammer, 2006; Lester et al., 2004; Murphy & Rosenbaum, 1999; Tuchman, 2010). In addition, many women fear of the apprehension of their children, which remains a significant reason for not disclosing illicit substance use. Many women who use substances during pregnancy recognize that once their history of substance use is known they may be labeled by care providers as 'risky' or 'at risk': a designation which brings forth scrutiny from child services and the state (Radcliffe, 2009). The sentiment of substance use leading to harm is often taken up by child protective services, and illicit substance use is considered a sign of abuse or harm often contributing to apprehension

(Olsen, 2015; Paltrow & Flavin, 2013). Punitive responses to substance use and negative attitudes from care providers have meant that many women delay seeking treatment or care (Radcliffe, 2009). It also means mothers may be reluctant to engage with harm reduction programs, as enrollment would serve as confirmation of substance use.

Research Objectives

Recognizing the need for responsive gender sensitive harm reduction services, this narrative inquiry aimed to better understand the experiences of women who use illicit substances during pregnancy and the early parenting period (defined as the first 2 years following birth). This work was embedded in an existing CIHR funded project, centered on the experiences of pregnant or early parenting women who were homeless or precariously housed and HIV positive or at risk for HIV (Caine et al., 2013). This research did not begin with a preexisting theoretical perspective to frame the lives of the participants, rather in keeping with narrative inquiry's methodology began by focusing on understanding the everyday and ordinary experiences of women and how the women accessed, perceived, and experienced harm reduction services.

Methodology

Narrative inquiry is a qualitative research methodology. It is underpinned by a pragmatic, relational, ontology in which experience is viewed as the beginning and end point of inquiry (Clandinin & Rosiek, 2007). Narrative inquirers recognizes that individuals understand and live their lives narratively. Narrative inquiry considers larger social, familiar and institutional narratives, which have a role in shaping an individual experience (Clandinin & Connelly, 2000). "Narrative inquirers make sense as they live alongside participants in narrative inquiries, each negotiating who they are and who they are becoming as they live alongside one another in the field, as field texts are composed and, later, in the composition of research texts." (Huber, Clandinin & Huber, 2006, p. 212). Numerous conversations, extensive field notes, researcher observations and self-reflective writing throughout the research journey were part of the field work. The methodological emphasis on individual experience leads to the development of final research texts return to participant stories and are grounded in a commitment to relational ethics (Clandinin, Caine & Lessard, 2018).

Ethics

This narrative inquiry study received ethical approval through the University of Alberta ethics review board. Community agencies within the city of Edmonton were part of the study, and researchers were embedded as volunteers at these agencies in order to facilitate recruitments. This work was grounded in relational ethics (Clandinin, Caine & Lessard, 2018). Participants were informed throughout various stages of the research process of the voluntary nature of their participation, and each relationship was grounded in the day-to-day life of participants. Individual participants were paid honorariums ($20.00) for each recorded conversation. Additional assistance was provided in the form of transportation and meals during research visits. The relationships with researchers were marked by ongoing negotiations of how to work together.

Participants

For this research, I connected with three women and their families. Each had faced very different challenges, but all of them had come to this research interested in improving care for others. Nikki was the first participant I met, and we have spent over three years, from 2015 to 2018, as co-researchers alongside each other. Nikki had grown up with little stability. During our research, she moved into transitional housing and eventually returned to school. During this time, I was witness to many of her life events. In this paper, I have chosen to focus only on Nikki's story, to highlight the strengths of existing harm reduction programs, as well as the impact of ignoring the complexity of an individual life.

Nikki and Cora

On our very first interaction, I remember Nikki looking at me and thinking that she was appraising me, perhaps she was checking if I was trustworthy. I was so nervous about meeting her, and I wonder now if she recognized my uneasiness. Somehow, we got talking about ordinary things and after joking about bad television and viral videos, Nikki agreed to be a participant. Later, Nikki told me that she wanted to take part in the study, so no one else experienced the same care that she had during the preterm delivery of her son.

I could sense Nikki's pain when she told me about her experiences in the acute care setting. After her son's birth, before Child Social Services apprehended him, Nikki tried to visit him in the Neonatal Intensive Care Unit (NICU). He had been admitted immediately after his delivery, and she came to visit him. When she arrived at the NICU, she was turned away, and told that she was not allowed to see her son. Instead, she was sent home in bloody clothes and left with a deep sense of longing for her child. Nikki had been actively using illicit substances throughout her pregnancy, and according to Nikki, her experiences in the hospital were impacted by the beliefs of care providers that attributed her pre-term delivery to illicit substance use. When Nikki was turned away heartbroken, at the NICU, she was told to take up her concerns with social services once her son was in the foster care system.

The delivery of her youngest daughter Cora, who I came to know over the course of our relationship, was decidedly different. During her pregnancy with Cora, Nikki stopped using illicit substances. When it came time to deliver her daughter, health care providers saw Nikki as a capable mother, and she was allowed to take her daughter home. In the weeks and months that followed Cora's birth, I was alongside Nikki for numerous appointments, hospital visits, and other errands. During my time with Nikki, I could see how she push herself to be engaged with the community and others and provide for Cora what she considered would bring a happy childhood. In many of the moments that I was alongside Nikki and Cora, I could see how hard it was for Nikki to live in poverty and under great economic duress. In one such moment, I remember talking to Nikki on the phone.

I received a call from Nikki at four in the afternoon.
She called stressed and tired, having to deal with income support and funding for her apartment. She said she was almost short on her rent by 50 dollars this month and that she was so tired of always being worried about money.
She said, "I never worried about money like this when I was an addict and working"
She talked about how she always had income coming in and that it was so much easier.
She said it wasn't fair that this was all happening when she was working so hard to stay clean and it was all at the 8th month of her sobriety.
I just stayed on the line while she told me this.
After she finished those sentences there was a pause and in response about illicit substance use,
I asked "but is that what you want?"
We talked about how challenging this month had been.

