A Narrative Inquiry into the Experiences of Accessing and Participating in Healthcare of Syrian Women who Arrived in Canada as Refugees

by

Alix Malloy

A thesis submitted in partial fulfillment of the requirements for the degree of

Master of Nursing

Faculty of Nursing
University of Alberta

Abstract

Gaps in healthcare exist for newcomers, with many experiencing poor quality healthcare compared to the general population. Immigrant and refugee women are particularly disadvantaged and often experience unmet health needs. Despite this, there is a lack of research inquiring into the experiences of refugee women when accessing and participating in healthcare in their host country. I conducted a narrative inquiry study into the experiences of two Syrian refugee women of childbearing age when accessing and participating in healthcare in their host country. Narrative inquiry is a way to inquire into experiences as stories lived and told. By attending to these stories, I gained a better understanding of the complexities surrounding their experiences of healthcare in Canada. By engaging in telling and retelling these stories across time, place and social contexts various narrative threads emerged. The threads that resonated across the experiences of both participants included intentionality and *good* care, as well as agency and action.

Preface

This thesis is an original work by Alix Malloy. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “A Narrative Inquiry into the Experiences of Accessing and Participating in Healthcare of Syrian Women who Arrived in Canada as Refugees”, No. Pro00117091, February 01, 2022.

Acknowledgements

This work would not have been possible without the time and contributions of the research participants and I am incredibly thankful for their willingness to take part in this research project and for the knowledge they shared. Their stories will forever be part of my own.

I would like to express my deepest gratitude to my supervisor Dr. Vera Caine for her continuous support, guidance and invaluable feedback through every stage of this Master's degree and research project. I am extremely grateful for my committee members, Dr. Simmee Chung, Dr. Rebecca Gokiert and co-supervisor, Dr. Dianne Tapp, for their insights, and generous provision of knowledge and expertise. I would like to extend my sincere thanks to Dr. Randolph Wimmer for his time and counsel as part of my defense committee.

I would like to thank my family and friends for their encouragement and support throughout my studies.

Table of Contents

List of Abbreviations

Abbreviations	Unabbreviated
BScN	Bachelor of Science in Nursing
BVOR	Blended Visa Office Referred
CSS	Catholic Social Services
ED	Emergency Department
GAR	Government Assisted Refugees
NCHC	New Canadians Health Clinic
PSR	Privately Sponsored Refugees
RHC	Refugee Health Coalition
U of A	University of Alberta

CHAPTER 1

Narrative Beginnings

Early Childhood Experiences

Language and communication have been important concepts throughout my life. My parents placed me in French immersion starting in kindergarten. I don't remember many specifics of learning French as a second language at such a young age, but I do remember the joy of learning common words and being able to point at things and know the French translation.

The summer after completing first grade, my mom had the opportunity to attend a conference in Paris, France and so my parents decided to turn this work event into a family vacation. The morning of departure day, my dad was involved in a workplace accident that led to him badly breaking three of his fingers. My parents decided not to cancel the trip and equipped with a few finger splints and some bandages we embarked on our journey to Paris that evening. Fortune was not in our favour as when we arrived in Paris our luggage was lost and did not arrive for several days. As the medical supplies for my dad's fingers were packed in our lost luggage, we needed to purchase more.

My parents did not speak French, and as most Parisians speak English this was mostly a non-issue; however, I distinctly remember being at the counter of the pharmacy and listening to my parents desperately trying to communicate their medical supply needs with the clerk. The item in question was tape. My parents were trying to communicate anyway they could think of, mimicking the action of using tape, looking to see if they could find tape or something that resembled it so they could point at it. I can remember the confused and apologetic look on the clerk's face as it was evident, she had no idea what they were asking for. I don't know if I was asked or if I was feeling brave enough to

speak up, but tape was one of the French words I knew. I recall the clerk laughing and proclaiming “Oh! Papier Collant!” when we were finally able to communicate our need for such a common object. I remember feeling very elated that I was able to *save the day* and help in a time of need (and slightly smug that I could do something my parents could not). Little did I know the impact this experience would have on me many years later. It provided me a living example of how communication can affect health and wellbeing and directly impact the care one receives.

After completing secondary school, I pursued a Bilingual Bachelor of Science in Nursing (BScN). While all determinants of health were a focus of this program, an emphasis was placed on the impact of language and marginalization on health and wellbeing. This exposed me to existing barriers in healthcare for populations experiencing structural marginalization and deepened my understanding of the importance of accessible, culturally safe healthcare. I found this area fascinating and became passionate about improving access to healthcare for marginalized and underrepresented populations.

A Feminist Turn and a Turn Towards Women’s Health

After completing my BScN, I began working full time in a large Urban Emergency Department (ED). Around the same time, I began to learn more about my personal identity as a woman, as well as a feminist. I was beginning to ponder more deeply the injustices women experience as part of living in a patriarchal society. The evidence was everywhere, and honestly, I was angry. Unattainable beauty standards, and societal pressures aside, I was struggling with entering a female dominated profession in a society that gives little value to women’s work. As well, I noticed inequalities in

relation to the treatment of women compared to men within the healthcare system. I have seen women have the severity of their symptoms be downplayed or overlooked or labelled as mental health issues, when compared to the same issues experienced by men.

Throughout my career as a registered nurse, I have experienced working with diverse populations and became acutely aware of gaps in care and existing disparities for different groups of clients accessing care. Perhaps it was a combination of my interest in language and communication as well as my bourgeoning interest in feminism, but I noticed that some population groups, including immigrant and refugee women appeared to be particularly disadvantaged. I became aware that often the health services offered did not fully meet the client's specific needs. Some of the identified challenges that contributed to these gaps in care that I noticed, included a lack of knowledge regarding existing health services and appropriate access of those services, as well as cultural and communication barriers with little utilization of interpretive services by healthcare providers.

Working in the ED allowed me to experience building trust and therapeutic relationships with many different clients. However, I would often leave feeling that there was more I could have done, worrying that I was not able to provide the most culturally safe care available. I also worried that while the client may have nodded in agreement to treatment plans, they might not have fully understood the health information that was being provided to them. As a result, I may not have fully understood their health concerns, therefore negatively impacting their health. As well, I would sometimes find myself feeling frustrated when emergency healthcare was being accessed for non-emergent health needs and then would feel guilty when I realized that our healthcare

system was most likely never explained to people, particularly those who had newly arrived in Canada.

Seeking to Understand Diversity

There have been many moments in my career when dealing with diversity that have left me feeling uncomfortable or uneasy. For example, the large urban hospital that I worked in did not provide specific obstetrical or gynaecological services and often immigrant/refugee women would not be aware of this. They would present to the ED in search of these services while experiencing miscarriages or other pregnancy concerns. We would try and most often fail to convey that we would do what we could to provide services as we did not focus on maternal health at our hospital. Frequently, patients would vocalize that they felt they were not being properly cared for, and I'm sure this added to their emotional distress during these difficult situations.

As I think about diversity, I am reminded of another experience, one where I was working with a young Indigenous mother and her child. Upon entering the room and introducing myself to the mother and her child, it was apparent that the mother did not want to answer questions from the medical staff. She appeared very angry and was very vocal in expressing that she and her child were experiencing racism and discrimination. It became apparent that she was afraid that her child would be treated differently or provided inadequate care. Reminders of the mother's trauma and their encounters with discrimination and racism were very present. Building a therapeutic relationship with patients, especially in such a high stress environment, has always been extremely important to me in my work as a nurse. I feel that lessening someone's anxiety and fear while they navigate the healthcare system is part of providing ethical care. In the moment

of entering a relationship with the Indigenous mother, I knew it was important for me to take the time to listen to her concerns. As well, providing detailed answers and explanations to assist with her understanding of how her and her child's trajectory might unfold was paramount. Her concerns centred around wait times and interventions for her child, feeling that since they had to wait for treatment that she was being treated unfairly. She did not know or understand the reasons why there was a need to wait for an intervention. All she had been told was that the intervention could not be done right away, which led her to believe that we were not helping her child. I took the time to explain to her what the treatment would entail, the reasons for the need to wait for treatment due in fact to patient safety and success of the treatment. I explained to her my nursing assessment and what I was watching for, what each wire connected to her child was monitoring, and that even if I left the room, the monitor transmitted her vital signs to a big screen outside the room so we could continue to monitor her child. At many different points in time during her stay in the ED I took the time to answer any questions, explain the work that was being done, and why certain steps were necessary for care. When she was told she would not be let in the procedure room during the intervention, I could see the fear in her eyes when she asked, "*why not?*" The medical resident, unsure how to answer this question, said in return "*well no one is.*" After the resident left, I can distinctly remember her looking at me, asking *"is that true?"* While I took the time to explain to her why this was necessary, she asked me again *"who will be watching her?"* I just remember thinking *"no wonder she is terrified"* - while the medical procedure itself was explained, the rest of the process was not. I decided to explain the medical process, and that many people would be in the treatment room with some specifically assigned to

watch her child, I saw that the mother's worries lessened. By taking the time to explain this, she felt more comfortable moving forward with the procedure, and with letting the team take care of her child.

Throughout my nursing career, I have become more and more aware of inequities and gaps in care that women and racialized people face within the healthcare system. Working with a diverse population has continued to open my eyes and provides me with living examples of the effects of intersectionality and the impact that race and gender have on the quality of healthcare one receives. Through these encounters, I have become more aware of my own privilege as an educated, white woman, familiar with this healthcare system (and a part of it). I think back to personal experiences that have left me feeling frustrated and unheard as a patient. Of having to push for certain tests to be ordered, to have my concerns investigated or to advocate for the treatment and care that I felt was in my best interest. This makes me wonder how someone who is not familiar with the language, the environment, and the healthcare system would be able to navigate the healthcare system, and advocate for themselves. I hope to be able to better understand the experiences of refugee women from Syria who are of childbearing age when accessing healthcare services in order to contribute to bridging existing gaps in care.

Turning Towards the Research Puzzle

Purpose of the Study

The purpose of this study was to better understand the experiences of refugee women from Syria of childbearing age when seeking healthcare. Newcomers are important members of Canadian society and contribute greatly to Canada's population, economic and cultural growth (Government of Canada, 2020a). Gaps in healthcare exist for newcomers, with many experiencing poor quality healthcare compared to the general

population (Ahmed et al., 2016; Filler et al., 2020). Refugee women are particularly disadvantaged and often experience unmet health needs (Filler et al., 2020; Refugee Health Coalition, 2020). An important aspect of this research was to simultaneously explore the participants' previous experiences, understandings, and personal beliefs that contribute to their decision-making when seeking and accessing healthcare services in their new host country. The knowledge gained by the study identified what experiences and beliefs influence the access of healthcare services, as well as existing gaps in care with the aim to inform solutions.

Literature Review

Syrian Refugee Crisis

Since 2011, over 6.6 million Syrians have fled their country of birth, with another 6.7 million remaining internally displaced, making this the world's largest refugee crisis (USA for United Nations High Commissioner for Refugees, 2021). Including refugees, greater than two thirds of Syria's pre-war population of 22 million have required humanitarian aid, whether they have remained inside the country or fled (Mercy Corps, 2021). The Syrian refugee crisis was a result of violent governmental response to protests against President Bashar al-Assad's government (Mehta, 2016). In March of 2011, fifteen students were arrested and tortured for writing anti-government graffiti on city walls (Mehta, 2016). This event sparked public action and Syrian residents responded to this event with peaceful protests. Although these protests were peaceful, they were met with significant violence by government security forces (Mehta, 2016; Mercy Corps, 2021; USA for UNHCR, 2021). Conflict continued to escalate leading to a civil war, and many Syrians were forced to flee their homes, with many experiencing displacements more than once (Mehta, 2016; Mercy Corps, 2021; USA for UNHCR, 2021). Many countries

have welcomed Syrian refugees, with Lebanon, Jordan and Turkey housing the majority (Mercy Corps, 2021).

Despite the decade of time that has passed, the crisis in Syria persists, and hardships continue to be experienced by people in Syria, which now include the added impact of the COVID-19 pandemic (Mercy Corps, 2021). Poverty, harsh weather conditions, lack of safe living conditions and resources along with recent outbreaks of violence in 2019-2020, particularly in Northwest Syria, has led to an additional 1 million residents to flee, with over 80% of these being women and children (Mercy Corps, 2021; USA for UNHCR, 2021).

Syrian Immigrants/Refugees in a Canadian Context

The Canadian government values immigrants and refugees as important members of Canadian society (Government of Canada, 2020a). Between 2015 and October 2020, Canada has welcomed 44,620 Syrian refugees (Government of Canada, 2021a). Canada prioritized the resettlement of families and young children, with 85% of Syrian refugee families consisting of a couple with children (Houle, 2019).

In Canada, the refugee system has two main protection programs: 1) The Refugee and Humanitarian Resettlement Program, for those needing protection from outside of Canada, and 2) The In-Canada Asylum Program, for those making refugee claims from within (Government of Canada, 2019). Unlike immigrants, external refugees are unable to apply directly to Canada for resettlement and are instead identified by the United Nations Refugee Agency, as well as private sponsors for resettlement (Government of Canada, 2019). There are three programs through which Canada accepts refugees:

Government Assisted Refugees (GARs), Privately Sponsored Refugees (PSR) or Blended Visa Office-referred Refugees (BVOR) (Government of Canada, 2020b).

The Government of Canada offers a Resettlement and Assistance Program, which provides government assisted refugees with essential services and income support upon their arrival to Canada to help them settle (Government of Canada, 2019). This income support for GARs is available for the first year or until they are able to support themselves, whichever comes first (Government of Canada, 2019). PSRs are supported by their private sponsors for the length of their sponsorship period, and BVORs are provided six months of government support and six months of private sponsor support (Government of Canada, 2019).

Refugees in the Edmonton Context

The influx of Syrian refugees greatly increased Alberta's population. Alberta was one of the top three provinces to receive Syrian refugees following Ontario and Quebec (Alberta Association of Immigrant Serving Agencies, n.d.). Refugees were accepted throughout Alberta, with large centres accepting the largest number (Government of Canada, 2021b). Of the major Albertan cities, Edmonton welcomed the most, with 1,375 Government Assisted Refugees, 710 Privately Sponsored Refugees and 165 Blended Visa Office-referred refugees (Government of Canada, 2021b; Mahaffy, 2018). Many of the refugees that were welcomed into Edmonton consisted of large families with many family members being under the age of 17 (Mahaffy, 2018). The rapid influx of refugees led to existing structures being overwhelmed at all stages of the welcoming and resettlement process (Mahaffy, 2018). Luckily, there was a response from many

Albertans, which triggered the collaboration of multiple agencies to work together to meet the existing demands (Mahaffy, 2018).

In a study conducted by Mahaffy (2018) that looked at how Edmonton welcomed refugees from Syria, many challenges were present during this time for the various groups of refugees. Government assisted refugees were found to have more pre-existing health concerns than expected, and 90% of GARs did not speak English or French (Mahaffy, 2018). Although many Arabic-speaking physicians expanded their practice to meet the health needs of Syrian refugees, the healthcare system was challenged to address their needs holistically. During the influx, GARs initially received intake and screening through the New Canadians Clinic, which was housed by Catholic Social Services. The clinic had developed about a decade prior to the current influx, which was known for providing "excellent, culturally sensitive health assessment, orientation and referrals" (Mahaffy 2018, p. 51). In March of 2017, this Clinic lost funding and refugees who received government assistance were then directed to the East Edmonton Health Centre for initial intake and then referred to family physicians for follow-up care (Mahaffy, 2018). This caused some controversy in the community as Edmonton went from being one of the first major Canadian cities with a clinic dedicated to Newcomer health to being the only large city without one (Mahaffy, 2018). After considerable advocacy efforts, and renewed funding, in August 2021 the New Canadians Health Centre opened its doors to fill this gap.

It is evident that newcomers face many challenges when resettling in their host communities (City of Edmonton, 2021; Mahaffy, 2018). Among these challenges are financial hardship, language training, employment, housing, health, mental health, social

engagement, family reconfiguration and education (AAISA, n.d.; City of Edmonton, 2021; Mahaffy, 2018). It is evident that the challenges Syrian refugees face are complex and often interrelated, therefore difficulties in one area often affect another (City of Edmonton, 2021; Mahaffy, 2018).

Syrian Cultural Background

Syrian families are generally large and extended. Moreover, these families are often close and supportive and feel a sense of duty to take care of each other (Cultural Orientation Resource Center, 2014). Syrian culture is patriarchal in nature and everyone in the family is under the protection of the eldest man, and women are believed to need protection, especially from unrelated men (Cultural Orientation Resource Center, 2014). Gender roles vary based on factors such as socioeconomic background, family, and geographical location (urban vs rural), with women performing domestic tasks, caring for children and family members, as well as working outside of the home in jobs that range from low to high profile (Cultural Orientation Resource Center, 2014).

Pre-migration experiences impact how refugees settle and integrate as well as make decisions regarding accessing healthcare services (Refugee Health Coalition [RHC], 2020). Prior to the war, the Syrian public healthcare system was well established in urban settings, offering quality health services that were easy to access and navigate (RHC, 2020). Rural settings experienced limitations due to a lack of resources and established health clinics (RHC, 2020). Research suggests that Syrians typically believe in Western medicine, however their healthcare beliefs, practices and preferences will reflect their cultural and social realities (Cultural Orientation Resource Center, 2014). It is noted that Syrians generally trust doctors and are often quick to seek medical attention and

treatment for health concerns (Cultural Orientation Resource Center, 2014). It is noted that some common Syrian beliefs, practises and preferences may include the following (Cultural Orientation Resource Center, 2014; Wehbe-Alamah, 2011).

- Syrians typically prefer to be seen by the same-sex healthcare professionals and this is extremely important when providing reproductive healthcare.
- Syrians generally avoid discussing topics relating to sexual health and therefore these topics must be approached with caution and care.
- Modesty is important and women may wish to be fully covered during a medical exam.
- Syrians may request meals in accordance with Islamic dietary restrictions (Halal) during hospital stays.
- Syrians may fast or refuse certain medical treatments (such as taking oral medications) during certain periods of religious observance.
- Syrian men and women consider it their duty to care for elderly or ill relatives and members of their communities, and support from family and friends is very important during illness.
- Once symptoms or ailments disappear, there is a likelihood for Syrians to stop following treatment plans and they may not return for follow-up appointments.

Gaining a better understanding of the Syrian culture, especially how Syrians participate in healthcare, can facilitate positive health outcomes for Syrian patients (Cultural Orientation Resource Center; Wehbe-Alamah, 2011).

