

A Narrative Inquiry into the Experiences of Syrian Refugee Families with Children Living with Disabilities

by

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## **Abstract**

Children with disabilities are among the most at-risk groups for marginalization due to compounded disadvantages from the intersection of risk factors such as refugee status and disability status. Despite this high risk, there is no systematic data collected on this group and scant literature on the topic contributing to a feeling of invisibility. We conducted a narrative inquiry on the experiences of two Syrian refugee families with children living with disabilities. Narrative inquiry is a way to understand experience as a storied phenomenon. In order to understand the complexities of the experience as a refugee with a child living with disabilities, attending to the lived and told stories is essential. In hearing the narration of these experiences across time, place, and social contexts various narrative threads emerged. The narrative threads that resonated across the experiences of two families included waiting and a struggle for agency, as well as disruption and continuity.

## Preface

This thesis is an original work by Vanesa Beka. The research project received ethics approval from the University of Alberta Research Ethics Board, Project name “A narrative inquiry into the experiences of Syrian refugee families with children living with disabilities”, No. Pro00099200, October 1, 2021 and May 11, 2021.

Chapter 4 of this thesis has been submitted for publication as V. Beka, V. Caine, D.J. Clandinin, and P. Steeves “A Narrative Inquiry into the Experiences of Syrian Refugee Families with Children Living with Disabilities”. I was responsible for the data collection and analysis and contributed to manuscript composition. D.J. Clandinin and P. Steeves assisted with data analysis and contributed to manuscript edits. V. Caine was the supervisory author and was involved with concept formation, data analysis, and manuscript composition.

## **Dedication**

This thesis is dedicated to my mom and dad who fled their beloved country of Kosovo in 1999 and arrived in Canada with 4 young children and not much else. Thank you for teaching us kindness, strength, and curiosity. Without your story, I could not tell the stories of others.

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## Table of Contents

<b>Abstract.....</b>	<b>ii</b>
<b>Preface.....</b>	<b>iii</b>
<b>Dedication .....</b>	<b>iv</b>
<b>Acknowledgements .....</b>	<b>v</b>
<b>Abbreviations .....</b>	<b>ix</b>
<b>CHAPTER 1 .....</b>	<b>1</b>
<b>Introduction.....</b>	<b>1</b>
<b>Narrative Beginnings.....</b>	<b>1</b>
<b>Turning Towards the Research Puzzle .....</b>	<b>10</b>
<b>Purpose of Study .....</b>	<b>10</b>
<b>Literature Review .....</b>	<b>11</b>
<b>Syrian Refugees in a Global Context.....</b>	<b>11</b>
<b>Syrian Refugees in a Canadian Context .....</b>	<b>12</b>
<b>Syrian Refugees in the Alberta and Edmonton Context .....</b>	<b>14</b>
<b>The Health of Syrian Refugee Children.....</b>	<b>15</b>
<b>Disability and Syrian Refugee Children .....</b>	<b>17</b>
<b>Parental Perspectives on having a child with disabilities .....</b>	<b>20</b>
<b>Research Puzzle.....</b>	<b>23</b>
<b>Methodology .....</b>	<b>24</b>
<b>Ontological and Epistemological Underpinnings.....</b>	<b>26</b>
<b>World Travelling.....</b>	<b>27</b>
<b>Participants.....</b>	<b>28</b>
<b>Field Texts.....</b>	<b>29</b>
<b>From Field Texts to Interim and Final Research Texts .....</b>	<b>31</b>
<b>Ethical Considerations.....</b>	<b>34</b>
<b>References.....</b>	<b>36</b>
<b>CHAPTER 2 .....</b>	<b>42</b>
<b>Narrative Account of Abbud.....</b>	<b>42</b>
<b>Introduction.....</b>	<b>42</b>
<b>Life in Syria .....</b>	<b>44</b>
<b>Syrian War and Journey for Refuge .....</b>	<b>46</b>
<b>Journey to Canada.....</b>	<b>49</b>