That she had fought through so much to stay sober.
That if she wanted to keep going, that she could do it.
Our conversation ended with Nikki stating that she just needed to vent. And that she would see me at the Outreach Halloween party.
Field Notes: October 30th

I saw Nikki and Cora at the Outreach Halloween party the next day – I was glad to see them. Nikki came in her ordinary clothes, but Cora was dressed as a little cat in a black onesie with whiskers drawn on her face. Nikki looked tired, but she carried Cora in her car seat with pride. It was her first time with Cora at the support agency, and she introduced her daughter to staff, outreach workers and peers. After the party, I drove Nikki to a school Halloween dinner; as we sat in traffic, we talked about how to make the perfect bannock. Nikki laughed, telling me she always uses her granny's recipe but that it never turns out as good. I reminded her she is still one of the best cooks I know. It had been almost half a year since I met Nikki, and at this point in our relationship, I was well aware of her anxiety in social situations. I was moved when I watched her be part of the Halloween dance and dinner.

Our medical visits were not always so positive. During one of our hospital trips, Nikki struggled with a difficult kidney infection. Curled up on a hard plastic chair, Nikki waited hours for care. Even while bent over from pain, Nikki instructed me gently on how to correctly measure and mix infant formula for Cora. During all of her discomfort, Cora was always Nikki's priority. She never asked for pain medication in the clinic, even as the IV antibiotics dripped slowly into in her arm and the pain seemed overwhelming. She worried about and knew she had to keep watch over Cora.

Defining Harm Reduction: Who Decides?

Over the course of our research relationship, Nikki and I became closer and I slowly learned stories of her family, as well as her past and present life. Just as Nikki learned about my life. With time, Nikki would sometimes call me for advice or support. Most often, these were difficult times for Nikki. On one such occasion, she phoned me after a relapse with injection drugs. She was in tears worried about the possibility of HIV transmission. Stress had become crushing; parenting her young daughter was overwhelming. She had used illicit substances as a way to cope. She needed a break she told me – yet, she was devastated.

I was hard to listen to Nikki that day; but I never doubted Nikki's ability to parent. I knew her daughter was safe in her care. Before Nikki had gone out that night, she had purchased groceries to make sure that there was food in the house. She had arranged for Cora to be under adult supervision. However, I learned over the phone, that while Nikki had put all the measures of safety in place for Cora, she had not been able to manage the same for herself. On the telephone, Nikki told me that she was worried; she had shared needles with someone she knew to be HIV positive. Terrified and scared, we talked.

Lessons in Access

Program Goals

Nikki connected to care services after she had used illicit substances, she relied on her previous knowing of who to call and what programs to access when she was using prior to Cora's birth. By the time she used illicit substances again, she had distanced herself from harm reduction programs. This gradual shift away from programing meant that only after the incident did she connect with these services again. Nikki had no longer participated in the programs as the programs she was part of provided services to people who were actively using; in many ways, she no longer fit the required program criteria and the goals of care providers no longer aligned with Nikki's goals. For Nikki one such goal, her decision to abstain from illicit substances use was important.

Abstinence as a Client Goal

Abstinence, or the enforced restraint against all substance use, as the ultimate goal for many clients, is not uncommon (Thurgood, Crosby, Raistrick & Tober, 2014). In their work, McKeganey and colleagues (2004) surveyed roughly one thousand individuals who use substances to better understand their motivation and goals when accessing services. They found that overwhelmingly, abstinence was the primary desire of both men and women who use substances. Abstinence as a goal, however is significantly impacted by the repercussions of pregnancy and motherhood.

Pregnancy has been shown to be one of the strongest motivating factors for women to stop or reduce illicit substance use. In the context of many women's lives, the decisions around substance use are the perception that abstaining may improve the likelihood of maintaining custody of their children. This perception continuous to persist, even so in North America, the guidelines now state that a history of substance use is not incompatible with the ability to parent (Wong et al., 2011). Despite this shift, illicit substance use in pregnancy is considered by many social services agencies as constituting child abuse and harm (Seddon, 2008). Abstinence as an individual goal becomes much less a choice than a necessity in this context.

Most women who use illicit substances in pregnancy face stigma, it is furthermore important to acknowledge the impact that racism has on Nikki's life. When we talked about her life, the impact of her heritage was always present. Nikki self identifies as Indigenous and the majority of strangers label her as Indigenous based on skin colour and appearance. The impact of this designation was that many times Nikki was treated differently than those around her. During hospital and care agencies visits and even in shopping centres, it appeared that care shifted when I was alongside. There were numerous times throughout our research relationship where I stepped in to advocate for access and services that Nikki should have received without my support.

Nikki's experience with care continues to be shaped by social norms surrounding abstinence that are not applied equally to individuals. In the context of substance use, Indigenous communities remain highly represented, with increased rates of use (Firestone, Tyndall, & Fischer, 2015). They face amplified scrutiny in the parenting of their children. In the Canadian context, Indigenous women remain significantly overrepresented in rates of child apprehension (Boyd, 2015). Research regarding substance use in Indigenous communities has demonstrated the impact that trauma, both historical and intergenerational, has on substance use (Ross et al., 2015; Shahram et al., 2106). Indigenous communities in particular, are under increased scrutiny, with emphasis on an individual's capability to parent (Salmon, 2010). Similar perceptions exist for those who use illicit substances. The necessity for Nikki to focus on abstinence should not be explored without recognition of the additional social views of women within Indigenous communities.

Women with past substance use are more likely to have social service involvement and intervention in future pregnancies. Mothers who use substances often believe as part of negotiating their identities that they have to disclose illicit substance use, to become a 'normal mother' (Radcliffe, 2011) or a good mother. Abstaining from substance use signaled a shift from an abnormal to normal mothering identity. All too often, "two mutually exclusive worlds are presented of chaotic drug use and ordered family life. As a way of staking a claim to motherhood, in order to manage the identity of substance misusing mother/ pregnant woman, women thus located themselves at different points on a career out of drug use" (Radcliffe, 2011, p. 987). In a recent study, exploring involvement of child protective services in the lives of women engaged in substance misuse treatment, Falletta and colleauges (2008), found that the fear of investigation was a barrier to accessing care, and that even with active engagement with treatment plans and programs, participants felt an inability to please or satisfy child protective services.

When Nikki and I discussed substance use, it was always in terms of past tense. Nikki often distanced herself from the category of current substance user and instead, reframed these conversations about former misuse. For Nikki, discussing substance use at an arm's length may also be representative of a way to reestablish a separate story of herself as a mother. Women who state abstinence as their goal may link this choice or conscious decision to achieve this goal, to the idea of 'normal mothering'. Nikki and I had many conversations around the idea of being a different kind of parent and providing a more stable loving home life for Cora than she had in her own childhood; in particular, Nikki wanted Cora to have a parent who was not actively engaged in substance use. Identifying abstinence, as both a goal and current life circumstance poses challenges for service delivery that focusses on harm reduction.