Focus on Women and Girls

Women and girls have been particularity impacted by the threat of sexual violence both in Syria and asylum countries (Alrifai & Dore-Weeks, 2018; Cultural Orientation Resource Center, 2014). The experience of or the threat of sexual violence caused many women and girls to flee the country. In asylum countries, the fear of sexual violence from other refugees or host country residents caused many refugee women and girls to stay inside the home and rarely venture outside (Alrifai & Dore-Weeks, 2018). Sexual violence however is not socially acceptable to discuss and therefore women and girls rarely discuss these issues in front of male family members (Cultural Orientation Resource Center, 2014).

Women and girls are often disproportionately affected by conflict (Guruge et al., 2018; Sami et al., 2014). This is due to increased risk or experiences of exploitation, marriage and/or pregnancy at an early age, as well as a lack of essential services, including access to sexual assault treatment and emergency obstetrical care (Guruge et al., 2018; Sami et al., 2014). Women and girls are at greater risk of experiencing gender-based violence (particularly sexual violence), negative mental health impacts, and maternal and newborn complications (Sami et al., 2014). As is common in areas of conflict, Syrian refugee women and girls belong to the majority of those displaced, making it vital that their health needs be considered and addressed (Sami et al., 2014). Inside Syria, many women of reproductive age do not have access to reproductive health services, as attacks on civilians and hospitals make it unsafe or impossible for women to access safe deliveries, antenatal and postnatal care (Sami et al., 2014).

Refugee Health Experiences in Canada

Gaps in healthcare exist for newcomers, with many experiencing poor quality healthcare compared to the general population (Ahmed et al., 2016; Filler et al., 2020). Studies show that immigrant and refugee women are particularly disadvantaged and often experience unmet health needs, with GARs often reporting lower perceived physical and mental health, as well as higher unmet health needs than PSRs (Filler et al., 2020; Oda et al., 2019; RHC, 2020; Tuck et al., 2019). Reproductive, mental, as well as preventative healthcare have been identified as key health services that are often lacking (Filler et al., 2020; Redwood-Campbell et al., 2008; RHC, 2020). Furthermore, when looking at chronic health conditions, Syrian women are more likely than men to suffer from anemia and iron deficiency, which can lead to poor pregnancy outcomes, fatigue, reduced exercise tolerance, as well as impaired physical and cognitive development in children (Gruner et al., 2022).

A recent study by Guruge et al. (2018), which explored the healthcare needs and experiences of Syrian refugee women in the Greater Toronto Area, found that Syrian refugee women enter Canada with pre-existing, as well as new and emerging health needs. It was noted that many have experienced war-related trauma prior to fleeing Syria such as detention, loss of loved ones, torture, and exposure to chemical weapons, all of which have direct impact on their health and the health of family members. This study reports that while many refugees are thankful for the safety and security they receive in Canada, many feel that their existing and emerging health concerns have worsened since arriving in Canada. This has been attributed to delayed access to healthcare, as well as feeling that healthcare providers did not respond quickly or seriously enough to their

health problems (Guruge et al., 2018). Often refugees felt that there was a discrepancy between their self-rated health concerns and how healthcare professionals evaluated them and expressed sentiments of feeling dismissed as they felt their concerns were not seen as urgent (Guruge et al., 2018).

Other concerns include the termination of GAR's financial support after one-year, which has implications on future healthcare costs, as well as dental costs (Guruge et al., 2018; Khanlou et al., 2017; Oda et al., 2017). On top of this, other issues such as social disconnection, lack of accurate and user-friendly information regarding navigation of the healthcare system, language/communication, physical barriers to accessing services, long wait times, and a lack of cultural competency from healthcare practitioners are prevalent for Syrian (and other) refugees (Guruge et al., 2018; Khanlou et al., 2017; Oda et al., 2017). It is largely reported by refugee women that poor quality of care and lack of support leads them to distrust and avoid seeking healthcare (Khanlou et al., 2017; RHC, 2020). Furthermore, Guruge et al. (2018) note that Syrian refugee women will prioritize the health of their family members over their own health needs.

Pregnancy and prenatal care can be an entry point to the healthcare system, and care for pregnant refugee women includes managing the multitude of barriers that refugee women face compared to Canadian born women (Winn et al., 2018). These barriers include language and cultural barriers, lack of resources, a health system that is difficult to navigate, migration journeys and experiences that impact health and diverse refugee system categories that impact access to care/funding for services (Winn et al., 2018). Due to their experiences, refugee women may lack trust in healthcare professionals and may be hesitant to engage in North American healthcare practices and procedures (Winn et al.,

2018). Another factor that may add to this hesitancy to trust and engage in North American healthcare practices is the obvious lack of naturopathic or alternative medicine in western healthcare (Guruge et al., 2018).

There are many health concerns that affect Syrian refugee women of childbearing age relating to postnatal experiences when accessing healthcare and social support in Canada (Stirling Cameron et al., 2022). This study highlights the importance of family and social supports that are often lacking after resettling in a foreign country, noting that this absence was greatly evident during the postnatal period (Stirling Cameron et al., 2022). On top of this, language barriers were found to be a main contributor to negative health experiences. This study reports that there was often a lack of interpreter services, leading to long waits for, as well as poor, medical treatment. On top of this, Syrian women described feeling “shy” or “uncomfortable” when sharing their medical history through an interpreter, especially if the interpreter was male. The authors recount a story of a woman who was forced to deliver her baby without an interpreter present and received no pain management due to language barriers. The authors also reported challenges relating to affordable and trustworthy childcare for their other children, as well as challenges relating to proximity and transportation to and from healthcare services. Furthermore, the study found that many of the women felt that their decision-making autonomy was restricted by health care providers and that their decisions regarding their care were not acknowledged. This caused participants to feel disrespected and frustrated, and led to a lack of trust (Stirling Cameron et al., 2022). On top of this, research supports that the COVID-19 pandemic and associated public health restrictions has further exacerbated pre-existing barriers to care and postnatal health experiences by

resettled Syrian refugee (Stirling Cameron et al., 2021). Stirling Cameron et al. (2021) noted that Syrian refugee women who were “postnatal” during the pandemic experienced difficult healthcare interactions, which included socially and physically isolated child deliveries, barriers to accessing in-person interpreters, as well as cancelled or unavailable in-home services. It was noted that the pandemic restrictions led to a lack of informal supports as well as increased childcare responsibilities, which caused these women to feel exhausted and overwhelmed (Stirling Cameron et al., 2021). Stirling Cameron et al. (2022) found that women who were separated from their extended family and social supports attributed this isolation to certain mental and physical health challenges after birth. This was further exacerbated during the COVID-19 pandemic when the “stay at home” orders led to some of the women reporting feelings of loss and isolation which impacted their mental wellness (Stirling Cameron et al., 2021).

Another health concern that affects Syrian refugee women of childbearing age includes postpartum depression. In a study by Ahmed et al. (2017) found that immigrant and refugee women are five times more likely to experience postpartum depression than Canadian women (Ahmed et al., 2017). This is important as many Syrian refugee women settling in Canada are of children bearing age. Research has found that refugee women are exposed to many factors that influence their mental health, including a lack of social support, language barriers and socio-economic hardships (Ahmed et al., 2017). Due to stigma and privacy concerns, many Syrian women do not seek healthcare for postpartum depression. They may not understand or recognize symptoms of postpartum depression and face isolation and lack of familial support in their host country which has an impact on their mental health. As well, another consideration cited by Ahmed et al. (2017) is that

many Syrian women feel uncomfortable participating in public physical activities and other social settings that could improve their mental health, as they avoid spaces where genders mix.

Over time existing problems in serving refugees within the healthcare system have been magnified, creating a more complex system to navigate and leaving many refugees without coverage (Winn et al., 2018). This directly impacts refugee's health and often leaves patients without adequate care (Winn et al., 2018). As well, due to the changing coverage levels for different groups of refugees and conflicting information from government agencies and ever-changing policies, many healthcare providers feel that they are responsible to determine the level of coverage and ensure that patients received the maximum care that they are eligible for, needing to find creative ways to ensure coverage, at times needing to rely on donations and even paying out of pocket to ensure patient needs were met (Winn et al., 2018). Lack of clarity on the refugee health system, as well as a lack of understanding and training on how to support refugee's health can lead to difficulty navigating the healthcare system; this negatively impacts the quality of care received by refugee patients, and many women have likely been disadvantaged (Stewart et al., 2018; Winn et al., 2018). The COVID-19 pandemic has significantly strained the healthcare system for anyone accessing it. For those who were already experiencing barriers and challenges to accessing and participating in healthcare, these challenges and barriers will be exacerbated (Stirling Cameron et al., 2021).

Health of Refugee Women in Edmonton

There is a lack of publications focusing specifically on Syrian refugee women's experiences of accessing healthcare services in Edmonton; however, information does

exist for refugees as a population. A community engagement report was published in 2020 by the Refugee Health Coalition, which included conversations with ten different communities, front-line service providers, private sponsors, and healthcare providers. This community engagement report shows that although there are many differences experienced by refugee communities settling in Edmonton, there were also many common experiences. Many refugees spoke highly of their experiences with the healthcare system and appreciated that services were free and spoke positively regarding the quality of care received (RHC, 2020).

However, concerns arose around physicians not treating health concerns holistically and a lack of focus on overall wellbeing (RHC, 2020). Furthermore, there were reports of a lack of language services available during healthcare visits and often the person seeking healthcare was made responsible for finding solutions to these communication barriers (RHC, 2020). Many refugees whom the RHC spoke with commented that the physicians did not spend enough time with them to adequately address their health concerns (RHC, 2020).

In addition, reports of unsafe or inappropriate healthcare surfaced, especially regarding mental health (RHC, 2020). Many women from the Eritrean community shared experiences of Albertan physicians encouraging them to have abortions; the women's understanding of these encounters was that the healthcare provider thought they already had too many children (RHC, 2020). Another woman shared a story that while pregnant, her physician told her the child had a birth defect, showed her pictures of children with birth defects, and told her that if she did not have an abortion, her child would look like this. Up until this point in the conversation, an interpreter had not been used in the

encounter with the healthcare provider. In the end, the woman went through with the pregnancy and delivered a healthy baby (RHC, 2020). Stories like these were common and have led to distrust in the healthcare system (RHC, 2020).

Research Puzzle

To identify my research puzzle, I reflected on my experience as a woman navigating the healthcare system and as a nurse working within it. Reflecting on my own privilege as a white, educated female who was born and raised in Alberta, I have still experienced challenges when navigating the healthcare system and seeking healthcare services. I think back to experiences where I have sought care and had felt that I was not listened to and my concerns were brushed aside or was told that what I was experiencing was "normal." As well, on occasion I was personally lacking knowledge on what services exist for reproductive health and how to access them. This made me wonder how other women, especially those belonging to minority groups, experienced navigating the healthcare system and their healthcare encounters.

My research puzzle was also informed by my work as a registered nurse in a large urban Emergency Department (ED) in Western Canada. As this ED provides care to those with diverse backgrounds, I was made increasingly aware of health disparities experienced by women, especially those belonging to visible minority groups. Complaints that concerns were not being taken seriously, minimal use of translation services by healthcare professionals, a lack of awareness of cultural practices/preferences by healthcare professionals where among things I noticed frequently. As well, patients often seemed to visit the ED for concerns that could be more appropriately treated elsewhere.

During my graduate studies, I connected with Dr. Vera Caine and the RHC. Through these connections it became apparent to me that we needed to understand the experiences of refugees better. With the original health clinic closed, the healthcare system has become increasingly difficult for refugees to navigate. Conversations with others, as well as reading a community engagement report done by the RHC allowed me to gain insight on barriers to health and experiences of care received. With the recent influx of Syrian refugees and the promise of more, it was evident that strain had been and would continue to be placed on existing healthcare structures. As most Syrian refugees are young families comprising five or more members, and many adult women are of childbearing age, it was evident that these families would have many health needs. I began to wonder about how Syrian women experienced navigating the healthcare system and their healthcare encounters.

The knowledge gained from working with the RHC as well as my personal experience as a nurse raised many questions for me. These questions included: *What are the stories of Syrian Refugee women of childbearing age? How do their lives as refugees impact their health needs? What previous health beliefs contribute to decisions made regarding seeking out and accessing health services by Syrian Refugee Women? What are their experiences of navigating the healthcare system and maternal healthcare in particular? What are their experiences of accessing these healthcare services? What are their experiences of the healthcare they receive?* The purpose of this narrative inquiry was to inquire into the experiences of Syrian refugee women of childbearing age as they access and participate in healthcare.

Methodology

As Clandinin & Connelly (2000) write, narrative inquiry seeks to inquire into experience and is about "stories lived and told" (p. 20). Allowing for both a view of another's lived experience and a way to narratively inquire into that experience enables an intimate and deep understanding of another's lived experience "over time and in context" (Clandinin & Caine, 2013 p. 166). This is accomplished by engaging with the individual's experience in a "three-dimensional narrative inquiry space" that is composed of temporality, sociality and place (Clandinin & Caine, 2013, p. 167). Engaging in a three-dimensional space requires directing attention inward and reflecting on the thoughts, emotions and responses to outward events by both the participants and researchers. It also requires attention to the physical space where lives were lived and where the events being inquired into occur (Clandinin & Caine, 2013).

Ontological and Epistemological Underpinnings

Narrative inquiry recognizes that humans live storied lives, and that these lives and stories should be attended to by researchers (Clandinin & Connelly, 2000). Narrative inquiry is largely set apart from other methodologies by its relational quality and is strongly influenced by Dewey (1916) and his theory of *experience* (Clandinin & Connelly, 2000; Clandinin & Caine, 2013). In Dewey's work, experience is both personal and social, and includes, "interaction, and continuity enacted in situations" (Clandinin & Caine, 2013, p. 168). This way of thinking about experience grounds the concept of attending to experience through a three-dimensional space (Clandinin & Caine, 2013). The personal and social concepts of experience help to shape the philosophy that "people are individuals who need to be understood as such, but they cannot be understood only as

individuals" (Clandinin & Connelly, 2000, p. 2). The relational and contextual aspect is always present, and narrative inquiry focuses not only on the individual, but also on the social, cultural, and institutional context within which the individual's experiences are shaped (Clandinin & Caine, 2013).

When pondering the direction of my thesis, I considered my own life experiences and the ways in which these experiences have shaped my interests and practice as a nurse. I reflected on my experiences of growing up privileged, learning how to understand and navigate the healthcare system here in Western Canada. I reflected on my experiences as a woman, as well as my experiences as a nurse.

Clandinin and Caine (2013) outlined twelve qualitative touchstones for narrative inquiry that were considered throughout the research process. These touchstones include: 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 in ways that show temporality, sociality and place; relational response communities; justifications-personal, practical and social; attentive to audience; and commitment to understanding lives in motion (Clandinin & Caine, 2013). While all of these are important pieces of my research, I highlight five main touchstones. I chose these touchstones as they were most relevant to guiding my work.

Relational Responsibilities

Clandinin and Caine (2013) explain that in narrative inquiry, it is imperative that we remain aware of what it means to engage in research that is at its core relational and collaborative. Ethics, open attitudes, mutual vulnerability, reciprocity, and care are

hallmarks of ensuring that narrative inquiry spaces remain spaces of belonging for both the participants and researcher (Clandinin & Caine, 2013). Relational ethics encompass responsiveness, as well as responsibilities that are both short and long term. Attending to relational responsibilities also extends to attending to matters of social justice and equity, which informs the significance of the research work being done. As Clandinin and Caine (2013) write, "narrative inquiry opens up a relational knowing and understanding of experience, each relationship between researcher and participant opens up a relational world" (p. 169). In my work with refugee women of childbearing age, this relational world was important to cultivate as I attended to the lives of participants. Relational responsibilities are of great importance in my work and reflecting on this was important while I navigated negotiating relationships, composing, co-composing text and engaging in the inquiry field with participants. Understanding that attentiveness, presence, and response matter, existing in this relational space involved a process of continuous self-reflection, contemplation and openness as well as uncertainty (Clandinin & Caine, 2013).

In the Midst

Narrative inquiry involves entering research relationships "in the midst" (Clandinin & Caine, 2013). Entering into the midst has several meanings and includes in the midst of the researchers' ongoing lives, researchers' lives enacted with institutional and social, political, linguistic and cultural narratives (Clandinin & Caine, 2013). As well, the participants are in the midst of their own lives, lives that are shaped by their past, present and future social, cultural, institutional, linguistic and familial narratives (Clandinin & Caine, 2013). As I designed the narrative inquiry study, it was important that I placed myself imaginatively amidst possible lives of my potential participants in

order to be attentive to the imagined temporality, sociality and places of their lives (Clandinin & Caine, 2013). Moving forward with narrative inquiry research, it was vital that I inquire into my own life, using a range of field texts (such as journal entries and photographs) to allow myself to understand who I am and am becoming in relation to potential participants (Syrian refugee women of childbearing age) and the phenomenon of interest (their experiences of accessing healthcare in host countries).

A concept to consider when placing myself "in the midst," is Lugones (1987) concept of "world-traveling." Lugones (1987) asks us to consider entering into the midst as a sort of world travel, from our own world into the world of the other. I entered the narrative inquiry space from the world of a healthy, educated white woman, who is coming from a stable environment, free from conflict. I have lived in Canada my entire life and recognize that many of my experiences come with privilege. I also entered from a world of a registered nurse where I am responsible for caring for patients with the aim to provide safe, competent, and patient centred care, where forming therapeutic relationships is one of my main priorities. Lugones (1987) invites us to travel lovingly to another's world. While I recognized that I did not come from the same world as my research participants, it is with love that I reached out and travelled into their world. In this way, I came to know them and in doing so, explored their experience in relation to my identified phenomenon so that "we" came to know it differently.

Negotiating Entry to the Field

The initial phases of a narrative inquiry involve the composition of field texts that are created from working closely with participants over multiple interactions, creating co-constructed texts that address the participants' and researchers' reflections on life

experiences (Clandinin & Caine, 2013). As the "field" in narrative inquiry refers to the relational space in which the researcher engages with the participant, the "field" is being negotiated on an ongoing basis (Clandinin & Caine, 2013). In narrative inquiry, listening as individuals share their stories, and living alongside participants as they live and tell their stories are the two starting points for entry into the field. To do this, conversations, oral histories, and interviews will be used with participants (Clandinin & Caine, 2013).

Living alongside participants involved going with participants where they are willing to take me; allowing me to become a part of their "world" and therefore enabling me to attend to the ways their "individual narratives of experience are embedded in social, cultural, familial, linguistic and institutional narratives" (Clandinin & Caine, 2013, p. 171). Ambiguities, complexities, difficulties, and uncertainties encountered as I lived in the field and wrote field texts are reflected in the inquiry (Clandinin & Caine, 2013). A large challenge to living alongside participants that presented itself was the ongoing COVID-19 pandemic and the associated restrictions and safety measures. This hindered my ability to live alongside participants during the research process, by restricting physical proximity, as well as, by having to wear face masks.