Healthcare in Canada .....	51
References .....	57
<b>CHAPTER 3 .....</b>	<b>58</b>
Narrative Account of Mahir .....	58
Introduction .....	58
Life in Syria .....	62
Arriving in Canada .....	69
References .....	78
<b>Chapter 4 .....</b>	<b>79</b>
Publication .....	79
Background Information .....	81
A Focus on Disability .....	82
Turning to the Research Puzzle .....	83
Methodology .....	83
Narrative Accounts of Abbud and Mahir .....	86
Coming to know Abbud .....	86
<i>Leaving Syria for Lebanon.</i> .....	86
<i>Becoming disabled later in life.</i> .....	87
<i>Arriving in Canada and experiences of waiting</i> .....	87
<i>Language Barriers</i> .....	88
Coming to know Mahir .....	88
<i>Born with a disability</i> .....	89
<i>Meeting Abia in Canada</i> .....	89
<i>Questions of Identity.</i> .....	89
<i>Moving to Turkey.</i> .....	90
<i>Moving to Canada</i> .....	90
<i>Experiences of Waiting</i> .....	91
Resonant Threads .....	91
Thread 1: Waiting and a Struggle for Agency .....	92
Thread 2: Between Disruptions and Continuity .....	96
Study Limitations .....	100
Conclusion .....	101
References .....	103

<b>CHAPTER 5.....</b>	<b>107</b>
<b>A Reflective Turn.....</b>	<b>107</b>
<b>Personal: Looking Backwards.....</b>	<b>107</b>
<b>World Travelling.....</b>	<b>108</b>
<b>Practical: Reconsidering Practice.....</b>	<b>109</b>
<b>Social: The Bigger Picture.....</b>	<b>110</b>
<b>Future Research.....</b>	<b>111</b>
<b>Conclusion .....</b>	<b>112</b>
<b>References.....</b>	<b>113</b>
<b>Bibliography .....</b>	<b>115</b>



## Abbreviations

<b>Abbreviation</b>	<b>Unabbreviated</b>
BVOR	Blended Refugee Program
CSS	Catholic Social Services
GAR	Government assisted refugees
HI & iMMAP	Humanity and Inclusion and Humanity & Inclusion and Information Management and Mine Action Programs
IFHP	Interim Federal Health Program
PSR	Privately Sponsored Refugees
RAP	Resettlement Assistance Program
UNHCR	United Nations High Commissioner for Refugees
UN	United Nations
WG-ES	Washington Group Extended Set
WHO	World Health Organization

# CHAPTER 1

## Introduction

### Narrative Beginnings

When I was three years old, everything I knew about my life up until that point, changed. It was 1999, a time that was rife with political turmoil in Eastern Europe. I lived in Kosovo, a small state in the Balkans that was formerly a part of Yugoslavia (Nikolić, 1998; Encyclopedia Britannica, 2019). With the collapse of former Yugoslavia in the nineties and early two-thousands, the nations that comprised it were divided into separate states (Nikolić, 1998; Encyclopedia Britannica, 2019). Kosovo was among the nations with a desire to be recognized as an independent country. However, due to a contentious history with Serbia, the fate of Kosovo was uncertain. Serbia was adamant that Kosovo was a part of Serbia and therefore cannot be independent, but Kosovo had a distinct religious and cultural (Kosovo is ethnically Albanian) history separate from Serbia that prevented them from conceding (Nikolić, 1998; Encyclopedia Britannica, 2019). Efforts by Kosovo to gain independence were violently suppressed by Serbia (Nikolić, 1998; Encyclopedia Britannica, 2019). This led to mass killings in Kosovo and what the North Atlantic Treaty Organization (NATO) termed an ethnic cleansing by Serbia, forcing hundreds of thousands of people to flee Kosovo (Nikolić, 1998; Encyclopedia Britannica, 2019). The war in Kosovo was resolved after intervention from NATO in 1999. However, the ramifications of it are still felt in the country of Kosovo, its people, and the refugees that experienced it. Among them is my family, who left Kosovo as refugees.