While the goal of harm reduction is not abstinence from substance use, it recognizes abstinence on the spectrum of goals (Rhodes & Hedrich, 2010). Yet, abstinence is often considered an adversarial approach to harm reduction programs. Philosophically many consider abstinence programs based around a moralistic view of substance use, while harm reduction is based on respecting individual choice and agency (McKeganey, 2011). This opposing view of harm reduction and abstinence programing further exacerbates an environment where agencies compete for the same health care dollars. The alternative, recognition of harm reduction and abstinence as collaborative goals for clients, offers individuals, women in particular, improved access to services. Offering a range of services to engage women on the spectrum of substance use, could improve care as well as partnerships with the patients (Ritcher & Bammer, 2000).

Program Structures

On the day that Nikki phoned me, worried about the risk of transmission for HIV, we talked about her fears. Nikki told me, she has been considered ‘at risk’ for years and nothing has happened. She had been in the same situation many times before, and during her years of illicit substance use on the streets but she had never contracted any blood born infections. Even more so, if she did get a diagnosis it was not anything more than what she was currently dealing with. She knew she would be able to manage – she had always been able to manage. Returning to her experience, Nikki’s recognition of the label of ‘at risk’, which she had carried for years, demonstrates the impact that these categories have on her identity. When Nikki told me about her ‘at-risk’ status, she acknowledges that shifting this categorization seemed unattainable, if she was connected with programs who centered on harm reduction.

Scholars working both in and outside of harm reduction challenge the discourse of individual versus societal risk. Rhodes (2009) argues that risk environments link many of the harms of substance use with the setting of drug consumption, rather than individual behavior. This perspective requires a shift in responsibility in mitigating harm from individuals who use illicit substances to the larger social and political institutions. The structural factors, political and economic, hold a key role in the social production of harm (Rhodes, 2009). It is important to acknowledge that social bias influences our perception of illicit substance use, with rates of use for populations already deemed ‘low-risk’ reflecting middle class and non-minority groups (Lester et al., 2004).

In the context of harm reduction services, the predisposition to focus on ‘high-risk’, in many cases the risk of those from lower socioeconomic status and marginalized populations further perpetuates the designation of substance use as a particular problem of a group or community. In critical analysis of Australian drug policies, pregnant women who used substances were over represented as an ‘at-risk’ population (Thomas & Bull, 2008). There was a lack of emphasis and support for harm reduction policies and programs that focused on women and their particular needs, and much of the discussion of risk framed the women as possible sources of harm to their unborn children (Thomas & Bull, 2018). The designation of particular populations as those in need or ‘at risk’ often further perpetuate exclusionary social practices (Souleymanov & Allman, 2016). Harm reduction policy has the ability to impact and influence individual choice and situates people in particular context. Safe consumption sites and NSP programs demonstrate value in reducing cost and access for individuals who use illicit substances (Wilson et al., 2015). There are concerns that with increased funding to support harm reduction programs instead of focusing on the larger societal issues, in particular poverty, discrimination, racism, and stigma that influence use, program goals will align predominantly with the substance use itself, rather than the underlying and often mitigating factors of illicit substance use. The assumption exists that the priorities of policy makers and women who use injection substances align (Olsen, Banwell, Dance & Maher, 2012), which for women like Nikki, is not always the case. In the long term, by focusing only on outcome measures – in particular rates of transmission, number of visits, and number of clients served, we risk overlooking the complex interplay of factors that present risk for people like Nikki. In Nikki's experience, racism, sexism, socioeconomic status, as well as housing needs, shifted her risk experience. Although Nikki received positive support from programs that recognized the value of community and relational based care, her experience was marked by the inability to change larger social factors.

Individual Needs and Complex Lives

Complex lives require comprehensive programing, which often does not fit into a neo-liberal model of healthcare that is focused on narrow outcomes and an emphasis on cost reduction. It also requires a recognition of the individual factors affecting people's daily life. Supporting women's health requires and acknowledges the forces that influence choice and access to services (Olsen, Banwell, Dance & Maher, 2012). For Nikki substance use and the associated harms were predominantly focused on life in general and use was often a way to cope with overwhelming life stressors - a response to circumstances. Others (Souleymanov & Allman, 2016) have also shown that substance use is a response to a social climate of exclusion, loneliness, and stress, and requires a different social response than if use was grounded in individual choice and agency.

Addressing complex needs requires the continued funding and support of collaborative programs that people can access over long periods of time. In Nikki's experience, social support provided by harm reduction programs were much more focused on holistic and psychosocial support than the services they directly offered – despite significant resources constraint of these agencies, they often provided comprehensive services. Nikki recognized the value in experienced staff and nonjudgmental care provided at the agencies she accessed. Islam and colleagues (2010) cautioned against the mainstreaming of harm reduction services into the larger health care system, partially due to the risk that many clients may find discomfort in the new delivery of care and loss of flexibility in services. It is disconcerting to witness harm reduction shift from care that recognizes complexity in a life to a model that is structured on managing symptoms or outcomes, or measured only in outcomes such as number of needles access or rates of blood born viral infections.

Returning to Experience

Over the time I have come to know Nikki, she has changed; she has grown into a confident mother and is now back at school with her three and a half year old daughter Cora keeping her busy. Nikki remains abstinent and many harm reduction programs would no longer consider her 'at-risk' to the degree that would allow Nikki to access their services. Her social circumstances could and do trigger substance use as a means of coping; it is in these moments that Nikki becomes at risk and yet, is left without access to meaningful and comprehensive services. It is necessary for those developing harm reduction practices and programs to remain attentive to the complexity present in the client experience and recognize the understanding harm across a life, rather than as a fixed or depersonalized category.

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The authors report no conflicts of interest. The authors alone are responsible for the content and writing of the article.

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Chapter 6: Implications for Nursing Practice

This research, and its focus on harm reduction, came during what many considered a public health crisis, with morbidity and mortality rates associated with opioids, specifically fentanyl, a synthetic opioid substance, continuing to rise (Kerr, Mitra, Kennedy, & McNeil, 2017). In Canada, governmental change and the need for programs to address substance use have led to increased support for harm reduction (Kerr et al., 2017). Yet, even with these advances in the support for harm reduction approaches to substance use, there are communities that remain underserved and highly stigmatized (Pinkham & Malinowska-Sempruch, 2008).