Moving From Field to Field Texts

For this narrative inquiry, I engaged with two participants. I was able to engage in 3-4 one-hour conversations with each participant over the course of two months. The participants were involved in negotiating the boundaries surrounding their participation and were involved in setting limits on the amount of time we spent together (Clandinin & Caine, 2013). We met in a place of their choice, and due to COVID-19 health and safety measures and participant comfort, interviews were held at a community centre and a cafe.

Due to ongoing challenges stemming from the COVID-19 pandemic, virtual meetings were offered, however not needed. The study began with conversations that allowed participants to determine the experiences they would like to share. I also asked questions that were intended to guide the conversation towards the research puzzle (see Appendix A for Guiding Questions).

In narrative inquiry, the relationship between the researcher and participant may be described as "being a tenuous one, always in the midst of being negotiated" (Clandinin & Connelly, 2000, p. 72). Relationships between the researcher and participant may not always come naturally, and rapport can be difficult to establish (Clandinin & Connelly, 2000). Using skills that are familiar to me through my work as a registered nurse, I was able to build trust slowly and by listening carefully, I ensured that participants felt cared for and that the space in which we met was safe for them to share their experiences. The negotiation of relationships was vital and was ongoing throughout the research process (Clandinin & Connelly, 2000).

My field texts are composed of data that includes, but is not limited to, "conversations, interviews, participant observations, as well as artifacts" that were gathered during my interactions with participants (Clandinin & Caine, 2013, p. 172). I also gathered field notes which are reflective and include "observations, assumptions about what is being heard or observed, and a personal narrative about what is experienced by the researcher during a particular encounter" (Streubert & Carpenter, 2011, p. 43). As there are many ways for participants to share stories, I encouraged participants to share any artifacts they were comfortable sharing with me as we co-composed field texts (Clandinin & Caine, 2013). All conversations were transcribed, field notes and accounts

of participant observations contributed to ensuring that the complexity of the experience was captured in this study.

From Field Texts to Interim and Final Research Texts

All conversations were audio recorded with the consent of the participants, and the recordings were transcribed verbatim. Artifacts and field notes collected during the study were included in the data analysis. Analysis of the data remains a relational process and the field and interim research texts were negotiated and co-constructed with participants (Clandinin & Caine, 2013). While constructing the interim texts, I continued to remain attentive to the three-dimensional space, paying attention to the temporality, sociality, and place of the field texts (Clandinin & Caine, 2013). As I moved into the final research texts, it remained important that I attended to the audiences for my research findings (Clandinin & Caine, 2013). To do this, I considered the "personal, practical and social justifications of the collaborative work" (Clandinin & Caine, 2013, p. 173). Narrative accounts, also called interim research texts, were co-constructed and negotiated with participants and reflect both the narratives of participants, as well as myself (Clandinin & Caine, 2013). However, it is important to note that I was unable to reconnect with Sky to negotiate her narrative account, despite multiple attempts. In disseminating my research findings, I plan to work closely with the members from the Refugee Health Coalition and New Canadians Health Centre to engage in knowledge mobilization with the aim to inform positive change to the delivery of healthcare services.

Resonant Threads. Two levels of analysis were conducted during this narrative inquiry study; the second level of analysis is called resonant threads and will be discussed below. In the second level of analysis, I looked across the individual narrative accounts to

identify resonant threads, or patterns that reappear throughout the narrative accounts (Clandinin, 2013). Doing so allowed for a deeper and broader awareness of the experiences of Syrian refugee women accessing healthcare in a large city in western Canada. This enabled new wonders and questions in regard to experiences of healthcare by refugee women to appear and assisted in gaining increased insight into the healthcare system so that positive change may occur. By focusing on threads, I followed "plotlines" or patterns that thread and weave through time and place within each participant's narrative account (Clandinin, 2013). I then laid the accounts alongside one another to search for resonances that reappear throughout the accounts (Clandinin, 2013).

Justifications: Personal, Practical and Social

As Clandinin and Caine (2013) write, the researcher must be able to justify the need of their research by answering the questions of "so what?" and "who cares?" (p. 174). The research study needs to be justified in three ways: "personally, practically and socially" (Clandinin & Caine, 2013, p. 174). In the final chapter, I will be discussing these justifications.

Participants

For this study, I engaged two Syrian refugee women of childbearing age. Both participants were comfortable conversing in English and did not require a translator. I was able to work with the New Canadians Health Centre and the Health Promotion team from Catholic Social Services to invite participants to take part in this research study. Convenience sampling was used when selecting participants. All elements of the study were explained to potential participants and oral and written consent was obtained once I had verbal confirmation that they were aware of all elements of the study, including time

commitment, confidentiality, expectations and purpose of the study (see Appendix B for the Information Letter and Consent). I spent the time and care needed to develop trust with each participant to engage in meaningful conversations. Considering the socio-economic status of most Syrian refugee women, as well as the time commitment to this study, I provided beverages and a $20.00 gift card for each meeting I had with participants.

Ethical considerations

Prior to beginning my research, ethics approval was obtained from the University of Alberta's Ethics Review Board. I obtained both oral and signed informed consent from each participant prior to beginning research conversations (See Appendix B). As part of the consent process, I explained my background as a nurse, my interest in this research study, and the potential impacts thought this research may have, while being careful not to make promises of benefit to the participants. As narrative inquiry is a relational methodology, the frequency, length, and location of meetings were negotiated with participants. I was able to meet with participants between 3-4 times for conversations that ranged from 45 minutes to an hour over the course of two months to obtain data, with an additional 3 meetings to negotiate research texts. Participants were made aware of their right to withdraw from the study at any time, with no consequence and no explanation needed. Use of a translator was offered to each participant, however, was not used. To ensure the safety of myself and participants, my supervisor was made aware of the locations and times of meetings/conversations included in my research itinerary.

Confidentiality and anonymity were ensured throughout the research process, and measures were taken to uphold these standards such as providing the participants with

pseudonyms. However, I recognize that issues relating to this appeared throughout the research process (Clandinin & Connelly, 2000). Such issues include community members and others in the "field" recognizing that I was a researcher when meeting at the community centre (Clandinin & Connelly, 2000).

As it is my responsibility as a researcher to cause no harm to participants, I recognized that this narrative inquiry unearthed stories of unresolved trauma, pain and hardship for the participants (Clandinin & Connelly, 2000). Sensitive topics were approached with great care throughout the duration of the research study, including the initial conversations as well as when composing research texts. Furthermore, participants were able to choose to not answer questions and this was explained when obtaining consent, as well as prior to each conversation. I was able to utilize the resources of the New Canadians Health Centre to be able to refer participants to receive care, including counselling if needed.

CHAPTER 2

Narrative Account of Abby

Introduction

Abby was the first person to show interest in my study. We were connected through contacts at a community centre, and prior to meeting in person we spoke over the phone about my study. We agreed to meet at the community centre. I was happy with this meeting location as it was a place she was familiar with, and with my background as a nurse, the meeting location was a place that I felt fit within my professional boundaries. I arrived to the community centre early as I was not certain about the location and wanted to make sure I was in the right spot. While I was excited, I was also nervous. Sitting in my car outside of the community centre, many questions ran through my mind. I imagined how the meeting might go; would we connect? Would she feel comfortable sharing her story with me? Would there be awkward silences? And if there were any awkward silences, how might we best navigate them?

The community centre is in close relation to a settlement agency. When I arrived, I was greeted by a receptionist and told to wait in the reception area. I nervously waited in the reception area. The Executive Director of the community centre came to meet me in the waiting room, gave me a brief tour and introduced me to other staff so they would know my purpose when seeing me around. Staff members thanked me for my interest in the population they served (refugees) and I remember thinking for the first time that the research I was doing was real and may be significant. As I went on the tour I noticed that every possible space in the community centre is used for multiple functions in order to see clients and patients.

Meeting Abby

When I first meet Abby, I was nervous as this was my first encounter with a research participant. She greeted me warmly, although still slightly reserved. As we had already spoken over the phone regarding the research study, we made some small talk before jumping into more discussion regarding the study. I introduced myself as a nurse and explained my study and my interest in this area. We went over the study and there was some hesitancy when we went over the section on publishing my work. Abby expressed that while she wanted to share her experience, she did not want one specific experience to be published and was apologetic and worried that this may impact my research. I reassured her that her participation was still significant and that nothing would be published without her approval. She remained adamant that she wanted to participate in the study and share her story.

Life in Syria before the war

Abby starts her narrative account by sharing experiences of her life in Syria. Abby came from Syria. Prior to the war, Abby shared that they were living in peace. She completed a university degree in accounting and started working. She met her now husband during university and felt that everything was good, that they were living a "normal" life. Abby was very guarded about her personal life and provided little information.

Healthcare in Syria

Syria has two different healthcare systems. One is government funded and is free and the other is private and is fee for service. The private system is quite expensive given the average income of Syrian people. Although the government tries to "*bring in good*

doctors" and "*clean up*" the hospitals, the government-funded hospitals are typically "*quite dirty*". The private system is preferred if people have funding to pay. According to Abby, the people who go to the government hospitals and clinics do not respect the property or equipment, and things are often broken. As the government is a "*poor*" government, there is not a lot of money to keep things clean and bring in new equipment. The physicians in private hospitals are very expensive and refuse to treat people unless they can pay up front. Abby speaks of people dying at hospital doors because they cannot pay. She thinks the private system lacks humanity. Typically, the doctors are good as they have to study medicine abroad, most often in a different language.

Abby did not have to access healthcare services for herself when living in Syria. She shared some of her father's experiences of healthcare. Abby's father had to have heart surgery. She recalls that she was young at the time and therefore, unable to remember the details. However, she remembers the difficult decision on where to have the procedure done as her father was advised to not have the surgery in Syria.

> *No one tell him like, it's okay. Do it in Syria. There is, this doctor is good. Everyone tell him, like, don't do it in Syria […] go to do it in Jordan or like, uh, in Lebanon wherever, but not in Syria.*

Abby recalled how cost made the decision harder saying that the cost was in American dollars. She remembers her mom saying "*they don't have a decision. It was so hard. So in the end she say, no I can't, I don't have money to go outside Syria."*

Abby also shared a recent story of her father's experience when he was diagnosed with COVID-19. He needed to be admitted to the intensive care unit due to his history of open heart surgery. She described this stay as *"so expensive. Lots of money*". She learned

there were other difficulties when she spoke to her sister who "*was in Syria at this time."* Because he had COVID-19, her sister was told that no one from the hospital could come into his room. She was told to get a family member to come and look after him.

> *So, you have to bring one of* your *family because doctors and nurse can't go to his room. They might get COVID. Ask someone from your family, come to look after him. Or like give him the medication. We can put him in the room, but no doctor or nurse can look after.*

Her sister questioned how this could be the situation because *"Like it's hospital, I'm paying you."* Her sister said she would *"live with him in a house"* but was told that *"yeah, if you want to live at house, which is fine, but there is no oxygen to, you know."* Her sister felt like she had no option and had *"to put him in the hospital."*

Abby described how her sister went to his hospital room at five in the morning. Because he had *"COVID she need to feed him. Because no one would allow to go to this room. And he was so tired. So, he's taking off his mask. All the room is COVID."* She began to question the situation saying to Abby that *"If you're going to someone[who] have COVID so you protect yourself, you wear the right things."* However, in the hospital, she had *"Nothing. They tell her, just put two masks, two masks. You will be fine before you go home. When you go home, before you go inside house, just take off your clothes."* She questioned that when she left his room in the hospital, she walked *"everywhere and it's not just a mask. It's everything, you know? So, this is the stupid things."* As Abby listened to her sister's story of caring for her father in the hospital she said, *"it makes me, it's like, oh my God, nurses, like, excuse me. And we pay like, because I'm here, I send the money for them."*

Abby is clearly distressed by the money that she sent to provide care for her father. She spoke of the high cost that she paid*, "a million lira like it cost me, like, I don't remember the number, like more than, I don't remember like how many [millions] we pay for them for nothing."* She was frustrated that the hospital gave him *"nothing. This is the oxygen. Like it's nothing."* Her sister hired a nurse that she paid to stay with him. While her sister sat with her father *"from midnight to the morning, six or five morning, because she needed to go to her place. And sometimes he [the nurse] just take money and he didn't show up and you know, they're not respect*." She was upset because everything costed so much money. She did not *"blame them because life is there's, hard, you know, they have to fight to live because this guy has five kids at home, hungry. They need food, you know, but that is still, it's not a humanity things right. You need to be a human."*

She was distressed as she spoke of the money that had to be paid even as she knew that people needed protection. While she knew that COVID was *"a global thing,"* she was concerned that sometimes the money that was sent to the healthcare system did not go to support people but that things were sold and people made money. *"So yeah, in Syria, everything is money, money, nothing more than that. So, this is my last experience with Syrian hospital."* She ended the story of her experience with the Syrian health care by saying that she felt that people should not get sick in Syria*. "Please don't be sick. No one allowed to be sick in Syria. No."*

Leaving Syria

Abby left Syria to seek refuge in Lebanon when the war broke out. She expressed how the war seemed to just start and then everything changed. Abby spoke of the lack of government protection for the people of Syria due to the war. She shared a story of how a

family member was killed for money and when the people who were responsible for their murder were asked why they killed them, their response was because they were Christian. Abby vocalized how shocked she was by this. As Abby herself is Christian, after this event she began to feel unsafe in Syria. She shared how, as a Christian, she felt that she could be raped, murdered, or persecuted at any time just because she was different than the majority of Syrians who identify as Muslim. She said,

> *I'm a Catholic… our community is so small in Syria. Like even you can count how many we are.... So felt unsafe…the people there it's religion. It's their closed mind. They don't like…. if you are not the same, that means you are strange. You are dangerous. You're not same. So it's okay. They will try to kill you or do anything to keep you away.*

Abby described how life in Syria was very uncertain, with many explosions happening. One morning she overslept for work and woke up to many phone calls as the building where she worked was bombed early in the morning. Had she been at work on time, she would have been in that building. She shares that she lost many friends during this war.

Another key reason for her departure from Syria was that in Syria military service was mandatory and her partner (now husband) was against killing and did not want to serve with the military, so he left for Lebanon. She followed as she felt she was "*not able to live*" in Syria. She said, that "*I decide to go out and even my parents, they left the city, they went to the town because it was terrible, miserable there in the city."*

Abby decided that life and a future no longer existed for her in Syria, with so much stress, fear, loss, and lack of basic amenities such as water and electricity. She felt

that she had nothing left to lose and so she and her sister set out for Lebanon. The journey to Lebanon was long and precarious. While they travelled by bus, it often stopped for 5 or 6 hours at a time due to shooting, landmines and unsafe traveling conditions. The bus driver did not think they would be able to safely complete the journey and suggested that they turn back, however Abby was determined to continue. They continued on foot down a portion of the road and were caught in crossfire. Abby shared that she lost her sister during the chaos and spoke to how hard this was, saying that it was "*miserable.*" Abby's body language was tense as she recounted this story and she made little eye contact. I moved the conversation onward as the emotion in her voice let me know how difficult this was for her to recount.

Life in Lebanon

Life was difficult in Lebanon and it was illegal for Syrians to work there. However, Abby stated that not working was not an option for her. She refused to live in a refugee camp and to rely on others for money or food. She described how in a refugee camp, she would

> *have to live in a tent and I, feel like, no, I, I prefer to work under table. Just to not live in a tent, you know, I don't want this life. Like even like, if I'm refugee, that doesn't mean like, I can't do nothing.*

She was able to find a job that was very different from her work as an accountant in Syria.

> *But when I moved to Lebanon, it was hard to be in the office. It's not legal for me to work as a Syrian refugee. So I decide, okay, I like nails. I like, like, uh, I know how to do threading or this stuff, which is like, people like it. I will work on the*

spa. I improve myself on this kind of things, and yes, after that I start working with spa.

Abby married in Lebanon and they rented a small room to live in. The room was tiny, with a little kitchen and a bathroom. She said they were lucky to have a private bathroom, as many had to share. Abby said they took life day by day in Lebanon, sharing how tight finances were. Some days, if she did not receive tips at work, she did not have enough money to pay for the hour-long bus ride home. The walk home took seven hours.

Abby described how difficult life was in Lebanon even after a couple of years, "*it wasn't easy until the day I heard that a church is sponsoring from Canada."* Abby was hopeful that they would be able to make a new life. She shared that she felt like she wasn't able to have children in Lebanon. She did not want to be pregnant and bring a child into a miserable life and included these stories in her application. Applying for sponsorship required sacrifice and Abby explained that mailing the paperwork costed a lot of money. She was happy to make the necessary sacrifices though in order to come to Canada. The process took around a year and a half, and they were successful in migrating to Canada under private sponsorship.

Coming to Canada

Leaving for Canada, Abby vocalized some feelings of fear about meeting their sponsors. She was worried about finding them, maybe they would have a sign and she would not recognize it as she did not read or speak English at the time. However, those anxieties dissipated, and she said that her sponsors were very nice people that gave her a future. They gave her "*everything.*" Abby spoke fondly of her sponsor family, saying that they continue to keep in touch and visit one another. She considers them family and a

part of her support system. Abby and her husband arrived to a small town. Abby's husband also did not speak English upon arriving to Canada. English classes were not offered in the small town where they resettled and they travelled to a neighbouring city for lessons in the summer. Once winter arrived, they found it very difficult to travel for classes.

Experiences of Healthcare in Canada

Introduction to healthcare

There was a small health centre in the small town. Abby was glad she was not sent to a city to access healthcare. Upon arrival, they accessed the healthcare centre for immunization review and set up appointments for needed immunizations. When Abby became pregnant, she needed to travel to a city for some tests that were not offered in her town. I asked Abby how she learned about the healthcare system in Canada. Were there any public health handouts or information sessions that explained the health care system? There was not and Abby learned about the healthcare system through her sponsor when Abby asked questions.

> *So, I would, when I ask them, we keep like, talking about it, like for all visit two, three hours sometimes, you know, then it will be like next day I will bring other question because it's a new country, new things for me. There's always something to ask every day.*

Accessing healthcare was a bit complicated as Abby did not have a car and there was limited public transportation. She relied heavily on her sponsor family to arrange and transport her to appointments. Abby was left to navigate the healthcare system on her own with help from her sponsor.