When I reflect on my experience as a young child during the war in Kosovo, I was unaware of the political turmoil around me. All I knew was that things were rapidly changing, and my home could no longer be my home. I do not remember all my feelings at the time, but I

do remember feeling confused. I lived an ordinary life until then with familiar surroundings and people. Kosovo is a small country. It takes 3 hours to drive from one end to the other. I recall visiting when I was older and wondering to how somewhere so small could be in the middle of so much conflict. Kosovo has a beautiful landscape. I remember, on a clear evening, I could see the mountains in the distance that bordered Kosovo from my balcony. There are vast fields with various fruit trees along the paths lining our house and neighbour's homes. It is very common for families to build their homes beside each other and therefore growing up I had all of my aunts and uncles within walking distance of my home. Some of my earliest memories are of my dad and I walking hand in hand across the field to my uncle and aunt's house, picking fruits along the way. There is a strong sense of safety when everyone in your community is your family. Playing outdoors was never a concern as there would be someone to help if needed nearby. It was a pleasant life, and I was comfortable there. I did not want to leave. When the conflict started occurring near our homes, I don't remember feeling scared. This was largely because my parents never let me believe there was anything to fear. I never understood the severity of the situation, I was just told one day that we would be going far away. My parents always told me about the beautiful life in Canada and that we were going so far that we had to fly on a large plane to get there. They told me that my aunts would welcome us with gifts and food. It all sounded so exciting, and I could not comprehend any sort of disruption this would cause to the life I knew.

I do not recall the day we left our home in Kosovo for the final time. When I try to remember, I see fragmented scenes across various landscapes. Memories of commotion and large crowds. Memories of separation from my family. At one point, I was told to get into a carriage with my neighbours, and my mom would join me, so we did not have to walk on foot many miles to the neighbouring country for safety. Among the commotion, my mom did not get on the

carriage, and I was left alone with family I was vaguely familiar with. We were travelling far, and at the time, we were not sure I would ever be reunited with my family. Many years later, I reunited with the family that had taken care of me while I was in the carriage with them and away from my own family. "Do you remember me?" I had asked them. They told me I was hard to forget. Apparently, at the ripe age of 3 years old, I would not stop talking about the pain it caused me to be separated from my family and had the entire carriage in tears the entire way. This was a story I had heard many times. It was a way of laughing about a time that did not offer much opportunity for laughter. I was eventually reunited with my family in a camp once we reached Albania. I recall being in a car, and as soon as someone opened the door, I was swarmed by open arms by various family members. We were reunited at last. I do not remember much after that. When I ask my parents about this time, they both talk about the extreme distress they felt not knowing if they would see me again. I was in the better situation out of my family members by all accounts. I did not have to walk the long journey they walked, and I was in the hands of safe guardians. However, the feeling of our family structure separated made everything painfully difficult. All we had was each other, and when we reunited, it felt like we could get through anything.

We arrived in Canada two days before my fourth birthday. We celebrated my actual birthday with a cake, and I met my extended family who lived in Canada. I was so excited that I celebrated my birthday with my aunts in Canada that all I can recall from that time is happiness. Everything felt new and like an adventure. I did not know that it would be many years before I could return to see my extended family, and I did not have any worries.

However, in the weeks, months, and years that followed, I became more acutely aware of the challenges that moving to a foreign country entail. I was enrolled in a school where I was

expected to learn a new language, a place where I was exposed to cultural narratives and a way of being that was different from my own. There were new foods, attitudes and customs and the influx of new cultures in my life was nothing short of a shock. I recall various occasions when others made fun of me for bringing food to school that was different from what everyone else was eating. There were also times where children referred to TV shows, movies, or pop culture, which I did not understand. I often felt that I did not belong; or was misunderstood. It was a tumultuous process learning to integrate into different cultural ways whilst also retaining parts of my culture. As I got older, my experiences began to change and the transition into my Canadian life slowly became easier. I became fluent in English. I started to meet people who were also first-generation immigrants and found camaraderie among those who also felt that they didn't quite fit in. It was not long before my English language skills and cultural integration surpassed my parents. Soon, my parents began to rely on my siblings and me for interactions with the world outside of their Albanian customs. This new responsibility is when I first began to interact with the health care system.