The lack of gender sensitive policies and programs have meant that many women continue to face additional challenges in accessing harm reduction services. Women who use substances face further scrutiny during pregnancy; they are viewed as harming not only themselves but also their unborn child (Boyd, 2015; Campbell, 1999). These social perception impact care and many women who use illegal substances during pregnancy continue to face discrimination, often leading to their avoidance of care (Cleveland & Gill, 2013; Selleck & Redding, 1998; Seybold et al., 2014; Wong et al., 2011). This is further complicated given that surveillance of substance use is heavily tied to discrimination of both socioeconomic status and racial heritage (Benoit et al., 2015). There is a documented trend of increased involvement of social services for mothers who use substances, are homeless, and/or Indigenous (Boyd, 2105).

The need for gender sensitive harm reduction programs mirrored my own experiences working in maternal health. I witnessed first-hand discrimination and a lack of care for women who disclosed substance use. For these and other reasons, this research centered on the experiences of women who disclosed substance use during their pregnancy or early postpartum period. This work focused on how Nikki, Renate, and Marilynn understood and defined harm within their life stories. Each participant shared stories of stigma and discrimination, but often their experiences and identities were not defined solely by substance use. Instead, their lives and their experiences of becoming mothers helped shape a more complex understanding of issues surrounding access and care.

Commonalities and Threads

The experiences of Nikki, Renate, and Marilynn and my time alongside each of them was central to this inquiry. They each faced challenges in their daily lives but their strength when managing these difficulties was inspiring. While Nikki always told me about her childhood and daily struggles, our visits were most memorable for Nikki's sharp sense of humour. I was alongside Nikki during moments of joy and happiness, but I also witnessed her struggles with substance use and loneliness. In these moments, I was moved by her ability to shift the focus back to Cora and the love they shared. Renate and her connection with Kayden was remarkable. In moments when I thought his lungs would fail and his life would end, Renate held onto hope. I was alongside to witness her unwavering belief that life can only get better. Marilynn had a dream for her future; she told me often of her desire to have her daughters grow up feeling loved. I watched, as she stayed positive and optimistic, even while fighting for custody of her children. With each of the women, I came alongside for errands and appointments and was welcomed into their homes and their worlds.

The articles: (*Re)considering Harm Reduction: A recognition of an individual life and gender; Lugones' metaphor of 'world travelling' in narrative inquiry* and *Waiting as performative and relational: A narrative inquiry study into the experiences of women who use substances,* reflected my relationships with Nikki, Renate, and Marilynn. In *(Re)considering Harm Reduction*, Nikki's experiences draw attention to the challenge of programs that do not acknowledge the complexity in her life. In sharing her experiences with harm reduction services, I make visible the gaps created in care when programs do not explore harm as evolving over time. Nikki's experience with harm reduction was not simple; her choice to access programs was complicated by stigma and gender norms. Exploring Nikki's experiences in relation to the services she accessed is a critique on programs that seek to focus on outcomes rather than the individuals they aim to serve. Acknowledging the complexities that exist outside the program parameters also draws attention to the need for integrated community services and continued advocacy, which focuses on human rights.

Lugones' metaphor of 'world travelling' in narrative inquiry drew from my experiences in writing Nikki's account. In this article, we explored how narrative inquirers take up Lugones' work and how this metaphor can be a means to understand the relational process in all phases of research. The importance of this work is twofold; firstly, it identifies how Lugones' metaphor serves to ground the work of narrative inquirers throughout the research process, both in the field and in the writing process. By sharing two different stories from Hiroko's (Kubota, 2018) and my respective doctoral research, we show how Lugones' metaphor is not bound by place or circumstance, rather it is a concept that is embedded in the relational work of narrative inquirers. This article focused on Nikki's account, but in all of my research relationships, Lugones' metaphor helped me think about how the composing of worlds occurred in different ways. Integrating the principles of playfulness and a sense of openness were critical to the development of Renate and Marilynn's narrative accounts. Working with Renate, given her desire to focus on the future, we playfully composed her account as a hopeful letter to her son. In the article, we also offer ethical ways to gain understanding into another individual's experience.

Lastly, the article *Waiting as relational and performative: A narrative inquiry study into the experiences of women who use substances* explored Marilynn and Renate's experiences. Waiting was an issue that all three women faced in their daily lives, but by highlighting two experiences in greater depth and the relational nature of these interactions, we explore a more nuanced consideration of waiting. While our paper focused on Marilynn, Renate, and my own waiting experiences, the importance of acknowledging the impact of power and other normative expectations could be relevant to care providers in other areas of care. In this paper, we explore waiting and draw attention to the relational nature of an experience that many understand as neutral. By focusing on waiting, we offer possibilities to understand and disrupt, often overlooked, practices that could allow for the development of relational care.

Across these three papers, there are links. Firstly, in all three papers, we are attentive to narrative inquiry's relational commitment. They all begin with experience and throughout each work, I attempted to learn and think *with* Nikki, Renate, and Marilynn's stories. Thinking *with* stories is a concept that draws from Morris's (2002) work. He outlines the difference between thinking *with* stories, a perspective that allows for a narrative understanding of experience rather than thinking *about*, a process that objectifies stories. Thinking *with* their stories meant that this work does not attempt to answer, generalize, or gloss over differences in the experiences of three women. It also meant that in the final research texts, narratives of participants were shared in rich detail as a way to develop readers understanding of the complexities within the women's lives.

The experiences of Nikki, Renate, and Marilynn are unique, as are the relationships we formed. For this reason, each narrative account was written in a way that represented shared meaning making. As co-researchers, we discussed the structure and aim of their accounts. Nikki asked me during a discussion on her narrative account "*When do I get to stop telling these* *stories*?" It was a question that led to us to write her account as letters. It was a choice we felt shared her experiences but allowed for more hopeful spaces. Renate and I chose to write her account in the form of a letter written to her son Kayden, while Marilynn wanted her account to be a way to connect with her daughters. Each of the accounts were developed in relational ways, but across all the narratives, there were also places for readers to come alongside and acknowledge their thoughts, experiences, and perceptions.