During her medical appointments, no interpreter was present. She used Google Translate to communicate her medical needs. I wondered if they ever offered her a language line (medical interpret). Abby said, they did not even though they found me "*like struggling and having very hard time to, to tell them what is my question? What I feel."* She also felt rushed as "*the doctor want to come finish fast because there is like a hundred clients outside waiting."* She felt like they did not *"really want to open this opportunity to ask more and more, you know, if there is something, so you will go in the emergency, then they will find an emergency. But if it's you're okay, fine."* She thought it might be because it was her

> *first kid, the woman, she would so many new things. She don't know if that's normal or not normal. So, I feel like women on like first the pregnancy, they have more question than after you have the second or the third, you know?*
>
> She said, that she went to the doctor but felt like they were busy and
>
> *they didn't really give me enough time. I don't, I don't feel like, like it's nice to me, like sit and open a Google and try to ask them sometimes before I go, I put my question in Arabic, in English on a piece of paper. I make them ready because I really want to know. But even the answer I'm not, I can't understand very well. Cause I'm getting the idea what he's talking because he's not like writing for me so, I use it Google.*

I tried to understand just how the communication went and she explained, "*They try and use a very simple word to me."* She had a feeling that she should *" just stop asking, you know?"*

I was struck by so much of what Abby told me in this conversation. As a healthcare provider I often think of the importance of language and communication and its effect on understanding and health outcomes. I, too, have used patient family members to communicate as I felt the pressure of time and the lack of readily available phones with which to use a language line. I also thought about the times when a patient could have used interpretive services but since they ask health-related questions in English, even broken English, I felt they did not require it and so I did not offer it. I was also struck by Abby describing the feeling that the doctors did not want to spend the time to listen to her concerns and had an uncomfortable feeling that I, too, as a registered nurse have made patients feel this way. While I did not share these strong feelings with Abby, I strongly resonated with her words.

Pregnancy

Abby shares her experience of being pregnant and states that it was a bit difficult. As she was living in a small town, Abby states she did not see a specialized Obstetrician/gynecologist. She found it difficult to trust that the physicians who were part of her care were "*experienced enough.*" Abby appreciated that she was given a book by the health centre that described the pregnancy process. This book was in English and she was able to take the time to translate the information into Arabic. She found this very helpful, and felt she better understood the doctor during appointments.

Abby had good things to say about the nurses at the small health clinic in her town. As the nurses were constant in the clinic and involved in her care, she felt comfortable with them. While the physicians were nice, Abby never felt completely comfortable with them. This was her first pregnancy and she was far away from her

culture and support system. Abby felt that she had a lot of questions, and little knowledge of English. She needed time to ask them, however, felt that the doctors did not have a lot of time and then was unsure who to ask. Her sponsor was an older woman, Abby was concerned she may not receive up to date information on pregnancy. "*I was seeking about those information, I try to get, but at some point you feel you ask too much.*"

In the small town, healthcare practitioners often changed. Abby was unhappy that every time she had a doctor's appointment, she was seen by a different physician. She felt uncomfortable as she wanted to create a relationship with her physician. Late in her pregnancy, around 39 weeks, Abby started to notice her abdomen getting smaller. When she went to see a doctor about this concern, a different physician from the previous appointment assessed her and told her that maybe the doctor before had simply measured her incorrectly. However, when she went for an ultrasound, she was told that the baby was getting smaller. Abby shared that after this news, nothing else was done. Abby felt it was unacceptable to be told that maybe the other doctor had measured wrong, and felt that it was a sign that the doctor didn't have enough knowledge and was blaming it on someone else. She was scared that she did not know what was going on.

At 40 weeks, Abby asked if she could be induced as she was worried and ready to have the baby. She was told that there was nothing they could do for her and that they would not induce her at that time and asked her to go another week. Abby shared that in Syria, it is rare to carry a pregnancy past 40 weeks, and they will often induce at that time as there is fear that the placenta will "*dry-out*." While she was planning for her delivery, the medical team informed her that in case she needed a c-section, the operating room was leaking and could not be used. If she needed a c-section, she would need to be

transported to a different city to deliver her baby. When she asked how she would get to the city, she was told she would be taken by helicopter, but would have to go alone and her husband would have to go independently. When she vocalized her concerns about not wanting to deliver in the town, she says that they wanted her to deliver there and reassured her that she was young and that nothing should go wrong. However, Abby described herself as someone who thinks a lot and even though she was being told that everything was normal, she did not feel comfortable delivering her baby there. She had a friend who was living in a bigger city close by who had recently delivered a baby and had a good experience and helped Abby arrange to deliver in the city.

Delivery

Abby traveled to the city to deliver her baby. After deciding not to deliver at the hospital in her small town, she said she was not helped to arrange for an appointment or transfer of care to an obstetrician in the city where she wished to deliver. The health care staff gave her file to her and told her she could go where she wanted to go. They did not refer her anywhere. Abby relied on her friend in the city to help her arrange for an obstetrician to deliver her baby. Abby was frustrated and said it would have been easier if the doctors had arranged this. She wondered if they refused to help her because they did not like her decision to deliver elsewhere. She says she expected better. She now questions the appropriateness of the situation.

She was induced and then sent back home to wait for labour to start. The next day she returned and was given more medication to induce labour. After this, Abby recalls everything in the room beeping and alarms sounding as the baby's heartrate decreased. She was immediately taken for an emergency c-section. All went well and she delivered a

healthy baby. Abby speaks fondly of the physician who delivered her baby, saying that she felt that she was a very good doctor. Interestingly, she did not provide further explanation about this. Abby stated that due to stress she had to take blood pressure medication for around a month post-delivery to control her blood pressure levels.

Experiencing Healthcare with her Child

Abby experienced pregnancy and the birth of her first child in Canada. When asked about her experience of healthcare with her child, Abby expressed that while it was good, some things were missing. Abby said how nice it was to have a nurse check on her post pregnancy. She described how the nurse

> *came to my house every day to check, like showing me how to wash, to give him a shower and show me how to breastfeeding and show me like how to take care of baby, how to hold the baby everything. So, it was so nice. And I have C-section so she checked also the, what we say this….* [she was struggling to find the right words for this]

She liked the nurses because they "*keep smiling. They're so nice. Kind. You know, they give you time."*

Ongoing Healthcare Experiences

After her delivery, Abby moved to a different province and was unable to find a family doctor. After around 8 months, Abby and her family decided to move back to the previous province but to a different city where she found a clinic where the practitioners were fluent in Arabic and there was a female practitioner. This was important for Abby as from a cultural and language standpoint she felt most comfortable with a female, Arabic speaking physician. She told this practitioner about her health history and they arranged

for her to see a specialist. The physician asked if she wanted a referral. Abby consulted her friends and they were unable to suggest a specialist, Abby asked her physician to refer her *"to someone speak Arabic... And we need a doctor Arabic to understand everything. I went there."* The office was about a 40 minute drive for Abby and it was a *"medi-centre. Not to [the specialist], I mean like the doctor with [their] clinic… But looks like this is [doctor] comes once a month.*" Abby was disappointed and frustrated with the care received from this specialist. Abby did not like what she saw as "*rude*" reminders about her appointment and she did not like being told that they "*charge you a hundred bucks because the doctor […] come, like I said, I didn't, you call me… And I confirmed my appointment that week before that's when I'm coming. Why you saying […] just so you know that? I feel that's so weird.*" She felt that the physician was concerned that if Abby did not come for the appointment that the physician's time would be wasted. But

> *[the doctor]'s not wasting [their] time to read why I'm going to [them], why they do this referral to [the doctor]. So, when I went there, I wait probably, I don't know how many minutes then [the doctor] saw me. I sit on a very, very small room […] And [the doctor] came and [the doctor] say, […] "Why, why you here"? I say […] And [the doctor] said, "um, let me back to you" because there is no computer, nothing on the room. [The doctor] went there like 10 minutes.*

Abby was told that everything was normal and was sent home. She shared how she felt dismissed by this physician and felt that the physician was not taking the report seriously, or respecting her time.

Abby continued to try and take her health into her own hands and followed up with her family physician a year later. It was after this follow up appointment that Abby was given a serious health diagnosis. When the specialist informed her of her diagnosis, Abby was shocked. *"Are you sure it's me? Like, because I know like everything normal, everything is okay. And [the doctor] say, no, it's not […] And I, I just, like, I cry on the phone. Like I, are you talking to me?"* Part of Abby's shock was because this conversation and the conversation with the other doctor were close together in time, and she was told by this specialist that this issue was not new and would have been ongoing for years. *"I would say a week between this and this, the conversation on that time. I was so mad because I'm not the one who left myself, you know?"* During this conversation, my eyes filled with tears. Even as I wrote this account, I found my tears welling up.

I noted so much emotion when Abby recounted this story. It seemed to be a mix of anger, frustration and sadness as she communicated this event with strength. What Abby was saying resonated with many of my frustrations with the healthcare system, and hearing the detrimental effects of poor care from someone who was actively seeking healthcare was difficult for me, especially as I know that others likely share her experience. I wonder who is accountable to make sure that the healthcare being provided is adequate?

Looking back into her case, a betrayal of trust was identified. The diagnosis that Abby received will have lasting effects on her physical body, health and well-being. A diagnosis which Abby feels could have been avoided with proper care. When Abby was being told that everything was fine, she trusted the doctors, but now she feels like she

should not trust anybody. Abby vocalized on numerous accounts that she expected better from Canada.

> *You know like it's, it's very bad. Like always you feel like Canada, Canada, everything is good in Canada. Everything is better. The better life. Like you know, like when you plan everything, you escape from everything and for, to make a better life. You want your family and then what? You are shocked.*

Trust

Lack of trust is apparent throughout Abby's accounts. Abby told me that her current specialist had recommended treatment, and Abby was worried that this recommendation was not in her best interest. Despite Abby sharing that she trusted this current physician and felt that they're *"a good doctor"* who looked *"after me very well,"* she felt that although they are *"nice to me. But in some point, you can't trust like a hundred percent."* Abby mentioned wanting a second opinion. Due to her mistrust, Abby admitted to sending her file to a trusted physician in Syria to receive a second opinion about the recommended treatment. She said,

> *I feel a little bit shame because I take my report and I send that to Syria, to a doctor from Syria. See this report. If the doctor is telling me the right thing or not because I can't trust doctor here. That is like, it's very hard. It's very hard.*

Finding a New Family Physician

As mentioned previously, Abby and her family moved to a city in a different province for a brief period of time. Abby explained that the entire time she was there, she was unable to find a family physician. I asked Abby how she found her initial family physician after relocating. Abby mentioned that she saw that a new clinic was opening up

when she was in the community. She saw the clinic was clean and big and when she saw the posters about different languages, she decided to *"ask if they have like female Arabic doctor.*

> *So just, I went there and I asked the reception, do you accepting a new patient? And she say, absolutely. And I ask her, do you have a female, uh, doctor speak Arabic? And they say, yes, absolutely […] and I took an appointment and I start, go to her.*

After her poor healthcare experience, post diagnosis, Abby went without a family physician for some time. Abby found her current family physician through a website that lists available family physicians in the area. When I asked Abby how she found out about this website, she said that someone in the health system, perhaps one of the nurses told her. She went without a family doctor for a while but on visits to her specialist, they asked who her family doctor was. She told the nurse, that "*I don't know how to find one."* She likes the website and has recommended it to her cousin who came from Lebanon.

Abby spoke further about her current family physician and said that she found it "*hard to trust*" a family doctor. I asked Abby if she felt that her concerns were listened to when she went to see a family doctor. I wondered if she had ever felt that she needed to pressure the doctor to follow up on a concern or had ever felt that her concerns were brushed off.

> *Yeah, absolutely. Because in [the small town], like they don't listen to me…unfortunately I felt for, for doctors we're numbers, how many clients I meet on a day that's good, So I make this amount they don't really have time to sit and listen. I just a doctor, one doctor. I really like [them]. And I feel like [they] don't*

mind sitting with me like hour talking he's a doctor […] yes. I will say, yeah. [They are] just the one, the doctor who talk to me and give me time, uh, like how [they] said answer… I hate when the doctor clock, when you're talking so I feel that is most of them do this.

Deciding How to Access Healthcare

When asked if her experiences of healthcare in Syria affected how she accesses healthcare in Canada, Abby paused, *"I'm trying to find this for it. So yeah, for actually I get a mix between Syria and Canada, because it's, you can't compare."* However, Abby did compare her experiences in the Canadian system with the Syrian system. When Abby described the nursing care given in Syria with the care in Canada, I was quite shocked. She said in her two experiences here in hospital, she found nurses are *"so kind like taking care of the patient. You feel like your most relation, like you will talk and see mostly the, the nurses."* She described that when she was in the hospital for her C-section, she needed a needle *"in my tummy."* When the nurses awakened her at night they were *"very nice and kind, and you know, like she wake me. I'm sorry, Abby."* She contrasted this with nurses in Syria who are *"very rude if I don't give her the tips and money…. she don't come even to give me a pill, you know, even if she have to."* Abby sometimes gave very general examples that she knew of. She gave another example of a nurse who felt she would be in *"a trouble if she didn't give this needle, so she will come to the room, she will slam the door. She will be so mad. She'll show you like that is, you are not good. You don't give me money or tips."* If you do provide some money and gifts, the nurse *"will be so good, you know, and amazing. And looking after you and she can clean the garbage, do, do everything for you just because of the money."*

The first time that Abby was in the hospital in Canada, her and her husband asked if they needed *"to give bribes for a nurse here."* They did not know who to ask as the only people they knew in Canada besides their sponsors were Syrians who were now in Canada. None of them had been in the hospital. She and her husband thought that the nurses were so nice because *"they're expecting some money. We have to like bring some cash, but then we feel like it's would be so rude to give them money."* Finally, they asked their sponsor what to do. And the sponsor said*, "No, no, don't do it at all. It's not acceptable here at all."*

Abby explains explained that she uses Google to check wait times in emergency departments as well as the rating of physicians prior to deciding where and when to access healthcare services.

> *I have not very good experience here. But still there's so many things is good. But how I go, if like, um, say something happens, I need to go to emergency how I go to there. Absolutely. I will check which one is not waiting. List is like shorter […] Yeah. It's a time. I like the time. And you know what? Like after my experience, now I start looking for ratings for doctors…. I use google a lot to track the health system here"*

How can the Healthcare System Improve?

When asked what the healthcare system could or can do better, Abby often provided feedback for Syrian refugees other than herself. She is now in a unique position where she provides resources for other Arabic speaking refugees. Abby believes the healthcare system must provide more education to refugees/immigrants in their own

language, including information on the role of health care professionals such as doctors and pharmacists, as their roles are different in Syria.

> *...Arabic now is so common here in Canada. Like we are now more than before. So, like, for example, here we have like 50% or the clients Arab, speaking Arabic. So, if there is something to more, give them knowledge about like, how is the health system is here. That would be perfect. ...last time I saw a lady she's pregnant, she's looking for, uh, a program that is show her how to take care of baby, how to give him a shower, everything, because she's by herself here. But all the program we found it's in English….Like not of people they're very low, low, low educated. So, I'm thinking, yeah, just to have like more common, like programs in other language than other than English, that would be very helpful…. So just this, I would be very helpful. I think it would be so nice. to just give them more knowledge about the health system."*

Education For New Mothers

When Abby talked about her experiences with healthcare when giving birth to her daughter, she spoke about the care she received from the nurses post-delivery, and about their kindness and the time they spent with her.

> *Those are things, people really looking after that, you know cause that in the end, like each one of those Syrian refugees, they need to someone and understand that because everything is a new, it's very hard. It takes while to understand a new country because it's not, the health system was a new, everything is in this city or this is a new word. It's a new for them. But the health it's something you can't, you leave it. You need to be in the process. ... Just be a little bit calm and patient to*

give time, give time there is bunch of question like, and have been here, like almost this is the six years going to seven years and I'm still, there is so many things. I don't have enough information. How is the system? Don't forget. Don't forget. I know there is a website you can translate and put the language you want. Lots of them don't have a computer or they don't know how to use a phone. And especially women, especially women, they don't, most of them, they don't know even write. ... I would say like, I'm coming from the level high educated in Syria, but this is like more than at least 10% of that woman in Syria. Most of women in Syria in the grade three, they sit home because the cultures think they're not able to go to school. They have to marry like when like her period is come. So around 12 years old, 13 years old. So, what are you expecting from a child. I feel like this is a child because she didn't leave her childhood, how she will do, how she would be like, include with all these things. And she is just sitting on her room so they would say like, yeah, the website, you can see translate in English. There is somebody. Okay. But she don't know most of them.

Abby believes it is important for healthcare providers to educate refugee women about birth control. Abby mentioned that courses or information packages should be available as many Syrian women do not seek out birth control as they believe it will have negative effects on their body such as making them age and gain weight. As well, Syrian women are less likely to bring up women's health concerns with a doctor, especially if it is a male physician even though symptoms may lead to problems in the future.

Wait Times and Lack of Healthcare Services

Abby also brought up the wait times, and difficulty of accessing healthcare resources a few times during our interviews. Abby mentioned how difficult it can be to book an appointment with a family physician when feeling unwell, leaving no other option than to go to an emergency department to seek treatment for something that could be better managed by a family doctor. She avoids going to emergency because of the long wait. Abby also noted the lack of urgent care clinics open at night. To give an example of wait times, Abby shared a story of accessing urgent care for a foot injury she had. She described how she

> *broke my feet. I wait. It's seven hours. Okay…. It's so, too much. Even like we say, yeah, he get like a tylenol or whatever. I have a kid [she's] in my grandma's house. And because they open at five I got there at 5:30. I leave, more than six hours.*

Abby shared that during this visit she was told her foot was broken and had to pay out of pocket for an air boot cast. She was told that a specialist would follow up with her as soon as possible. After a prolonged period of time, Abby had not heard back from the specialist and sought private fee for service healthcare elsewhere to seek quicker healthcare service. At that time an X-ray was repeated and Abby was told that her foot was in fact not fractured, but that she had a cyst that would most likely require surgery. However, Abby explained that so far surgery has not been required.

Another issue with wait times that Abby brought up is booking for diagnostic imagining. While the wait might be more than two weeks, "*I have to be happy and very grateful because they found it for two weeks."* While she knew that sometimes *"it's not*

urgent, but it's urgent for the person." She felt that the system is not fast enough, *"I feel just not enough. You know, this is my point."*

Abby also spoke about the difficulties she has witnessed that other Syrian refugees have with laboratory services. Often the tests and the test collection processes are not explained. It is often difficult to get an appointment, even when the order is urgent, and that often people have to return for more bloodwork as things are missed.