Secondly, throughout the writing process, I was aware of the tendency for narratives to fall into the trope of "the Hollywood plot", the softening and molding of a story to a desired outcome (Connelly & Clandinin, 1990). I worked hard to ensure that the stories of Nikki, Renate, and Marilynn, did not follow "the Hollywood plot" or come to a fixed ending. As narrative inquirers "[we] work with others to attend to lives in the making, lives in motion" (Clandinin, Lessard & Caine, 2012, p. 8). All of the participants' narrative accounts acknowledge the times we came together in research. While acknowledging each participant's history, as well as my own, I stayed open in the narrative accounts to different ways of re-telling experiences. Similarly, we stayed open to different possibilities; as Marilynn reminds me: "*I know that I will change.*" The lack of finite conclusions is a relational choice and allows for possibilities in the future directions of Nikki, Renate, and Marilynn's stories, as well as my own stories.

All three papers return, at least in some ways, to the justifications that I set out when I began this research work. The papers all provide narrative perspectives on issues that are relevant to research and nursing care. In the following section, I will expand on the implications of this work for nursing and other caring disciplines by returning to my personal, practical, and social justifications for this research.

Justifications

At the beginning of this dissertation, I outlined the importance of this research in relation to the personal, practical, and social justifications for this narrative inquiry study. These justifications served as guideposts throughout what was a four-year academic journey. I returned often to reasons behind my return to graduate studies, wondering about what factors could change practice and society. Understanding the social justifications in relation to Nikki, Renate and Marilynn's experiences, however, offered me beginning places to do so. By thinking with their narratives, and an understanding of some the complexities within a life, we can attempt to address much larger social issues in program development, education and care. Beyond the broader implications for this research though, it has deeply changed me both as a person and as a care provider. I begin this section by returning to my personal justifications for this work.

Personal Justifications.

Returning to graduate studies began, in many ways, with my very first patient in labour and delivery. The story of the mother, judged, silenced, and in pain from a cesarean section, was a story I returned to often during my graduate work. Yet, on my first day as a student nurse, I only thought about my experience in relation to being part of a team. I did not consider the implications of her hospital visit and of how they were indicative of larger problems, issues within a health system that judged and stigmatized people, a system that allowed people to work based on their assumptions. Instead, it was only later, after similar deliveries, that I started to question the hospital structure and who I was within this. I began to notice processes that prevented, rather than helped relational care; processes that allowed me to honor my assumptions, rather than question what I had come to know. I gradually started feeling complicit in a care system that stigmatized and discriminated against particular patients, including women who disclosed substance use (or were suspected of using substances).

This experience influenced many of the questions I asked in my research. Thinking back to who I was in this experience has also served as an anchor; I return to this story as a way to recognize how I have shifted as a person throughout this academic journey. My time alongside Nikki, Renate, and Marilynn has been a deeply educative experience. Learning who they were both within and outside of a care setting led to a deeper understanding of how place, as well the social context, can shift a person's experience. It has helped me be more attentive to existing powerful structures within care settings. It also helped me understand the temporality of individual experiences, and how stories continue to carry forward into their lives, homes and communities.

Shifting Focus.

These understandings have changed how I interact with patients. Over the course of the study, I have found ways to slow down my practice and to look for, and find, the spaces for relational care. I returned to Greene's (1995) idea of seeing "big", a perspective grounded in the idea of attempting to view a life in an expansive rather than reductionist view. Seeing "big" is a challenge to the tendency for people to see "small", a perspective that begins by looking through a technical or institutional lens, favoring components rather than a complete person. This idea of seeing "big" and its ethical implications now guides my care, as I try to care from a relational and narrative place, rather than one focused on checklists and outcomes. This perspective has helped me shift my care to attend to each person I meet, rather than rely on assumptions, or return to 'cover stories' (Clandinin et al., 2015). When I ask a question, I try asking it in a way and with the intent that allows multiple answers. I know have a stronger sense of how my privilege shifts care. I think back to Marilynn's downcast eyes in her doctor's office and Nikki's hunched shoulders in her hospital appointments. I remember coming alongside Renate in the NICU, only to recognize that once I became a visitor and not a nurse, how arbitrary many of the hospital rules can be. These memories shift how I approach patients. Through these memories, I have learned to see that many aspects of my work, which to me feel routine, are often understood or experienced by patients in very different ways.

I think often about Greene's (1995) idea of seeing "small,", and I reflect back to opportunities I missed to connect in relational ways with clients, focusing on intake forms rather than a conversation about a woman's fears and concerns. In this sense, I think back to Nikki's words about care providers "*they just care about what's going on right now, 'cause we're probably just a statistic right."* I wonder about who I am working in labour and delivery with and Greene's (1995) statement about similar feelings that teachers can have in their practice, "How does a teacher cope with this? How is she or he to avoid feeling like a chess piece or a cog or even an accomplice of some kind?" (p.11).

Shifting this perspective has meant focusing on seeing "big" and beginning with the person. It has meant starting with each patient and their experiences as a source of knowledge, not a checklist of risk factors. It meant, for example, that I needed to get to know Marilynn and to come alongside her in meaningful ways, before ever stepping into her home. Throughout this research process, the commitment to relational ethics and understanding of a narrative view of experience has changed how I interact in moments of care. I ask questions that open, rather than close, possibilities, and I present not as an expert, but as a person who cares. I try to be myself.

A Return to Narrative Beginnings.

It is with this self-awareness that I think back to the story of my first patient. Five years have passed since this experience and I am at ease in hospitals in ways that I was not as a student nurse. Now as a nurse with experience and a researcher who has been alongside women, I wonder how I would care for her differently. If this mother were to come into the hospital today, she likely would still be sent for a cesarean section. I may not be able to change the care of the anesthesiologist, but I recognize that asking questions only to expect one answer reduces a person to a problem. With this understanding and my awareness of the complexities related to maternal substance use, I would try to find moments to connect to others, as I did with Marilynn and Nikki in my car. I would remember to speak with kindness and care and to not foreclose a sense of possibility. Perhaps this is to challenge, what Nikki said: "*it just seems like everything was just categorized or just put under like one specific labeling*". Through spending time with Nikki, Renate, Marilynn, and their children, I learned to slowly think about my own mother, and the mother I hope I will be one day. I learned to be more patient, as I learned to write slowly and with care – it is not easy to tell the story of another, without a sense of othering, without a sense of 'fixing' their story. I am grateful that those I worked with not only taught me patience, but also extended this patience towards me as I learned.

Practical Justifications.