Looking Back on a Life Journey

Abby and I ended our conversations by talking about how she has coped with her negative health experiences. Abby said that she is coping, although the past year had been hard for her when dealing with this, as well as COVID. Despite all she has been through, Abby is determined to take control of her health. Abby taught me a lot about her journey as a refugee woman, and the experiences other refugee women may have when accessing and participating in healthcare in Canada. I am grateful that Abby trusted me enough to let me travel to her worlds (Lugones, 1987) as I learn more about not only her worlds but my own worlds and who I am and am becoming as a woman, Canadian, nurse, and researcher.

CHAPTER 3

Narrative Account of Sky

Introduction

I first met with Sky at the community centre. The meeting was friendly and short and Sky seemed interested in participating in the study before I had even explained it. We went over the study and consent and then chose a location to meet for the upcoming conversations as Sky did not wish to start that day. I mentioned that I was open to meeting wherever Sky was comfortable and she recommended a café. At first, Sky seemed to want to accommodate me and have me choose where to meet. Wanting to ensure she was comfortable, I encouraged her to pick a location of her choosing reassuring her I was happy to meet wherever she would like. After the first meeting we moved to a local café that Sky chose. At first, I was nervous about meeting outside the community centre. However, I came to understand that meeting away from the community centre and in a community location allowed me to get to know her in a different setting.

Life in Syria before the war

When I asked Sky about her life in Syria before the war, she described it as "*okay*." While she lived in peace with her family, her family experienced some issues. Her father was an alcoholic, and it was difficult for her mother to leave him because in Syria, divorce brings shame to your family. "*We suffered a lot with him, but it's hard to leave him because we will suffer anyway."* After five years in the same home as their father, Sky and her brother and sister told their mom they had to go. They moved out. Sky explained that when people divorce in Syria, a person is allowed to keep property

registered in their name. As a result, even though their mother had bought their house, it was registered in her father's name and he kept the house. The family had to start again, first renting a house and then later buying one. Sky started working at age 17 while attending university, which was uncommon in her community. Most individuals in Syria do not work while in university and they rely on support from their parents. Sky liked working as she met lots of different people through different work experiences. Sky said, *"it was good. And we start like building our life. We bought a house."* However, less than a year later, the war started and Sky left everything.

Healthcare in Syria

In Syria there are two healthcare systems: a publicly funded one that provides free healthcare, and a privately funded one that requires payment. The public system is very poor, and there is the possibility of acquiring more serious illness when seeking healthcare services through that system. As Sky said, *"If you go there, like it's, it's not good. Like no way. Like I prefer to stay home sick and not, yeah. Not go there."* Sky and her family preferred to pay for private healthcare as typically the care was superior to the public system, however it was expensive with charges for everything. She never did share stories with me about accessing the public system. Sky elaborated by describing that there were fees for medication, for seeing the doctor and for going to the hospital. *"Everything you have to pay, unless like, you're going to public"* which is *"not good."* She said that her doctor was *"good for me. I don't know. Like, for example, he told me that I have a Celiac disease from the, when I was kid. […] but back, back in the days he was like, good. Me and my entire family. We go there."* She said that she had been in *"the hospital two, three times. Like, I mean the, not the public one, the private one, like it's*

clean and they take care of you and stuff like money talk there. Yeah, yeah, yeah. Money talk there."

Life in Syria During the War

Sky and her family are Christian, and when the war in Syria started, Christians were targeted. Sky speaks of the Islamic State of Iraq and Syria (ISIS) and how they targeted and kidnapped Christian men and forced them to join the military or be killed. Since her brother was more at risk than the rest of her immediate family, they arranged for her brother to be taken by helicopter from Aleppo to Latakia and from there he took a bus to Lebanon. Sky and her family stayed behind. Sky described life during the war as "*hard"* but "*when I, I think about it, it was so fun. I don't know. Yeah. Like to live without the electricity, to survive with everything there, it's hard, like to, to line up, to get bread. That's like something so stupid to, to think about it. But we lived it."* She described having *"lighters. I can remember it till now. Like there's no electricity, so there's a lighter. There's a, a light under me. But like, you know, I just like using this, just to walk in the street, yeah, like, just to see it."* She also spoke of not having *"a lot of foods"* and wearing extra pants and socks to be warm enough *"just to sleep. Imagine with the jacket, winter jacket. Because like there's no electricity, there's no gas. There's nothing*." I was somewhat surprised as Sky said that even though *"it was hard… like I learned a lot of things from it…. I don't regret for anything happen to my life."* As we talked about her experiences and she reflected on them, she laughed occasionally. I was struck by her ability to look back on these times in a positive way.

Leaving Syria

Sky sought refuge in Lebanon when she was 22 years old. In the winter the roads were a little safer to travel and when there was a chance to pass into Lebanon, she took it. Sky remembers her mother telling her she was crazy to go, but Sky was adamant that she needed to leave. "*Like every, every minute maybe you will lose yourself. Like you'll die. Or you will see your sister, your, your mom … anyone there, they will die."* She described the frequent phone calls about people being killed.

> *So, for me, like to risk my life and going to Lebanon, it's like, just the same, like I'm risking here. I can risk it on the road. Right. So, I said like, no, I will go there. Like, I'm doing nothing here. I'm just like trying to find the waters, trying to find the bread. Like, that's not life I want to go.*

Life in Lebanon

After spending 12-13 hours on what was normally a 6-hour bus trip, Sky arrived in Lebanon and was able to live with her brother. Sky had trouble finding a job in Lebanon. When employers saw that she was Syrian, they refused to hire her. By chance when Sky was walking through a mall looking for work, she came across a neighbour from Syria who helped Sky get a job through her employer. Working conditions were poor and Sky worked long hours for minimal pay. After a while, Sky found a job that paid better and sponsored her to get a visa to stay in Lebanon.

During her time in Lebanon, Sky shared that her brother also experienced difficulty finding work as it was even more difficult for Syrian men to find employment in Lebanon. He decided to go to Turkey and from there to take a boat to Germany, which was illegal at the time. He asked if Sky wanted to go with him and she refused because

she would be far away from her family, and it would be impossible to return to Syria. Sky said she would not be able to live with herself if something happened to her family in Syria and she was not close by. Her brother left and she remained in Lebanon.

After three years Sky's mother and sister joined her in Lebanon. They stayed in Syria so her younger sister could finish high school, something that would have been impossible to do in Lebanon. Without completing high school, she would not be able to progress to university. They lived in the small room that Sky was renting for a month and then rented a house. Sky's mother found a job as a tailor and Sky found a job for her sister with the company she worked for. They started to make a life there. *"And we start living there. We are fine. We start having fun, like going out in Lebanon. It's so nice country there. We had a lot of friends. We start like living our life, normally like normal people."*

Deciding to Leave Lebanon

Despite life in Lebanon beginning to feel more normal, Sky shared they were still living in fear. She described how "*we are not safe because any time they will fire you. And if he fire me, nothing money wise and even I can't live in this country. If he fire me, you know, it's hard. Like you always have to be perfect in your job, so they will keep you."* Prior to her mother and sister joining her in Lebanon, Sky shared that she began to look into leaving and that there were ample opportunities at the time to apply to Canada, to Australia, to *"go with my brother."* However, she did not *"apply for anything. And when they came, I told them like, we should apply. But it was the time that they closed everything."*

Sky tried for a while to apply to come to Canada with her family but was unsuccessful in finding applications. She spoke with contacts in Canada who told her there was no way to apply at that time, that applications for refugees were closed. Sky and her family resolved to live in Lebanon with the hope that one day they could return to live in Syria. However, Sky was contacted by a friend living in Canada and told of an opportunity to apply to come to Canada. She jumped at the opportunity and her and her family were successful and able to resettle in Canada.

Coming to Canada/Living in Canada

Sky and her family arrived in Canada as permanent residents under private sponsorship through a church. Sky arrived with her mother, and her sister joined them after completing University in Lebanon. Sky described that "*my sponsor is like close to me. So, I'm not shy to ask or like, it was easy for me. Like easier than other people"* who might be *"shy to ask."* She described how *"they helped me a lot. And the sponsor, the church, they give us like 4, 6 months I think, uh, rent for, uh, my apartment."* Sky shared that adjusting to life in Canada was made easier by having personal contacts from the Syrian community here. Even though her funding and sponsorship was through a church, it was her friend from Syria who made it possible for Sky and her family to apply and to come. The sponsorship and money from the church was very helpful because Sky was able to start working during that time and was able to save some money.

While Sky was happy to come to Canada, she spoke of the different challenges she faced.

> *I was so happy to come to here. Like it's like a new life. And here it's like, now it's new chapter, different things, different like problems, you know, it's not like our*

> *problems. So, it was like, there it's like suffering to survive. And here it's like suffering from cold, different culture. For me, it was something stupid. I can deal with it. You know? It's so easy to deal with it. but um, yeah, it's so hard. Like it's everything different, everything different tastes too. You know, it's it takes like a year to understand everything here, but we right away, we start working.*

Sky was able to find a job at a clothing store and shared that she likes knowing that if she has an issue at work, she is able to speak to the manager and can contact human resources if needed. Sky went from working part-time to being offered full-time employment with benefits and a pay raise as she was one of the best sellers in the store. However, Sky spoke of how hard the move to Canada was for her mother as she speaks minimal English and has had a hard time finding work. Her mother was able to find a job as a tailor, but recently lost her job. Sky feels responsible for her mother in Canada and often spends her days off helping her mother with daily activities such as grocery shopping and going to appointments.

Sky has reconnected with contacts from Syria and says that her contacts and sponsors helped her and her family to adjust to life in Canada. Sky spoke of how she had to learn many new things here such as how to cross the street and walk in the snow. *"I was afraid to walk on the snow because like how I should walk and it's like snowing there that's mean like we have to stay home, you know?"* Sky learned how to take the bus because she did not want to continue relying on people for transport like her sponsors who are "*so busy*." When Sky's sister joined them, she also taught her sister how to use public transport. She described how she was

> *not afraid, like maximum, I will stop anywhere and order Uber, Uber and come back again. But I want to try. Yeah, I tried. It was like it's, it was easy, but sometimes I get lost like two or three times, because like, you have to stop and take another bus […].*

Sky also took Ubers sometimes, especially when it was cold in winter. After a year Sky obtained her driver's licence and was able to purchase a vehicle. Having a vehicle was important to her and has made her life a lot easier.

When Sky arrived in Canada she had some knowledge of English. She understood spoken English but was afraid to speak as she had never spoken English. She learned English in school and in the movies. Sky forced herself to speak English and eventually felt more comfortable to practice speaking English when she saw that in Canada many people speak with accents and that no one seemed to be bothered by that. She did not use the translation services offered by the settlement agency. Sky took an English proficiency test at the settlement agency and was offered language classes. She went to a couple classes but found that what she was learning was not helpful. Adding to this, she was having to cancel shifts at work and pay for an uber to get to the classes, so she decided they were not worth it.

While Sky still experiences some struggles in Canada, they are very different from her experiences in Syria and Lebanon. She spoke of starting *"a life for many times,"* reminding me that she had started *"a new life for two times in Syria. And I started life in Lebanon. And after that I left everything and I started life here."* She told me that she

> *had a lot of dreams before, but now I don't care about anything. I'm just living, you know, that's something happened, like something nice happened with…all this experience. But in other hand, I'm living now, you know. My boyfriend…said like, "oh, you're taking like, that's fine. Like you, you were swimming…in the sea for eight years. Now you are, you arrived. You need to rest" But my rest it's like, it's been three years. I'm resting, you know, I, I get used to rest now and that's something, uh, I don't like it, but on the other hand, like, I don't know, I'm dealing with everything now here. I'm responsible for everything here.*

She spoke of not having time to *"think about my career, my future"* and how she does not want to think about her life but *"sometimes I need to think about it. It's the time, like enough wasting your time."* While she spoke of wanting to go back to school and study something else, she is unsure what she would like to study. At first Sky was unsure if she wanted to settle in Canada long term and had plans to maybe move to Germany to be with her brother. However, "*now I have my friends," "I have my boyfriend here and I get my car for the first year here."* She said that she "*spent like 22 years back home. And it's a dream to have a car there."* She noted that *"even to travel, you have to save a lot to travel and you will have a problem with a visa because you have a Syrian passport and stuff like this. So here I can feel it's so easy to live."*

She feels safe, is getting used to living here, and is happy here. Sky commented on how it is so much easier here than in Syria to purchase more expensive items, but she often does not appreciate them as much. She said that "*Back home. It's so hard to get everything. So…you will like, appreciate that you have this thing. And because other people, they don't have here. Most of the people, they have everything."*

Experiences of Health Care

When Sky first arrived in Canada, her Syrian contacts helped her get her healthcare card and find an Arabic speaking family physician. This was important to Sky as she was more comfortable communicating in Arabic. The doctor gave her a full medical check-up and Sky was impressed with this, "*it was wow.*" She liked being able to access health care for free

> *because like if I can't afford the money or someone can afford the money, he still have an option to go to the doctor. Back home, like if you don't have money, he can't, if you're sick and you don't have money, you will be sick forever. You will die. No one take care, take care of you. Here, the good thing it's like, it's free for everyone. So everyone can do a do the checkup every year. That's a, a good, a nice thing here. […]*

Sky shared that she was able to be screened for cervical cancer, which was new for her as in Syria there was no screening or preventative health measures. In Syria, people have to just find out if they had cancer and if they do not have money to pay for treatment, they die.

Sky stopped going to her original family doctor because she felt that they were not good enough, and that they took advantage of her being new in Canada. While Sky felt uncomfortable here, she said such situations are normal in Syria and people just deal with it themselves. Sky decided to stop going to this clinic and found another clinic.

Sky requested her file from the clinic, and, after a few weeks of not hearing back from anyone, she went to the clinic to follow up. While there she overheard the staff speaking in Arabic about how much they should charge her for her file. She felt they

came up with an arbitrary price, and Sky questioned if she should have been charged for it. "*I can understand them, but they, I don't know if they know that I'm Arab. I don't know."* Sky shares that all the problems she had at the health clinic are problems that are possible back home and would be normal for her to deal with but that she was shocked that they were happening here. Sky wonders if Canadians have similar experiences and do not do anything about it. This made Sky question if the people in the clinic are taking advantage of Arab people because they know what they can get away with but are more careful with Canadian people. When I asked Sky if her experience with that clinic has altered her trust and level of comfort with the healthcare system here, she responded by saying "*Actually. Yeah."* I questioned her further and she said,

> *Like when I came to, I told you, like, it was so good. Like my first impression about this it's like, wow, like they don't, you don't have to have the money…You can feel you are a human. But after that, like it's just the same. But in a nicer way, you know, it's same thing, same problems, but in a nice way, that's it? I feel like just the same […].*

Ongoing Healthcare Experiences

Sky found a new family physician close to her home by using google and looking at online reviews of the physician. She was able to do this on her own. While this doctor speaks Arabic, Sky shared that she often feels more comfortable communicating in English. She is more able to express her medical concerns and be understood in English. When there is something that she does not understand, Sky will use google translate. Sky shared that her new doctor is "*so good*" but feels that every time she seeks health care from this physician, she is the one asking for specific tests to be completed. When results

from tests came back as normal, even though Sky was still experiencing symptoms, no further investigations were completed. *"He's a doctor. Like he just wants to get paid, you know? Like, he's not like, like my sister, [her doctor] he's always following up with her, checking on her."* Sky has found this different then the care provided by family physicians in Syria. Even though the doctors back home "*are not good like here, they will find the things to you. Maybe because we pay them. I don't know, because like they will find, like, if I went there, I have a headache. He will find a different million things to do it for me. Here, I'm just like, can you please do this? Can you please check this?"*

Sky shared another story of being sent to a specialist for chronic nosebleeds. She was sent for a scope when prescribed treatments were not working. The specialist did the scope and Sky was told to wait for results. When she was not contacted with results from the procedure, she phoned the clinic for the results. She was told that she needed to book an appointment with the doctor and was booked for an appointment in a month. Five days before the appointment, she was contacted and told that they needed to reschedule her appointment and pushed it back again by a few weeks to a month. Sky had to switch shifts at work in order to make that new appointment time work. The day of the appointment, she was contacted again to reschedule her appointment for later in the day which she could not do because she had already switched to a later shift at work to accommodate the appointment. Sky did not reschedule at that time and decided not to follow up as her nosebleeds had improved. Sky compared this to Syria and explained that she would have expected more prompt medical care.

> *See, like back home, we will pay for the doctor. But…if I call him like now, next day, I will see him. Here, it takes time, and I'm a person that I can't wait…. Like,*

because I'm in pain now. But next week, maybe I'm not in pain. So, I will forget about it.

Even though Sky raised concerns about the health care system in Canada, when she compared it to Syria, she still finds it much better. *"The health there it's so bad. Like here, I mean like we're complaining because like, we need the perfect things here, but back there, like you are okay with everything."* However, now that she has been in Canada for a while, *"I need the perfect things, you know?"* When I asked her directly if the health care she had here in Canada was better than in Syria, she said, "*Yeah. It's better. Um, like you can feel they care about you. I don't know because there's no money between me and the doctor…That's why maybe I can feel it's better… He will do his job and I'm there. Like I never think about the money."*

Navigating healthcare

When I asked Sky about how she learned about how to navigate the Canadian healthcare system, she responded that she used Google and she also turned to her Syrian community here. *"They helped me a lot. Like…my friend, […] took me to [their] family doctor and we start like doing the checkup and all the tests and some stuff like this. Um, it was hard because like everything is new, but for me it was easy because like, I have like an idea about the stuff here."* I asked if she found it difficult to get to medical appointments. Sky responded that she found it easy enough to figure out. She has been able to access healthcare services close to her neighborhood. The only time Sky had to travel far from her house was for an ultrasound appointment that was in a different town. At this point she had a car and even though she was scared to drive that far, she did.

Experiencing health care with her family

Throughout our time together, Sky spoke of the experiences her family members had with the healthcare system. Sky shared some of her sister's experiences with health care in Canada, saying that her sister has found a good family physician that she likes and who she feels follows her health care well. Sky shared that she might switch to this physician as she feels he would do more than her current doctor.

Sky feels responsible for her mother here in Canada and goes with her mother to all of her medical appointments. Sky' s mother relies on her to translate and this can be difficult at times as she does not know all of the specific body parts or medical terms in both languages. When they arrived in Canada, translation services for medical appointments were offered through the settlement agency, however, Sky did not feel comfortable relying on others for help and chose not to use those services.