While this research has changed who I am and am becoming on a very personal level, it had a profound impact on my practice as a nurse. Through inquiring into the experiences of Nikki, Marilynn, and Renate, I recognized the possibilities that open up when care providers shift towards a narrative understanding of experience, grounded in relational ethics. Since beginning my doctoral work, I have gained greater confidence in conversations with colleagues when they tell me how frustrated and angry they are with patients who do not mirror, in their eyes, a ‘good’ patient. In the moments where a conversation with colleagues is possible, I now make an effort to explore what others understand as a ‘good’ patient, and I introduce and explore the idea that lives are always in the making, always filled with possibilities. I now intentionally seek these conversations. I also recognize that structural issues, politics, and history shapes the lives of people and the practices in which we can engage as care providers. The changes in my own practice have led me to reflect on my university experience, and I often wonder, what needs to occur in nursing education to help others understand the lives of people in their complexity?

Educative Spaces.

Throughout my four-year Bachelor of Science in Nursing degree, the social determinants of health were emphasized. However, most of the time, these determinants were explored as a neutral concept or factor influencing health, not one embedded within the context of a life. I think back to times when I was walking down the aisles of groceries stores with Nikki and the time we had to wait in line to return a broken stroller, the times when I knew that money was scarce. I remember the worry about the cost of housing, clothing, and transportation. These issues shaped all of the women’s lives, and were part of their experiences of accessing care, and also part of their experiences of racism and privileges that were denied to them. I no longer believe that we can disconnect the social determinants of health from each life. Instead, I recognized how experience is shaped by these determinants in profound ways. The connection between these determinants of health and a life lived is much closer and important to recognize. There is a need to create educative spaces on how to work within and from a relational ethical stance. The following section will address five dimensions that guide relational ethics in narrative inquiry, exploring both how these dimensions were present in this research and how they offer opportunities to shift education and practice.

Playful Spaces.

One key dimension of relational ethics outlined by Clandinin, Caine, and Lessard (2018) is the need for playfulness, in addition to the dimensions of imagination, improvisation and 'world-traveling'. Together these four aspects represent a way of approaching situations and experiences with a sense of openness and possibility. Drawing from the work of Lugones (2003) there is an acknowledgment that in order for 'world-traveling' to occur, researchers and participants need to share a sense of mutual vulnerability, be comfortable with being the fool, and with not being self-important. This dimension was integral to the research as Nikki, Renate, and Marilynn all shared with me a history of being constructed in particular ways by caseworkers or care providers and that they had few opportunities to disrupt these perceptions. Our time alongside each other allowed for constructions of different identities. During one visit with Nikki, as she lay on an emergency room cot waiting for an assessment for kidney pain, she asked me to mix a bottle of formula for Cora. "Of course" I replied before immediately stating that I had absolutely no idea what to do. Nikki laughed when I told her this and smiled before explaining the steps. Only with Nikki's guidance and expertise could I help with Cora. In this moment, a playfulness was present in our interactions that allowed our relationship to strengthen. Shortly after Nikki taught me how to prepare Cora's bottle, she shared for the first time her past experiences in a similar space. She told me that as a child she had repeated visits to emergency rooms related to sexual abuse, but that care providers repeatedly dismissed her symptoms and concerns. For Nikki, the emergency room was a place where she felt helpless and afraid and it is doubtful that this disclosure would have happened had I remained fixed to the role of expert 'care-provider' or researcher.

Introducing the condition of playfulness and its required vulnerability into my work as a nurse and researcher was not easy for me. It required a reimagining of who I was as a person and an acknowledgment that the parameters we place around particular roles often come at a cost. It was one of the most meaningful areas of growth for me, both personally and professionally. Introducing playfulness and imagination in nursing education could provide ways to imagine care practices in a new way.

Spaces to Move Slowly.

For Clandinin, Caine, and Lessard (2018), the dimension of moving slowly and in ways that allows for listening and living with stories draws on the teachings of Elder Isabelle and "the importance of slowing down so we could hear our own heartbeat, our own stories as they were embodied in us" (p.100). This dimension recognizes that relational ethics takes time and patience. The commitment to moving slowly and in ways that allow space to listen was present in my relationship with Marilynn. I spent months picking her up from her front porch. Together we ran errands and shared conversations, but it was only when we began to understand each other in relational ways that Marilynn invited me into her home. Marilynn's choice to invite me into her home was possible only once we had negotiated our research landscape and found ways to come alongside one another in meaningful ways. The ability to move slowly in current care environments is not easy. It requires patience that is challenging to find in fast-paced hospital floors and clinic spaces, but it is not impossible. It involves reimagining tasks and their associated sense of busyness into small moments to move slowly. In this space, tasks become opportunities where relational ethics can be embedded in each interaction.

Spaces for Wide-Awakeness.

The dimension of wide-awakeness to the ongoingness of experience returns to Greene's (1995) work on wakefulness (Clandinin, Caine & Lessard, 2018). This condition of relational ethics focuses on the belief that it is important to attend to our own worlds and experiences as researchers amidst our unfolding research (Clandinin, Caine & Lessard, 2018). The mutual nature of wakefulness means that both researcher and participant are under study. In much of my undergraduate education, I was asked to think about case studies. The problem with this is that case studies represent a way of thinking about problems that disregard care providers as agents or actors who can influence or disrupt a patient's health care experience (Clandinin, Cave & Berendonk, 2017). A shift to a relational ethics in educational experiences offers possibilities to recognize that the experience of care provider shapes their interactions with patients (Clandinin, Cave & Berendonk, 2017). This wakefulness encourages care providers to reflect on who they are amidst the relationships with patients and challenges seeing patients as cases to be analyzed and/or fixed.

Spaces of Uncertainty.

Engaging with a sense of uncertainty and acknowledgment of not knowing is a dimension of relational ethics that requires an attentiveness to the tensions present in research and when engaging in relational ways (Clandinin, Caine & Lessard, 2018). There were numerous periods in this research when there was a deep sense of uncertainty in responding to the stories of the three women. There were many moments spent alongside Renate when we thought Kayden would die, or moments when I worried Marilynn would never hear the news she wanted from her lawyers. These were tangible moments of uncertainty, but there were also moments of uncertainty I could not name so clearly – moments that didn't feel quite right, moments where I felt uneasy, where I was unfamiliar with places, contexts, and people. Some of this uncertainty lessened over time, but much of it remained, allowing me to stay wakeful to the multiple worlds I entered throughout my research.