Sky shared an experience of seeking healthcare with her mother for a deep wound to her hand. Sky shared that she was "*afraid… Like I put her in my car.*" She consulted her friend, who works in healthcare. Her friend told her she would need stitches and told her "*it's faster to go to emergency, emergency clinic more than the hospital. Because it's like something small. So, I went there…And there's a lot of people waiting too.*" Sky waited there with her mother, but she was concerned about the amount of blood her mother was losing. *"I'm seeing a lot of blood. She's like, she's losing blood."* The nurse told them to have a seat, but Sky was concerned and did not want wait. Sky felt that if the nurse at the emergency clinic had looked at the wound and provided some basic care or directed them elsewhere it would have been better than just telling them to take a seat and

wait. As Sky described the experience and what she wanted to have happen, there is a sense of her frustration.

> *So, if she took… a look on it… she can say like, you don't have to wait. You can go to any, any pharmacy, any clinic, they will do it for you. So, I feel like, I know it's busy there. I know like everywhere busy. But at first step they have to check everything. Like if you're not dying, they're not taking you as an emergency. […] But you can check, like you're wasting. Maybe I will stay there for three, four hours. and it's something so stupid. I can deal with it at like, out of here. Like you can tell me, go to there, but I'm wasting the time here and I'm stressed for nothing.*

Sky felt that because she did not know if the bleeding was normal. She was *"seeing a blood that's mean like something, like something big, you know, not everyone can deal with the blood and stuff like this."* What Sky wanted was to be told *"don't worry about anything."* Sky did not want to "*wait two, three hours …for me she's bleeding for me."* She spoke of how she and her mother were in *"an emergency situation now"* but for the nurse it was *"something normal."* Sky would have felt more reassured if the nurse had given her an assessment. Sky ended up leaving the clinic with her mom due to the wait time. She sought care elsewhere.

Medication and Dental Coverage

Sky was disappointed with dental services in Canada. Even with coverage from Sky's employer benefits, visiting the dentist/dental work is extremely expensive. She felt dental care should be something "*you can afford it. Like if you have a problem."* Sky shared her experience with dental care and was shocked by how much it cost her even

with 80% coverage from her employee benefits. While Sky has dental care benefits, her mom and sister do not. *"They don't have and so hard. Okay. Like, yeah, my mom, she had the crown and uh, it fall and she need just to put it and it takes like $300 to do it.*" Sky expressed that for the cost the dentist had not done anything else because *"to do something else, but it's too much."* Sky commented that she could book a ticket and go to Lebanon*, "It's cheaper than doing here."* Her sister had not received dental care in the past two years. After finding out how much Sky had to pay even with coverage to have a filling replaced, her sister has continued to wait to access dental care.

Sky herself *"went last year for a checkup and I have like six small things to fix with the 80%. I, I spend, uh, 1500 with the 80% imagine. Uh, yeah. And he told me, don't worry, you can put it in your tax and stuff like this. I said, okay, that's fine. Like I said, like 1500, it's like less than a ticket for, to go back home and fix it there."* Sky also spoke of the cost of medications in the Canadian healthcare system. While she has benefits, she understands that not everyone does. For something that is a serious health concern Sky wondered what people do when they cannot afford medications. Sky believes that medications for serious health concerns, as well as at least dental checkups should be a part of universal free healthcare.

Mental Health Care

At the end of our time together, Sky spoke of therapy in Canada. According to Sky accessing therapy in Syria is stigmatized and is "*like shame to talk about it*." Sky shares that when she came to Canada she was offered therapy but did not feel like she needed it. She spoke of being offered therapy because she "*came from war. So, you have*

like, not like it's you have to go, but we are offering this, if you want. I said, no, I'm fine. Like, I don't have anything."

However, she told me that it was *"nice to talk with someone about like everything. I never, like, we never talk about anything here and compare it with anyone there. Like we're comparing them the way that if we live here, comparing there, that's the things something like nothing there."* Sky shared that it has been easy and, in a way, nice to share her story with me, because she felt more open to sharing with a stranger.

In Canada she thinks that people care about therapy but in Syria *"we call the people that they using this it's like crazy people, you know."* Sky did not agree to therapy when she was offered it in Canada *"because in my mind it's like, they will call me crazy. You know? But now I think it's, I would try it one day."* While she would not feel comfortable talking about everything with family and friends, *"When you have someone you don't know in front of you, you will talk more like freely".* In part her changed views have resulted from her experience with talking with me as a researcher: *"it's something comfortable to talk to you".*

Final thoughts

Through my time with Sky I learned about her experience as a young woman experiencing war and fleeing her home country. I travelled to her world through her stories of her experiences of her journey from Syria to Lebanon and then from Lebanon to Canada. I admire Sky's strength and independence. I learned from her experiences as a refugee woman who accessed and participated in healthcare services in Canada. Attending to Sky's stories, I metaphorically laid my stories alongside hers and reflected on my healthcare experiences, as well as my experiences as a registered nurse working

within the healthcare system. Through attending to Sky's stories, I reflected further on my identity as a woman, Canadian, current student and researcher. Sky trusted me with her stories and opened her world up to me, allowing me to gain a better understanding of it, for that I am grateful to Sky.

CHAPTER 4

Resonant Threads

Through reading and rereading the narrative accounts, resonant threads, or patterns that reappeared throughout the accounts began to emerge. By focusing on threads, I followed patterns or plotlines that thread and weave through time and place within each participant's narrative account (Clandinin, 2013). After laying the two accounts alongside one another, two resonant threads became evident. These threads provided a deeper and broader understanding of the experiences of Syrian refugee women as they accessed and participated in healthcare in their host country. In the following section, the two key resonant threads are discussed.

Thread 1: Linking Intentionality with *Good* Care

After listening to Abby and Sky's stories it became clear that there was a lack of consistent provision of *good* healthcare. While both Abby and Sky had positive things to say about the healthcare system, such as it being free and appreciating the care they had received from nurses, listening to their experiences it felt that receiving *good* healthcare depended on luck. There was no apparent intentionality from healthcare professionals to provide *good* care. The etymology of the word *good* points to the ideas of excellent, valuable, desirable and beneficial (Online Etymological Dictionary, nd); *good* is not an arbitrary idea or experience but depends on intentions. According to Watson (2002), intentionality in relation to care conveys

> a more technical, philosophical meaning referring to a consciousness and awareness that are directed toward a mental object, with purpose and efficacy toward action, expectation, belief, volition, and even the unconscious. (p. 14)

According to Malle and Knobe (1997), intentionality includes a) the *desire* for an outcome, b) *beliefs* about an action that can lead to that outcome, c) an *intention* to perform the action, d) *awareness* of the act when performing it. Skill is integral for an action to be performed with intentionality (Malle & Knobe, 1997). What guides the intentionality is a strong sense of what is perceived as *good* by Abby and Sky.

Communication

In Abby's introduction to the Canadian healthcare system, she was left to fend for herself in terms of communication. Abby arrived in Canada with minimal knowledge of the English language. When accessing healthcare services, she was never offered interpretive services even though it was obvious that she was experiencing difficulties communicating. Abby had to resort to Google Translate and shared that this was often confusing. Even though healthcare workers often found her "*like struggling and having very hard time to, to tell them what is my question? What I feel,"* interpretive services such as a language line (translation services that can be access by telephone) were never offered. On top of this, Abby often felt rushed and described that healthcare professionals did not take the time needed to fully understand or respond to her medical concerns.

> *They didn't really give me enough time. I don't, I don't feel like, like it's nice to me, like sit and open a Google and try to ask them sometimes before I go, I put my question in Arabic, in English on a piece of paper. I make them ready because I really want to know. But even the answer I'm not, I can't understand very well. Cause I'm getting the idea what he's talking because he's not like writing for me so, I use it Google.*

Abby shared that often the doctors would use simple words to provide medical explanations and although Abby did not always fully understand, she was left feeling that she should "*just stop asking."* Abby is not alone when feeling that the physician is not spending the time to fully understand and address health concerns (RHC, 2020). Cultural and linguistic barriers are widely experienced by newcomers when accessing and participating in healthcare (Victoria, 2007; Winn et al., 2018;). As many refugees arrive in Canada with limited, if any, knowledge of the English language, communication barriers are common and have both direct and indirect impacts on health (Victoria, 2007). As well, since healthcare, and the healthcare system itself, vary among different countries, newcomers often bring with them beliefs, cultural values and expectations of how to interact with the healthcare system and healthcare professionals, which may differ from those aligned with the Canadian healthcare system (Victoria, 2007).

Communication barriers were also present in Sky's experiences as she shared her responsibility of acting as the interpreter for her mother's medical appointments. Sky shared with me that translating is difficult as she did not know all the specific body parts in both languages and felt that she has a hard time describing the medical issue to healthcare providers or translating the medical information back to her mother. Abby and Sky are not alone with experiencing communication/language barriers when accessing and participating in healthcare. This is a common theme throughout the literature, with many Syrian (among others) refugees experiencing similar situations (Guruge, et al., 2018; Khanlou, et al., 2017, Oda et al., 2017, Stirling Cameron et al., 2022). The lack of access to interpretive services during healthcare visits and the person seeking healthcare being made responsible for providing solutions to communications barriers have been

reported (RHC, 2020). Often these language barriers lead to extended wait times, as well as poor medical and health outcomes (Stirling Cameron et al., 2022). Often children or other family members are asked to translate for healthcare professionals which is impacted by family members lacking training and experience, causing interpretation errors that can lead to negative health effects (Rimmer, 2020; Rosenburg et al., 2008; Victoria, 2007). Other barriers relating to the use of family members as interpreters include difficulty maintaining neutrality when translating for a family member or loved one, and family members may give healthcare professionals their interpretation of events, which may not align with the patients' and a misdiagnosis may occur (Rimmer 2020; Rosenburg et al., 2008; Victoria, 2007). Furthermore, family members may find it difficult to share bad news and may withhold or alter the information being shared by the healthcare practitioner; and relying on minors to translate may have negative effects on them and can lead to emotional trauma/stress (Rimmer, 2020; Rosenburg et al., 2008; Victoria, 2007).

This raises the question that if translation services are available, why are they not offered? After listening to both Abby and Sky's experiences with communication barriers when accessing healthcare services, I wondered why is it the patient's responsibility to provide a translator or a solution for their communication needs? The lack of intentionality in ensuring that communication efforts are made, may lead to the perception that *good* care is not being offered.

Transpersonal caring-healing

In both Abby and Sky's accounts, a lack of intentional transpersonal caring-healing is evident. Intentional transpersonal caring-healing according to Watson (2002) entertains

> a view whereby health and healing are acknowledged as: a relational, energetic process by which individuals maintain their ability to cultivate and manifest deep values, beliefs, and meaningfulness in the midst of suffering and disease. Additional acknowledgment is given to attentiveness, presence, authenticity, personal relationships, perceptions, thoughts, and emotions as fundamental points of connection between consciousness, energy, and unitary theories and science models. (p. 15)

This is shown in Sky's accounts through many ordinary examples such as: her experiences with cancelled appointments and the frustration, disruption and lack of returning for health services that this caused; and her experience when accessing an emergency clinic for her mother's wounded hand, to name a few. Another example of a lack of intentional transpersonal caring-healing is Abby's prenatal experience. Abby shared that she did not receive consistent care and experienced many changes in physicians during her pregnancy. On top of this, she was never followed by a specialized care provider, such as an obstetrician or gynecologist. Abby shared with me that she was never able to fully feel comfortable with the physicians throughout her pregnancy, and that while she had a lot of questions, she felt that the physicians did not have the time that she needed to formulate and ask her questions. One positive thing that Abby was thankful for was that she was provided a book with information detailing what to expect during

the pregnancy process by a healthcare worker. However, though this book was in English, Abby was able to take the time to translate this book into Arabic and found the information quite helpful.

Abby shared with me that she noticed her abdomen getting smaller around 39 weeks and when she vocalized this to the physician, she was met with a response that the previous doctor must have measured her incorrectly. An ultrasound was done, and Abby was told that the fetus was getting smaller, however nothing further was done. Abby was scared that she did not know what was going on and felt that blaming another physician was a sign that they did not have enough knowledge. Even when Abby vocalized wanting to be induced at 40 weeks due to her concerns, she was told that they would not induce her and she would have to wait to go into labour naturally. This was very different from what Abby was expecting and explained that in Syria it is rare that a pregnancy would carry on past 40 weeks as there is fear that the placenta will "dry out."

Abby shared how the physician and other healthcare staff in the local small-town hospital wanted her to stay there to deliver her baby, even after explaining that the Operating Room was non-operational at the time. Their reasoning was that since she was young and healthy, her chances of experiencing complications and an emergency operation were rare or not necessary. If Abby had needed an emergency operation she would have needed to be transported via helicopter to a different city, adding time and increasing the risk of potential health complications for both herself and her baby. When Abby decided she was not comfortable with this, the care providers left her responsible to arrange her own care. After listening to Abby's experience, I wonder why, if the healthcare professionals knew that there was a chance of needing the operating room for

delivery and that this was not an option at the time, they would not have helped Abby arrange for alternative delivery plans when she vocalized not feeling comfortable? Were they intentionally dismissing her concerns?

Attentiveness and presence

Abby described a lack of attentiveness, presence and personal relationship when she shared her medical journey towards a serious health diagnosis. While she was sent to an Arabic speaking specialist, it meant she was sent to a medical centre that offered specialist services about once a month. The medical centre was far from where Abby lived. Compared to Syria, Abby says she was shocked with the healthcare system here. While she appreciated that healthcare is free, she feels that to physicians in Canada, she is just a number and is not acknowledged as a person who desires and values *good* care. She often felt that the doctors did not want to engage with her.

> *[the doctor]'s not wasting [their] time to read why I'm going to [them], why they do this referral to [the doctor]. So when I went there, I wait probably, I don't know how many minutes then [the doctor] saw me. I sit on a very, very small room […] And [the doctor] came and [the doctor] say, […] "Why, why you here"? I say […] And [the doctor] said, "um, let me back to you" because there is no computer, nothing on the room. [The doctor] went there like 10 minutes.*

Both Abby and Sky communicated stories of long wait times for healthcare services and a feeling of fear associated with not knowing what is going on. Abby shared a story of presenting to an urgent clinic for a foot injury and having to wait hours for medical care. Waiting was particularly difficult as it meant leaving her young child for a long period of time. After hours of waiting in the clinic, she was told she had a broken

foot, that she had to pay out of pocket for an air-boot cast and was told that a specialist would follow up with her regarding her injury. After days of waiting and not hearing from the specialist, Abby decided to seek care elsewhere through a private clinic, having to pay out of pocket. There she was told that her foot was not broken, that it was instead a cyst that might require surgery. Abby shares that after a month, the original specialist contacted her for an appointment.

In Sky's experience of accessing an emergency clinic for her mother's deep wound to her hand, they were told to sit and wait for hours with no reassurance that her mother would be okay. Sky shared that the nurse checking patients in the emergency clinic did not assess the wound and that Sky was concerned about the amount of blood her mother was losing. Sky was *"seeing a blood that's mean like something, like something big, you know, not everyone can deal with the blood and stuff like this."* Sky wished that she would have been told *"don't worry about anything".* For Sky, she was worried and did not want to "*wait two, three hours … for me she's bleeding for me."* She spoke of how she and her mother were in *"an emergency situation now"* but for the nurse it was *"something normal."* Sky would have felt more reassured if the nurse had given her an assessment. Sky ended up leaving the clinic with her mom due to the wait time. She sought care elsewhere. For Sky the intentions of *good* care were not upheld by the care provider.

Both Abby and Sky have shared personal stories of seeking healthcare services only to feel that they are being provided with the bare minimum or care that is inadequate. Sky shared how she sought care from her family physician for gastrointestinal issues. The physician ordered one test to investigate this concern and

when the result came back as normal, no further investigation or treatment was offered, even though the symptoms persisted. Sky noted how different the care she received is in Canada from the care she had received in Syria. Even though the doctors in Syria

> *are not good like here, they will find the things to you. Maybe because we pay them. I don't know, because like they will find, like, if I went there, I have a headache. He will find a different million things to do it for me. Here, I'm just like, can you please do this? Can you please check this?*

Both Abby and Sky have mentioned long waits for an appointment with a family doctor or a specialist, as well as having these appointments cancelled on short notice to be rescheduled weeks to months later. Sky vocalized her frustrations and shared that in Syria, she would have received prompt care.

> *See, like back home, we will pay for the doctor. But … if I call him like now, next day, I will see him. Here, it takes time, and I'm a person that I can't wait…. Like, because I'm in pain now. But next week, maybe I'm not in pain. So, I will forget about it.*

Furthermore, both Abby and Sky's narrative accounts highlight how the quality of healthcare received varies with different physicians. Sky shared that her sister received care from a family physician who is attentive to her needs and intentional in their care. *"Like my sister, [her doctor] he's always following up with her, checking on her."* Abby shared that throughout her healthcare experiences in Canada, there has only been one specialist that she is impressed by, who takes the time to listen to her concerns and follows her care.

> *I just a doctor, one doctor. I really like [them]. And I feel like [they] don't mind sitting with me like hour talking he's a doctor […] yes. I will say, yeah. [They are] just the one, the doctor who talk to me and give me time, uh, like how [they] said answer… I hate when the doctor clock, when you're talking so I feel that is most of them do this.*

The experiences of waiting and a lack of care have eroded both Abby's and Sky's trust in the healthcare system.

Collective Intentionality

Finsterwalder and Kupplewieser (2020) describe the concept of collective intentionality, which refers to intentions that are connected to joint actions, and involve individuals aligning towards common goals, and values. Individual actions become interconnected in the sense that there is shared intention to accomplish a common goal (Finsterwalder & Kupplewieser, 2020). Collective intentionality has the potential to affect value co-creation when it comes to well-being (Finsterwalder & Kupplewieser, 2020). This sense of collective intentionality was not experienced by Abby or Sky. They did not have common goals or values that they shared with their care provider.

Abby shared that she finds it "*hard to trust*" a family doctor. When asked if Abby felt that her concerns were listened to when she went to see a family doctor or if she has ever felt that her concerns were brushed off, she replied,

> *Yeah, absolutely. Because in [the small town], like they don't listen to me…unfortunately I felt for, for doctors we're numbers, how many clients I meet on a day that's good, So I make this amount they don't really have time to sit and listen. […] I hate when the doctor clock, when you're talking so I feel that is most of them do this.*

This lack of trust has led Abby to send her medical chart to a trusted physician in Syria for a second opinion on recommended treatments. Sky shared that experiences she has had here with family physicians have shocked her/ altered her level of comfort and trust with the healthcare system.

> *Like when I came to* [Canada]*, I told you, like, it was so good. Like my first impression about this it's like, wow, like they don't, you don't have to have the money…You can feel you are a human. But after that, like it's just the same. But in a nicer way, you know, it's same thing, same problems, but in a nice way, that's it? I feel like just the same […].*

Sky also wonders if, with all the difficulties she has experienced, Canadians have similar issues with the healthcare system, or if she was treated differently because she was a refugee and would not have knowledge regarding what she can expect from the healthcare system.

On multiple occasions, Abby spoke highly of the care she received from nursing staff. She appreciated their kindness as well as the time they spent with her to understand her health concerns and provide personalized care. This is especially important as Abby explains that most Syrian refugee women have received limited education and many not know how to read or seek information on their own. Abby explained how important it is for healthcare providers to understand that everything is new for Syrian refugees and therefore navigating the healthcare system can be difficult for them. She highlighted the importance of taking time to listen and answer questions for patients.

> *"[…] But the health it's something you can't, you leave it. You need to be in the process. … Just be a little bit calm and patient to give time, give time there is bunch of question […]"*

For both Abby and Sky, it is important that healthcare providers are intentional in attending to their lives. This intentionally is part of *good* care for them.

Thread 2: Linking Agency and Action

Agency refers to the "ability to make and act upon decisions and is related to one's *internal* power and the meaning, motivation, and purpose that can underlie an action" (Shankar et al., 2019, p. 165). Through Abby and Sky's stories, it is clear that both desire personal agency, but that this desire is not met by the healthcare system. Both women share experiences that describe how they desire independence and want to take ownership of their health. It is evident that Abby and Sky have sought out health care for specific concerns and yet, they are often met with the inability to take control over their health outcomes.

When arriving in Canada, there was no formal introduction to the Canadian health care system. While their sponsors were responsible for getting them set up to use the healthcare system, including arranging for healthcare cards and transportation to clinic visits, there was no formal education provided about the Canadian healthcare system. Both Abby and Sky had to learn on their own about what is included in universal free healthcare, when and how to access healthcare services, how to arrange for a family physician, among other things. This left Abby and Sky to rely on word of mouth and trial and error to figure out the healthcare system in Canada. Sky shared that she was able to learn about the healthcare system through guidance of Syrian refugee community

members. However, Abby arrived in a small town, with no Syrian refugee community to rely upon. She learned about the Canadian healthcare system through her sponsor.

> *So, I would, when I ask them, we keep like, talking about it, like for all visit two, three hours sometimes, you know, then it will be like next day I will bring other question because it's a new country, new things for me. There's always something to ask every day.*

When attending closely to both Abby and Sky's narrative accounts, a lack of personal agency and relational agency are evident. Drawing on work by Edwards (2005), relational agency can be defined as "a capacity to align one's thoughts and actions with those of others in order to interpret problems of practice and to respond to those interpretations" (p. 169). Relational agency relies on the "capacity for working with others to strengthen purposeful responses to complex problems" (Edwards, 2009, p. 39). Both Abby and Sky expressed a willingness to work with healthcare professionals to create healthcare plans, however, they expressed on many occasions a lack of being brought into the process.

Throughout Abby's healthcare journey, Abby shared multiple experiences of expressing concerns regarding her health and seeking health services to attend to her health needs. Abby shared that on many occasions she was disappointed with the care she received, often feeling dismissed by healthcare professionals. Starting with her pregnancy, Abby had a lot of questions during her pregnancy and felt that she could not ask them as it seemed that the physicians did not have the time that Abby needed to communicate. "*I was seeking about those information, I try to get, but at some point you feel you ask too much.*"

Sky shared similar experiences with the healthcare system where a lack of relational agency is evident. Sky was disappointed with her family physician and felt that every time she sought care from this physician, she was the one asking for specific tests to be completed. When results from tests came back as normal, even though she was still experiencing symptoms, no further investigations were completed. She said that she thinks *"He's a doctor. Like he just wants to get paid, you know? […]."* Sky shared how this was different from the care provided by family physicians in Syria.

A lack of collaboration is evident throughout the accounts, with Abby's experience of pregnancy and delivery being a prime example of this. When listening to Abby's story, it became visible that decision-making autonomy was not respected and that Abby's quest for agency was impacted.

Following her pregnancy and delivery, Abby shared further experiences where a lack of relational agency is evident. Abby sought healthcare services for a medical concern, yet she was not taken seriously. Abby shared that she felt that her time was disrespected; she was sent home with very little explanation or information regarding her health concern. When Abby followed up with her family physician a year later, she was given a serious health diagnosis which shocked her. Part of Abby's shock was amplified, as she was told by this specialist that this issue was not new and would have been ongoing for years. According to Moore (2016), agency allows an individual to feel that they are in control of their actions, and the related consequences, allowing them to feel in charge. While Abby took control of her health by seeking care for her medical concerns and following advice given to her from the physicians, she has suffered long term negative health consequences due to the lack of care she was provided. Abby has shared

that this has made it very hard for her to trust physicians and expressed how she expected better from the Canadian healthcare system. These examples highlight how Abby's attempts to attain personal agency were not met by the healthcare system.

Abby arrived in Canada as a healthy young woman and due to receiving poor care, she is experiencing long term negative effects on her physical and emotional wellbeing. Unfortunately, Abby is not alone when experiencing worsened health status in her host country. In a Canadian study performed in 2018, authors Guruge et al. found that existing and emerging health concerns have worsened for refugees since resettling in Canada. This is due to delayed access to care, along with feeling that healthcare providers fail to respond quickly or seriously enough to their health concerns (Guruge et al., 2018). There was often a discrepancy between their self-rated concerns and how healthcare professionals evaluated them, causing them to feel dismissed (Guruge et al., 2018). Furthermore, many women felt that their autonomy to make decisions was not respected by healthcare practitioners and that their decisions regarding care were disregarded (Stirling Cameron et al., 2022).

Building Agency

After listening to Abby and Sky, it is clear that both women sought agency for their own health and wellbeing, but they were not met with a system that assisted them in agency building. Building personal agency allows individuals to advance their own capacity and cultivate resiliency and adaptability when faced with diverse and changing situations (Shankar et al., 2019). Building personal agency, particularly with women, is important as they play an important role in "the intergenerational transmission of health, development, and equality" (Shankar et al., 2019, p. 165). Research supports that gender

equality and wellbeing can be achieved when women are "valued, enabled and empowered" as both consumers and providers of healthcare (Shankar et al., 2019, p.165). Enabling women to develop agency promotes equality and has broad positive impacts on the health and development of women, their families and communities (Taukobong et al., 2016).

Abby provided some insights into ways that could help cultivate agency. Something that Abby thinks is key to improving agency is to provide information and education on the healthcare system for newcomers. This includes providing information on the role of different health care professionals. This education should be provided to refugees and immigrants in their own language and should take into account their level of education. As Abby noted

> *Arabic now is so common here in Canada. Like we are now more than before. So, like, for example, here we have like 50% or the clients Arab, speaking Arabic. So, if there is something to more, give them knowledge about like, how is the health system is here. That would be perfect.*

Another way to promote agency that was brought up by Sky was the importance of mental health and the use of therapy in Canada. According to Sky accessing therapy in Syria is stigmatized and is "*like shame to talk about it*". Sky shared that when she came to Canada she was offered therapy but did not feel like she needed it. She spoke of being offered therapy because she "*came from war."* In Canada she thinks that people care about therapy but in Syria *"we call the people that they using this it's like crazy people, you know."* Sky did not agree to therapy when she was offered it in Canada *"because in*

my mind it's like, they will call me crazy. You know? But now I think it's, I would try it one day."

Conclusion

Through Abby and Sky's stories, I was better able to understand these resonant threads. The first being intentionality and *good* care and the second being agency and action. It became apparent to me that these threads in themselves are linked, as intentionality and *good* care go hand in hand with building agency and promoting action. Abby and Sky were both willing and wanting to actively participate in their care, had they experienced more intentionality and collaboration within the healthcare system, perhaps they would have been empowered to continue to develop agency over their health. This leads me to the next chapter, where I will be discussing the personal, practical and social justifications of this narrative inquiry.

CHAPTER FIVE

Justifications

As Clandinin and Caine (2013) write, the researcher must be able to justify the need of their research by answering the questions of "so what?" and "who cares?" (p.174). By providing personal, practical and social justifications for this narrative inquiry research study, these questions can be answered (Clandinin & Caine, 2013, p. 174). In this chapter, I will draw on the resonant threads as I emphasize the personal, practical and social justifications for this research.

Personal Justifications

At the beginning of this narrative inquiry, I explored my narrative beginnings. These narrative beginnings helped develop my research and shaped this narrative inquiry study (Clandinin & Connelly, 2000). By inquiring into my experiences, I was able to "study who [I am] and [am] becoming in relation to the phenomena" (Clandinin & Caine, 2013, p. 174). By doing so, I was able to consider who I am in relation to Abby and Sky, and place myself in the midst of the research (Clandinin & Caine, 2013). Looking back on my narrative beginnings, I told stories that alluded to individual power/empowerment, gender equality and the concept of *good, patient centred,* healthcare. From a young age, the importance of language and the idea of being "helpful" was present in my life. This was further built upon during my undergraduate nursing program where I studied in both French and English. Furthermore, my growing identity as a women and feminist positioned me to pay closer attention and recognize inequities I experienced as a woman seeking healthcare, and the differences in treatment that I saw other women experience. Throughout my nursing career, I have become increasingly aware of inequities/gaps in

care that women and racialized people face within the healthcare system. Working with a diverse population has continued to open my eyes and provided me with living examples of the effects of intersectionality (Hill Collins, 2019) and the impact that race and gender have on the quality of healthcare one receives. Through these encounters, I have become more aware of my own privilege as an educated, white woman, familiar with this healthcare system (and a part of it). I think back to personal experiences that have left me feeling frustrated and unheard as a patient. I recall having to push for certain tests to be ordered, to have my concerns investigated or to advocate for the treatment and care that I felt was in my best interest. Through my experiences as a nurse and as a woman, these narratives of experience have brought me to wonder about the stories of refugee women in relation to healthcare. As I listened to the stories Abby and Sky shared, my idea of what a refugee woman might experience when accessing and participating in healthcare was changed. I was awakened to struggles I had not considered, but also to a strength and yearning for agency to a level that I had not considered. I saw many similarities in the frustrations that Abby and Sky shared with feeling dismissed by healthcare professionals. However, the disruption of agency and the destruction of value that was caused, along with an evident lack of intentionality by healthcare practitioners, was not something I had previously considered or understood.

World-Travelling

Through Abby and Sky's stories, I was able to travel to their worlds and better understand their experiences. "World-travelling" (Lugones, 1987) helps me to identify with Abby and Sky as traveling to their "world" allows me to "understand what it is to be them and what it is to be [myself] in their eyes*"* (Lugones, 1987, p. 17). I entered the

narrative inquiry space from the world of a healthy, educated white woman, who is coming from a stable environment, free from conflict. As a woman, I found myself recognizing similar frustrations with the healthcare system. Feeling that my health concerns have been brushed off and that I have to strongly advocate for myself when accessing and participating in healthcare. I also entered from a world of a registered nurse where I am responsible for caring for patients with the aim to provide safe, competent, patient centred care, one where forming therapeutic relationships is one of my main priorities. As I travelled to the worlds of Abby and Sky, I began to better realize how the healthcare system can fail patients. It was difficult for me to deal with these relational tensions (Clandinin, 2016).

Relational tensions are "shaped by our ethical stance" (Clandinin, 2016, p. 209). Abby and Sky both introduced their stories with expressions of gratitude for free healthcare, and Abby was explicit to speak fondly of the nursing care she had experienced, at times making reference to myself as a nurse. However, when Abby and Sky shared their experiences of care received by healthcare professionals I felt dis/ease in Lugones' (1987) sense. This lack of ease stemmed from experiencing healthcare interactions from within their worlds. This was a very visceral feeling and caused me to rethink and better understand relational commitments. As a nurse, my first reaction is often "to fix" or "to do". Clandinin (2016) wrote

> tensions we experience often challenge our own ethical spaces. By attending to these tensions, we learn from them, even when there is no intention to resolve them; rather, our intentions are to learn and live in ways make visible our commitments. (p. 209)

Although I could not "fix" the difficulties that Abby and Sky encountered within the healthcare system, their experiences will forever shape my own. Through Abby and Sky's stories, I was able to travel to their worlds and better understand their experiences. In doing so, this brought forward many powerful questions and considerations for myself as registered nurse as I face inward. How can I bring mindful intentionality to the forefront of my practice and provide *good* care? How can I work with patients to empower them to build agency in their lives?

Practical Justifications

Practical justifications lend to the "so what?" of the research study (Clandinin & Caine, 2013). When reflecting on the practical justifications of this research, I found myself centring thoughts around my nursing practice. Throughout my nursing education and then in nursing practice, *patient-centred care* (now recognized as *person-centred care)* has been the preferred model of care (Picker Institute, n.d.). This model places the focus of care on the "person" where the individual is recognized as an important member of the health team and encouraged to play an active role in their care (Ortiz, 2018; Picker Institute, n.d.). This model values and recognizes the individual's needs and relies on positive, therapeutic relationships between the patient and care provider(s) (Picker Institute, n.d.). Founded on eight principles (respect for patients' values, preferences and expressed needs; involvement of family and friends; coordination and integration of care information, communication and education, physical comfort; emotional support and alleviation of fear and anxiety; transition and continuity; and access to care), patient-centred care is based on the belief that all individuals deserve high-quality healthcare (Oritz, 2018; Picker Institute, n.d.). I found it interesting that Abby, who had more

interaction with other members of the healthcare profession than Sky, had nothing but good things to say about the nurses with whom she had contact. She explained how she was able to build relationships with them, felt comfortable with them and trusted them. Furthermore, she focused on how they would be the ones to spend time with her, which she appreciated. This is in stark contrast to experiences that Abby and Sky shared when receiving care from physicians.

Reflecting back on this study as a registered nurse, engaging in narrative inquiry work has helped me further develop my understanding and practice of patient-centred care. This narrative inquiry has required me to become more wakeful to the person I am and the person I am becoming. Through Abby and Sky's narrative accounts I found myself comparing my practice to healthcare experiences described in their stories. When reflecting on both professional and personal experiences, I began to recognize how connected the two are (Clandinin & Connelly, 2000). My professional experiences have been, and continue to be, shaped by personal experiences and vice versa. The knowledge and experiences I gained through conversations with Abby and Sky are now part of my professional life.

Abby and Sky both shared stories of language barriers and the effect that had on their healthcare experiences. When Abby mentioned how she struggled to communicate and felt that she did not have the time needed to effectively communicate her concerns or ask questions, I reflected on times when I also rushed communication, relied on the patient's family member to translate, or was unable to offer language line to someone due to time and resource constraints. I have since found myself taking extra time to ensure that effective communication is established, even if the patient is able to speak English.

Abby and Sky both expressed experiences of healthcare that lacked intentionality and did little to encourage agency building. These concepts go hand in hand, and their experiences led me to reflect again on the principals of *patient-centred care* and how often the healthcare system fails to uphold these standards. Through their stories of poor care and struggles to build agency, I reflected on how the healthcare system fails to encourage, and value, active participation from the patient, often making decisions for their health that do not involve them. Moving forward, I wonder how I can ensure that the patient is an active participant in their healthcare? How might I engage them in agency building? How might I better attend to the needs of the patient? And the needs of women in particular? How might I begin to understand what they value as *good* care?

Social Justifications

The Canadian government has accepted and continues to accept many Syrian refugees that consist of young families, with many of the women being of childbearing age (Ahmed et al., 2017; Houle, 2019). Yet, these women and families experience inequities and disparities in the healthcare system as there are many health challenges unique to refugee women. A literature scan on the experiences of Syrian Refugee women accessing healthcare in Canada yielded minimal results, confirming the need for more research in this area. This narrative inquiry contributes to filling this existing gap in research.

Through Abby and Sky's accounts, it became evident that intentionality of care and agency building were linked and often lacking in their experiences with the Canadian healthcare system. Through their stories it was clear that there was a lack of collaboration, as well as a lack of *good* care. These women expressed actively wanting to

participate in their healthcare but were met with a system that did not invite them into this process. This discouraged collaboration and agency building and left both Abby and Sky feeling dismissed. Not only did this lead to serious health effects, but it also caused negative effects/emotions towards healthcare practitioners such as anger, grief, and a lack of trust. The doubt in the healthcare system is upsetting and it was evident that it is difficult to rebuild. Agency building empowers individuals to take control of their lives, and therefore also their health (Moore, 2016). This is particularly key for women as agency building with women has the possibility to transcend the individual and positively affect the health of their families and communities (Shankar et al., 2019; Taukobong et al., 2016). Furthermore, building agency in women helps to improve gender inequity (Shankar et al., 2019; Taukobong et al., 2016). Intentionality and *good* care leads to the co-creation of value and a lack of these can also destroy that value (Finsterwalder & Kupplewieser, 2020). We can see this through Abby and Sky's stories of avoidance of accessing healthcare or seeing a family doctor, not going back when dissatisfied with services, continuing to suffer from a health concern due to inconvenience, lengthy wait times, and dissatisfaction with care. Both Abby and Sky compared the healthcare available in Canada to that of Syria, mentioning on multiple occasions how they expected better from Canada. I hope in telling the stories of Syrian refugee women of childbearing age, others will gain insights into their life making. I hope this research will facilitate a greater understanding of the needs of this population and may be used to inform policy/program development specific to this population. Furthermore, this research contributes to the advancement of my own personal knowledge as a nurse, enabling me to provide more culturally responsive care and practices. Through Abby and Sky's stories, I

was able to travel to their worlds and better understand their experiences. In doing so, this brought forward many questions and considerations for myself as registered nurse, woman and researcher.

Future Research

Since 2015, the Canadian government has resettled thousands of Syrian refugees, with the majority of these being young families (Government of Canada, 2021a; Houle, 2019). Studies show that immigrant and refugee women are particularly disadvantaged and often experience unmet health needs (Filler et al., 2020; Oda et al., 2019; Tuck et al., 2019; RHC, 2020). Reproductive, mental, as well as preventative healthcare have been identified as key health services that are often lacking (Filler et al., 2020; Redwood-Campbell et al., 2008; RHC, 2020). In order to improve healthcare experiences for this population, research that attends to the unique experiences of Syrian refugee women needs to continue. Through hearing the lived experiences of Syrian refugee women, this informs policies and programs that best meet their needs and works to protect their health and wellbeing. There is a great need to develop, implement and assess interventions that focus on the intentionality of provide care that is considered good, as well as intervention that forefront the importance of building agency.

Study Limitations

Narrative inquiry aims to gain insights into an individual's experiences, rather than to create generalizable results (Clandinin & Connelly, 2000). While Abby and Sky's narrative accounts allowed me to better come to know them and their experiences with accessing and participating in healthcare in Canada, these narratives do not necessarily represent all Syrian refugee women's experiences.