Spaces for Ethics to be Understood as Lived Embodiments.

The last dimension of relational ethics is the acknowledgment that people carry embodied knowledge, shaped by their past stories, as well as the history that is shared with their family and community (Clandinin, Caine, & Lessard, 2018). This dimension and its grounding in narrative inquiry's recognition of place, as central to inquiry, helps me understand that ethics are embedded in particular landscapes. These spaces could be places of care, hospitals or clinics, or landscapes of homelessness and poverty. Across all of these places, researchers must be aware of how theses spaces are embodied within the experiences of participants. For Marilynn, this was evident in the shift of her demeanor when we entered clinic and hospital spaces. Her shoulders hunched and her gaze shifted to the floor. She was a different person in these spaces, and her physical shift signaled the embodied stories she carried around care, apprehension, and maternal health services. It was an important understanding that was possible because I was able to accompany Marilynn to places where she received care settings – in these moments; I understood the impact that history and place have in each patient's experiences.

Shifting Educative Spaces.

Together the five dimensions of relational ethics offer beginning places to imagine how education and practice could be different. Nikki, Renate, and Marilynn continue to face challenging social circumstances that will not be solved by shifting practice and education alone. Instead, addressing larger issues such as poverty, stigma, and racism will require broad social changes. The following section addresses these questions of justice and equity by returning to the social justifications that grounded this research.

Social Justifications.

When I began this work, I separated the social justifications into two sections: social action and theoretical justification. As I have moved forward throughout my academic journey however, I have come to see them as much more intertwined and that it is important to see the deep connection between social justice issues and individual lives. “As long as people remain constructed as problems, and are known first and foremost in relation to the issues or problems they face, social justice practice will be difficult to achieve” (Caine et al., 2018). While it was difficult for me to see this connection at first, it is Nikki, Renate, and Marilyn who have taught me how important it is to see them as people first, and not first as a cause for social justice.

Narrative inquiry is both a methodology and phenomenon (Clandinin, 2013). Recognizing that people live and understand their lives narratively, narrative inquirers begin with experiences as a source of knowledge, specifically recognizing knowledge is situated in time (temporality), social dimensions (sociality) and place. While all research methodologies follow ethical standards set out by Research Ethics Boards, narrative inquiry is also guided by relational ethics and an ethics of care. This commitment to relational ethics brings sensitivity to the sharing of stories that may otherwise be overlooked, silenced, or underappreciated. Moreover, this collaborative process serves as a source for comprehensive knowledge necessary for ethical care (Bergum, 1994). Relational responsibility and the conditions of mutual vulnerability and openness allow a place of belonging for both researcher and participant to develop (Clandinin, 2013). My own ability to share my personal experiences within a study has been challenging, though it has been some of the most rewarding moments of the research. I would not have the opportunity to understand and be a part of Nikki, Renate, and Marilynn's experiences had I not shared my own stories. It signals a change in how people can engage with one another, one that is grounded in a responsibility of recognizing the diversity of human life, rather than a singular focus on othering.

The narrative accounts of Nikki, Renate, and Marilynn, and how I was positioned alongside them, demonstrate that many of the challenges they faced were layered and complex and their lives consisted of much more than these challenges. Understanding their experiences is increasingly necessary in the development of programs and services that claim to serve them, however, are often designed based on their perceived challenges. Currently, harm reduction has gained traction and social acceptance; however, this has yet to translate to different care for many patients. There are documented trends of increased involvement of social services for mothers who use substances, are homeless, and or Indigenous (Boyd, 2015). Many women who disclose substance use continue to face stigma and discrimination in care and their needs remain under addressed in a care system that prides itself on patient centered care.

Harm reduction must be understood in relation to an individual life rather than as a stand-alone service. It too must be understood that care providers have agency within the narrative of substance use and treatment. While programs such as safe consumption sites and needle exchange programs are one aspect of harm reduction, when programs are described solely on the outcomes or deliverables, the connections and relationships between care providers and clients are often overlooked. Nikki told me once "*we're probably just a statistic right or just you know they kinda teach you through a textbook how some of these families are*". It was a statement that contrasted the parts of harm reduction that each of my participants told me were important. They shared that they accessed services not because of supplies but because of the meaningful and honest connections that they made with caseworkers and staff.

The choice to combine theoretical justifications and social action is rooted in the belief that by shifting to a narrative understanding of experience, social change is possible. The stories of women with similar experiences have been present in care, but they continue to be overlooked and are rarely considered outside the dominant narrative of 'bad' mother. This research's focus on Nikki, Renate, and Marilynn's stories is significant in that it does not aim to provide answers to the questions of inequity that each woman face. Instead, by inquiring into their experiences, there are opportunities to challenge the dehumanizing and unethical care they receive and imagine different possibilities for the future.

Touchstones of Narrative Inquiry

Throughout my research, I returned often to the twelve qualitative touchstones of narrative inquiry (Clandinin & Caine, 2012), to ensure that the research was progressing in ways that were consistent with the ontological, epistemological, and ethical tenets of the methodology. The twelve touchstones are: relational responsibilities; in the midst; negotiation of relationships; narrative beginnings; negotiating entry to the field; moving from field to field texts; moving from field texts to interim and final research texts; representing narratives of experience in ways that show temporality, sociality, and place; relational response communities; justifications—personal, practical, and social; attentive to audience; commitment to understanding lives in motion.

Attending to these touchstones was, and is, an iterative, process. Rather than a linear checklist, these touchstones layer upon one another and are interwoven together. The touchstone of relational responsibilities does not stand-alone; rather, it supports and informs negotiations within research relationships. Just as a commitment to understanding lives in motion, leads to the writing of final research texts without foreclosing for lives and relationships to continue. These touchstones have shaped my writing and thinking about experience, and it is important to acknowledge the value that these tenets had in guiding my doctoral research.

Conclusion

This dissertation includes three articles. Each article was attentive to narrative inquirers' commitment to recognizing that people live stories lives. Across the articles, there is an acknowledgement of the relational responsibilities that shape the work of narrative inquirers, care providers, and people in relation.

Nikki, Renate, and Marilynn continue to grow and change as mothers and their lives continued long after this research study ended. Cora started day programming and preschool, and Nikki has welcomed a son into the world. She continues to struggle with poverty. While she hoped that she could continue with schooling, the stress of raising children and attending classes meant she had to stop courses for now. Renate has a new partner, and they moved into a beautiful home together. They are currently raising Kayden with her partner's children. Kayden has been healthy since his discharge home, and my phone continues to receive messages and photographs of their smiling faces and updates on his growth. Before Marilynn and I ended our research relationship, she found out that she would be gaining increased custody of her girls. She moved the family from the blue house on the corner to a bigger home. They will need the space in the coming months and years as she recently found out she was pregnant again. While their lives unfold, so much has happened in my own life as well. As Clandinin (2013) has pointed out '[n]o one leaves a narrative inquiry unchanged" (p. 201). The experiences alongside Nikki, Renate, and Marilynn's, have forever changed who I am as a person. It has deepened my commitment to think *with* stories, and my commitment to work with people in ways that forefront experience as a source of knowledge.

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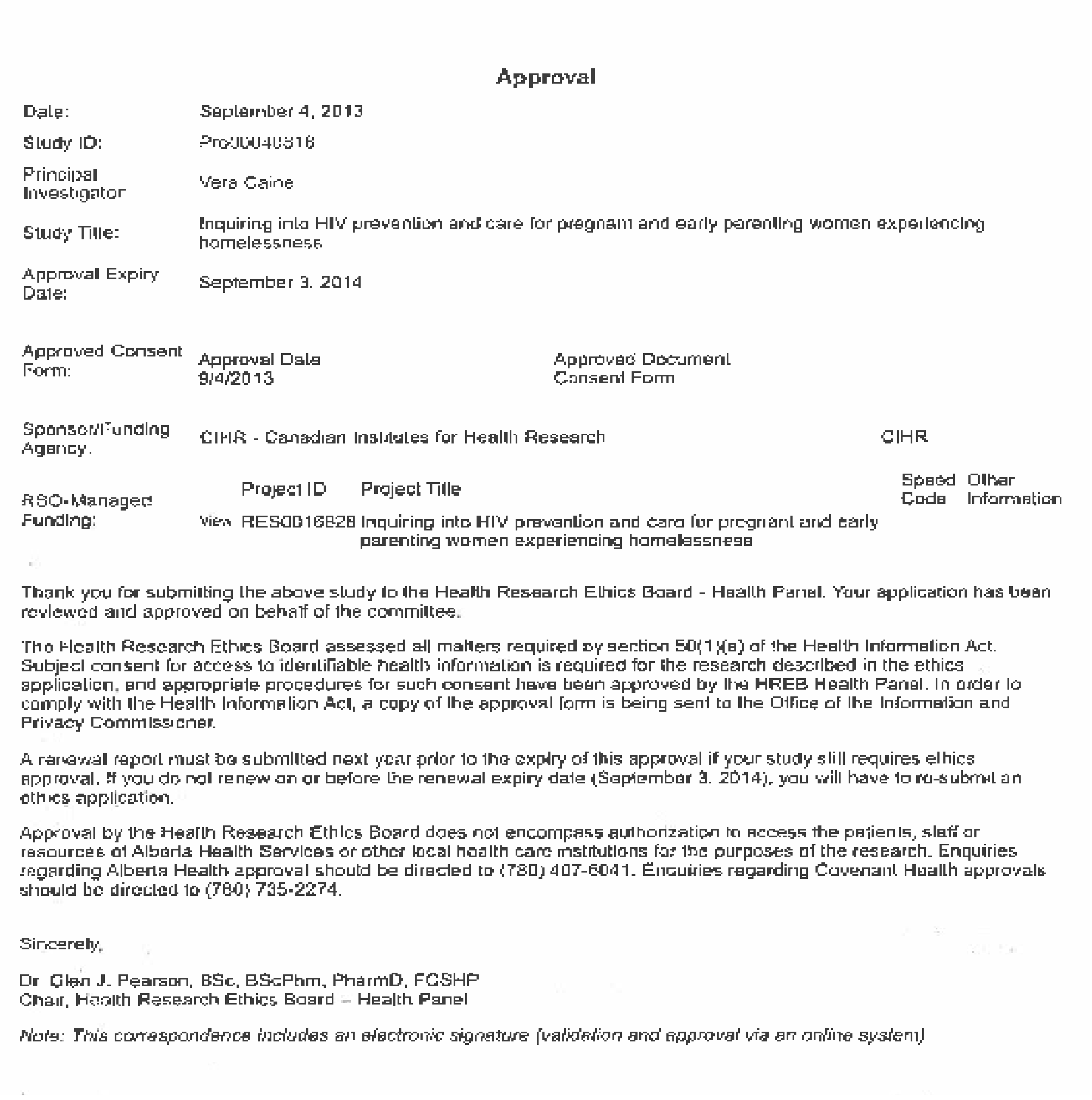
Appendix A

Ethics Approval



Approval

Date:	September 4, 2013	
Study ID:	Pro00040316	
Principal Investigator	Vera Caine	
Study Title:	Inquiring into HIV prevention and care for pregnant and early parenting women experiencing homelessness	
Approval Expiry Date:	September 3, 2014	
Approved Consent Form:	Approval Date 9/4/2013	Approved Document Consent Form
Sponsor/Funding Agency:	CIHR - Canadian Institutes for Health Research	CIHR

RSO-Managed Funding:

	Project ID	Project Title	Speed Code	Other Information
View	RES0016828	Inquiring into HIV prevention and care for pregnant and early parenting women experiencing homelessness		

Thank you for submitting the above study to the Health Research Ethics Board - Health Panel. Your application has been reviewed and approved on behalf of the committee.

The Health Research Ethics Board assessed all matters required by section 50(1)(a) of the Health Information Act. Subject consent for access to identifiable health information is required for the research described in the ethics application, and appropriate procedures for such consent have been approved by the HREB Health Panel. In order to comply with the Health Information Act, a copy of the approval form is being sent to the Office of the Information and Privacy Commissioner.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date (September 3, 2014), you will have to re-submit an ethics application.

Approval by the Health Research Ethics Board does not encompass authorization to access the patients, staff or resources of Alberta Health Services or other local health care institutions for the purposes of the research. Enquiries regarding Alberta Health approval should be directed to (780) 407-6041. Enquiries regarding Covenant Health approvals should be directed to (780) 735-2274.

Sincerely,

Dr. Glen J. Pearson, BSc, BScPhm, PharmD, FCSHP
Chair, Health Research Ethics Board – Health Panel

Note: This correspondence includes an electronic signature (validation and approval via an online system).