Furthermore, these conversations took place during the COVID-19 pandemic. All precautions and public health measures were adhered to by the researcher and participant to ensure safety. However, as narrative inquiry work is relational, the wearing of masks and distance kept between researcher and participant may have contributed to tension or impacted the relationships formed.

Conclusion

Narrative inquiry is not concerned with forming generalized statements or theories (Clandinin & Connelly, 2000). Rather, narrative inquiry allows us to travel to another's world through their stories of experience (Clandinin & Connelly, 2000; Lugones, 1987). Narrative inquiry gives voice to those not often heard and allows for those stories and life experiences to be told (Clandinin & Connelly, 2000). Through Abby and Sky's narratives, I came to know them, and in doing so, explored their experiences when accessing and participating in healthcare so that I could come to know it differently (Lugones, 1987). While I could never fully capture Abby and Sky's entire lives, these narratives offer a sense of the complexities of their experience that takes into account temporality (the timelines of their migration journeys and resettlement processes), sociality (the political and social contexts) and place (the various environments in which they composed their lives) (Clandinin & Caine, 2013). All experiences are unique, and by sharing the voices and storied experiences of Abby and Sky, I have come to understand them and my practices as a nurse in new ways.

References

Ahmed, S., Shommu, N. S., Rumana, N., Barron, G. R. S., Wicklum, S., & Turin, T. C. (2016). Barriers to access of primary healthcare by immigrant populations in Canada: A literature review. *Journal of Immigrant and Minority Health*, *18*(6), 1522. https://doi.org/10.1007/s10903-015-0276-z

Ahmed, A., Bowen, A., Cindy Xin Feng, & Feng, C. X. (2017). Maternal depression in Syrian refugee women recently moved to Canada: A preliminary study. *BMC Pregnancy & Childbirth*, *17*, 1–11. https://doi.org/10.1186/s12884-017-1433-2

Alberta Association of Immigrant Serving Agencies (n.d.). *Alberta Syrian refugee resettlement experience study*. https://aaisa.ca/wp-content/uploads/2020/07/Alberta-Syrian-Refugee-Resettlement-Study_Final.pdf

Alrifai, T. & Dore-Weeks, R. (2018). Here's why Syrian women are integral to peace. *UN Women*. https://arabstates.unwomen.org/en/news/stories/2018/8/why-syrian-women

City of Edmonton. (2021). *Belonging: Stories of the dignity and resilience of immigrants. The state of immigration and settlement in Edmonton annual report.* https://www.edmonton.ca/sites/default/files/public-files/assets/PDF/SIS-AnnualReport-2021.pdf

Clandinin, D. J., & Connelly, F. M. (2000). *Narrative inquiry: Experience and story in qualitative research*. San Francisco: Josey-Bass Publishers.

Clandinin, J., & Caine, V. (2013). Narrative inquiry. In Audrey Trainor and Elizabeth Graue (Eds.), *Reviewing qualitative research in the social sciences* (pp. 166–179). New York: Routledge.

Clandinin, D. J. (2013). *Engaging in narrative inquiry.* Walnut Creek, CA: Left Coast Press

Clandinin, D. J. (2016). *Engaging in narrative inquiries with children and youth*. Routledge.

Cultural Orientation Resource Center. (2014). *Refugees from Syria*. http://www.culturalorientation.net/learning/backgrounders

Dewey, J. (1916). *Democracy in Education.* New York: Macmillan.

Edwards, A.T. (2005). Relational agency: Learning to be a resourceful practitioner. *International Journal of Educational Research*, 43, 168-182.

Edwards, A. (2009). Relational agency in collaborations for well-being of children and young people. *Journal of Children's Services*, *4*(1), 33-43. https://doi.org/ 10.1108/17466660200900004

Filler, T., Jameel, B. & Gagliardi, A.R. (2020). Barriers and facilitators of patient centered care for immigrant and refugee women: A scoping review. *BMC Public Health*, 20(1), 1-12. https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-020-09159-6

Finsterwalder, J., & Kuppelwieser, V. G. (2020). Intentionality and transformative services: Wellbeing co-creation and spill-over effects. *Journal of Retailing and Consumer Services*, *52*. https://doi.org /10.1016/j.jretconser.2019.101922

Government of Canada. (2019). *How Canada's refugee system works*. https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/canada-role.html

Government of Canada. (2020a). *2020 Annual Report to Parliament on Immigration*.

https://www.canada.ca/en/immigration-refugees-citizenship/corporate/publications-manuals/annual-report-parliament-immigration-2020.html

Government of Canada (2020b). *Resettle in Canada as a refugee*. https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/help-outside-canada.html

Government of Canada. (2021a). *#Welcomingrefugees: Key figures*. https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/welcome-syrian-refugees/key-figures.html#popup1

Government of Canada. (2021b). *Map of destination communities and service provider organizations*. https://www.canada.ca/en/immigration-refugees-citizenship/services/refugees/welcome-syrian-refugees/destination-communities-map.html

Gruner, D., Lin, D., Magwood, O., Warmington, R., Muldoon, L., Alkhateeb, Q., & Pottie, K. (2022). Prevalence of chronic conditions in Syrian refugees to Ottawa. *Canadian Family Physician*, 68, e10-e15. https://doi.org/10.46747/cfp.6801e10

Guruge, S., Sidani, S., Illesinghe, V., Younes, R., Bukhari, H., Altenberg, J., Rashid, M., & Fredericks, S. (2018). Healthcare needs and health service utilization by Syrian refugee women in Toronto. *Conflict and Health 12*(46). https://doi.org/10.1186/s13031-018-0181-x

Hill Collins, P. (2019). *Intersectionality as critical social theory*. Duke University Press.

Houle, R. (2019). Results from the 2016 Census: Syrian refugees who resettled in Canada in 2015 and 2016. *Statistics Canada*. https://www150.statcan.gc.ca/n1/pub/75-006-x/2019001/article/00001-eng.htm

Khanlou, N., Haque, N., Skinner, A., Mantini, A., & Kurtz Landy, C. (2017). Scoping review on maternal health among immigrant and refugee women in Canada: Prenatal, intrapartum, and postnatal care. *Journal of Pregnancy,* 1-14. https://doi.org/10.1155/2017/8783294

Lugones, M. (1987). Playfulness, "world"-traveling, and loving perception. *Hypatia, 2*(2), 3–19.

Mahaffy, C. (2018). Lessons from the influx: How Edmonton welcomed refugees from Syria...and what we are learning as they strive to put down roots. *Edmonton Chamber of Voluntary Organizations*. https://ecvo.ca/wp-content/uploads/2019/06/Lessons-from-the-Influx-Final-Report-June-2-Web.pdf

Malle, B. F. (1), & Knobe, J. (1997). The folk concept of intentionality. *Journal of Experimental Social Psychology*, *33*(2), 101–121. https://doi.org/10.1006/jesp.1996.1314

Mehta, T. (2016). The Syrian refugee crisis explained: How did the whole problem start? *The Odyssey.* https://www.theodysseyonline.com/syrian-refugee-crisis-explained

Mercy Corps. (2021). *The facts: What you need to know about the Syria crisis*. https://www.mercycorps.org/blog/quick-facts-syria-crisis

Moore J. W. (2016). What Is the sense of agency and why does it matter? *Frontiers in Psychology*, *7*, 1272. https://doi.org/10.3389/fpsyg.2016.01272

Oda, A., Tuck, A., Agic, B., Hynie, M., Roche, B., McKenzie, K. (2017). Health care needs and use of health care services among newly arrived Syrian refugees: A cross-sectional study. *CMAJ open*, 5, E354-E358. https://doi.org/10.9778/cmajo.20160170

Oda, A., Hynie, M., Tuck, A., Agic, B., Roche, B., & McKenzie, K. (2019). Differences in self-reported health and unmet health needs between government assisted and privately sponsored Syrian refugees: A cross-sectional survey. *J Immigrant Minority Health* 21(3), 439–442. https://doi-org/10.1007/s10903-018-0780-z

Online Etymology Dictionary. (n.d). *Good*. https://www.etymonline.com/search?q=good

Ortiz, M. R. (2018). Patient-centered care: Nursing knowledge and policy. *Nursing Science Quarterly*, *31*(3), 291–295. https://doi.org/10.1177/0894318418774906

Picker Institute. (n.d.). *The picker principles of person centred care*. https://picker.org/who-we-are/the-picker-principles-of-person-centred-care/

Redwood-Campbell, L., Thind, H., Howard, M., Koteles, J., Fowler, N., & Kaczorowski, J. (2008). Understanding the health of refugee women in host countries: Lessons from the Kosovar re-settlement in Canada. *Prehospital and Disaster Medicine, 23*(4), 322-327. doi:10.1017/S1049023X00005951

Refugee Health Coalition. (2020). *Community engagement project report*. https://617330b4-fccf-4314-9619-017f27a6e2d9.filesusr.com/ugd/ fda787_ 0f3b634eff7c42d29ca35dcb57c9cff7.pdf

Rimmer A. (2020). Can patients use family members as non-professional interpreters in consultations? *BMJ*, *368*, m447 doi:10.1136/bmj.m447

Rosenberg E, Seller R, & Leanza Y. (2008). Through interpreters' eyes: Comparing roles of professional and family interpreters. *Patient Education & Counseling*, *70*(1), 87–93. https://doi.org /10.1016/j.pec.2007.09.015

Sami, S., Williams, H. A., Krause, S., Onyango, M. A., Burton, A., Tomczyk, B. (2014). Responding to the Syrian crisis: The needs of women and girls. *Lancet*, 383, 1179-81. https://doi.org/10.1016/S0140-6736(13)62034-6

Shankar, A., Sundar, S., & Smith, G. (2019). Agency-based empowerment interventions: Efforts to enhance decision-making and action in health and development. *Journal of Behavioral Health Services & Research*, *46*(1), 164–176. https://doi.org/10.1007/s11414-018-9592-0

Stewart, E. W., Souza, L. R. D., & Yudin, M. H. (2018). Access to prenatal care for pregnant refugee women in Toronto, Ontario, Canada: An audit study. *Journal of for the Poor & Underserved*, *29*(2), 687–700. https://doi.org/10.1353/hpu.2018.0052

Stirling Cameron, E., Ramos, H., Aston, M., Kuri, M., Jackson, L. (2021). "Covid affected us all:" The birth and postnatal health experiences of resettled Syrian refugee women during covid-19 in Canada. *Reproductive Health*, 18, 256. https://doi.org/10.1186/s12978-021-01309-2

Stirling Cameron, E., Aston, M., Ramos, H., Kuri, M., Jackson, L. (2022). The postnatal experiences of resettled Syrian refugee women: Access to healthcare and social support in Nova Scotia, Canada. *Midwifery*, 104, 103171. https://doi.org/10.1016/j.midw.2021.103171

Struebert, H.J., & Carpenter, D.R. (2011). Designing data generation and management strategies. *Qualitative research in nursing: Advancing the humanistic imperative* (5th ed., pp.33-55). Philadelphia: Wolters Kluwer Health/Lippincott Williams & Wilkins.

Taukobong, H. F. G., Kincaid, M. M., Levy, J. K., Bloom, S. S., Platt, J. L., Henry, S. K., & Darmstadt, G. L. (2016). Does addressing gender inequalities and empowering women and girls improve health and development programme outcomes? *Health Policy and Planning*, *31*(10), 1492–1514.

Tuck, A., Oda, A., Hynie, M., Bennett-AbuAyyash.C., Roche, B., Agic, B., McKenzie, K. (2019). Unmet health care needs for Syrian refugees in Canada: A follow-up study. *J Immigrant Minority Health* 21(6), 1306–1312. https://doi-org /10.1007/s10903-019-00856-y

USA for The United Nations High Commissioner for Refugees. (2021). *Syria refugee crisis explained*. https://www.unrefugees.org/news/syria-refugee-crisis-explained/

Victoria, G. S. (2007). Improving access to multilingual health information for newcomers to Canada. *The Journal of the Canadian Health Libraries Association = Journal De l'Association Des Bibliothèques De La Santé Du Canada, 28*(1), 15-18. https://doi.org/10.5596/c07-003

Watson J. (2002). Intentionality and caring-healing consciousness: A practice of transpersonal nursing. *Holistic nursing practice*, *16*(4), 12–19. https://doi.org/10.1097/00004650-200207000-00005

Wehbe-Alamah, H. (2011). The use of cultural care theory with Syrian Muslims in the mid-western United States. *Online Journal of Cultural Competence in Nursing and Healthcare,* 1(3), 1-12. https://doi.org/10.9730/ojccnh.org/v1n3a1

Winn, A., Hetherington, E., & Tough, S. (2018). Caring for pregnant refugee women in a turbulent policy landscape: Perspectives of professionals in Calgary, Alberta.

International Journal for Equity in Health, *17*(1), N.PAG.

https://doi.org/10.1186/s12939-018-0801-5

Appendix A: Guiding Questions

1. Tell me about who you are – do you have children? Who is part of your family?
2. What was your pre-migration journey like?
3. Tell me about the time after you arrived in Canada. What has it been like for your family?
4. What were your experiences accessing healthcare prior to coming to Canada?
5. What have been your experiences when deciding when and how to access healthcare in Edmonton?
6. What have been your experiences when accessing healthcare in Edmonton?
7. How do you access healthcare services? Are they accessible (mode of transportation, easy to find…)
8. How have your interactions with the healthcare system been? What was done well, and what do you feel could be done better/ was negative?
9. Do you feel that your needs were met when accessing healthcare services?

Appendix B: Informed Consent

Information Letter and Consent Form
Ethics Study Number: (Pro00117091)

Study Title:
A Narrative Inquiry into the Experiences of Accessing and Participating in Healthcare of Syrian Women who Arrived in Canada as Refugees.

Research Investigator:
Alix Malloy
5-021 ECHA
11405– 87 Ave.
University of Alberta
Edmonton, Alberta
Canada T6G 1C9
Email: amalloy@ualberta.ca
Phone: **********

Supervisor:
Dr. Vera Caine
5-021 ECHA
11405– 87 Ave.
University of Alberta
Edmonton, Alberta Canada
Canada, T6G 1C9
Email: vera.caine@ualberta.ca
Phone: **********

Background

You are being invited to participate in a research study entitled *A Narrative Inquiry into the Experiences of Accessing and Participating in Healthcare of Syrian Women who Arrived in Canada as Refugees*. This study is conducted by Alix Malloy and supervised by Dr. Vera Caine from the Faculty Nursing at the University of Alberta. The results of this study will be used in support of my Masters research.

Purpose

In this study, I am exploring the experiences of Syrian refugee women when accessing and participating in healthcare in Edmonton, Alberta. I am interested in how these experiences have shaped your life as a refugee and as a woman.

Study Procedures

If you choose to participate in this study, you will be asked to have audio-recorded

conversations with me over a 2 to 3 month time period. Each conversation is estimated to take about one hour. We will meet in public places, such as restaurants and cafés, or in places that work best for you, virtual meetings are also an option. I hope to meet you once every one to two weeks for a total of seven conversations. The conditions for a meeting will be negotiated between us.

As a participant, you are welcome to talk freely about your past and current life experiences. All the conversations will be audio-recorded and transcribed. I will invite you to take photos of the important places or people in your life, or to bring an item which has a special meaning for you to our conversations. These photos and items will help me better understand your experiences. All the photos and items shared will be returned to you during the conversations.

You are eligible to participate in the study if you: 1. Are currently living in Edmonton, Alberta 2. Are a Syrian Refugee; 3. Are a woman of childbearing age; 4. Plan to live in Edmonton for the next four to six months.

Benefits

You will be given an opportunity to tell your life stories within a safe relationship with the researcher. You might gain insights into what it is like to be a refugee woman of childbearing age and how this has shaped you. By telling your stories, you may become more aware of your life history, identity, belief/value, and strengths. You may also obtain a clearer understanding of how your life experiences are shaped by various familial, cultural, social, and political backgrounds. However, it is important to note that there might be no direct benefit to you.

Payment or Remuneration.

During each conversation, I will pay for a meal and beverages. You will also receive a $20 gift card.

Risk

As you tell your life experiences, you may encounter memories and feelings which could be distressing or discouraging to you. Also, you may perceive frustrations and limitations which could be stressful to you. It is acceptable to express negative emotions during the conversations, but if it is difficult for you, you are not obliged to tell me everything. If

unidentified issues surface during our conversations, I can direct and connect you to appropriate supports or resources without disclosing any of your information. In addition, you may choose at any time during any conversation to skip questions that may make you uncomfortable.

There is COVID-19 in Edmonton. Because we are meeting each other, there is a risk that we can spread COVID-19 to each other. I will try my best to prevent this. I will supply us with masks and hand sanitizer. If you want, I can give you gloves. We will keep 6-feet apart when we meet. If one of us gets COVID-19, we will let the other person know.

Voluntary Participation

Participation in this study is voluntary. Should you choose to participate in this study, note that you are under no obligations. Additionally, if you volunteer to be in this study, you may withdraw at any time up to the point before you give consent to the final narrative account. You may also refuse to answer any questions or talk about particular experiences. You can request to stop the audio-recording at any time. It is important to note that you will not be able to withdraw from this study once you review your narrative account.

Confidentiality & Anonymity

The information obtained in this study will be used in the writing of my master's thesis. It will also include various presentations or research papers. To avoid any personal identification the use of any particular names or places will be modified and you will be given a pseudonym. Before information is disseminated, I will share the narrative account, which reflects your story with you.

Please note that for a minimum of 5 years after the completion of the study, all the data will be stored securely in a locked cabinet or in electronic devices that is password protected. My supervisors and I are the only ones who will have access to the original data. You can ask for a copy of reports or publications on research findings at any time.

Further Information

If you have any further questions regarding this study, please do not hesitate to contact Alix Malloy at ********** or amalloy@ualberta.ca.

The plan for this study has been reviewed for its adherence to ethical guidelines by the

Research Ethics Board at the University of Alberta. If you have any concerns or questions regarding your right as a research participant you may contact the Research Ethics Office, at 1-780-492-2615 or reoffice@ualberta.ca.

Thank you for considering being part of this research. I very much look forward to working with you.

Consent Statement (please check the boxes)

☐ I have read this form and the research study has been explained to me.

☐ I have been given the opportunity to ask questions and my questions have been answered. If I have additional questions, I have been told whom to contact.

☐ I agree to participate in the research study described above and will receive a copy of this consent form. I will receive a copy of this consent form after I sign it.

_____ _____

Participant's Name (printed) and Signature Date

_____ _____

Name (printed) and Signature of Person Obtaining Consent Date