In the transition between being forced to leave our home in a war-torn country and adjusting to an entirely new life, my parents experienced a great amount of stress. My dad had a challenging time. He was dealing with trauma from the war that resulted in an acute form of insomnia and insufficient nutritional intake. This was compounded by his smoking habits and a diet that often consisted of solely coffee. He had felt unwell for some time before he finally consulted a doctor. This was shortly after we had arrived in Canada. It was during this routine health assessment that he was diagnosed with diabetes. In Albanian, the people refer to diabetes as *sheqeri*, the Albanian term for 'sugar', which alludes to sugar in the blood - this was the extent of my parents' familiarity with diabetes. The concept of diet and lifestyle playing into health was

foreign to my parents. The war had inflicted a survival mentality on my parents, and that meant eating what they had on hand. Moreover, smoking and drinking coffee were seen as an essential element of who they were in Kosovo. Moving to Canada meant leaving behind their home and former life. Smoking and drinking coffee were some of the ways my dad felt he could retain part of his old life in this entirely new place. With the new diagnosis of diabetes, my dad was told he must give up smoking and drinking coffee. The transition to living a life as a person with diabetes was arduous. It took many years for my dad to monitor his blood sugars and this was only due to various health complications that instilled enough fear in my dad to change. My dad quit smoking. He slowly transitioned from high carbohydrate, high sodium, high fat ethnic Albanian dishes to a diet that reflected more of a modern western image of health and consisted of vegetables, whole grains and, in my dad's opinion, "bland" meat dishes. From a public health perspective, transitioning to a healthier diet has significant health benefits and is widely regarded as a positive change. However, seeing my dad go through this transition was difficult. There were many ramifications for him and our entire family. My dad was the sole breadwinner in our family for many years and was heavily involved with raising his children. He had dedicated his life to providing a better future for his children, often at the expense of neglecting his own health. In addition, for my dad, food was an integral part of his Albanian heritage. When my dad was asked to change his diet, he would express that he felt as if someone had taken away who he was once again. Food was something that made him feel connected to his former life. My dad longed for food that would connect him with his life in Kosovo, but my mom felt the need to intervene with healthier options in order to prevent health complications. This created great frustration for my dad and, to this day, deciding on dinner often causes my parent's biggest argument.

Food had more significant implications than just stirring cultural sentiments. Food was once something my dad had enjoyed and indulged in. Suddenly, my dad could no longer enjoy desserts with the rest of the family on a celebratory holiday. He could not smoke or indulge in drinking coffee to relieve stress, as it would have ramifications on his blood pressure. Being stripped of things my dad liked put him in greater cardiovascular health but not without taking a toll on his mental health. Care providers often missed this.

As his daughter, I lived in constant fear that his health would deteriorate. My siblings shared that fear. I always felt I did not understand enough as a child and tried my best to interpret and translate accurately, but I could not keep up with the complexities of the care my dad required and the complexities of the healthcare system. As I got older and my English language skills surpassed my Albanian, I began to find it more difficult to describe complex medical language in Albanian. Furthermore, I began feeling barriers between my dad and me. My dad perceived health to be the absence of disease. That is to say; when you were diagnosed with an illness, you should be able to see and feel it. Diabetes is complex in that you may have prolonged high blood sugars long before you ever notice the complications associated with it. These complications are often linked to cardiovascular disease, nerve damage, kidney disease, among other things (Diabetes Canada, 2019). So, when his blood sugar was high but he was asymptomatic, he would not quite comprehend its ramifications or how it may impact him in the future as he felt fine in the moment. I found the task of educating my dad on primary prevention to prevent health complications both overwhelming and taxing. It only augmented my worries about my dad's health when I became a nurse. I was now working in an acute care setting where many of the surgical admissions were results of poor diets and uncontrolled hypertension and diabetes. This fueled my concerns, and I became even more invested in my dad's health.

However, this time, I was coming at it from a more holistic perspective. I was well versed in the healthcare system and the pathology of diabetes. Moreover, I had insights into my dad's cultural identity. I felt much better positioned to help my dad.

I wonder why it is only now that I feel I can think about my dad in this way. My relationship with my parents changed over time. As a child, I was learning the language for myself and was put in a position to be a translator, a role often left for fluent speakers. This never felt stressful to me as I was happy to be helpful. However, I recall disappointment if there was ever a word I did not know. As a refugee, we did not have much, and I often felt othered due to the clothes I wore, or the kind of food we ate. I did not know any other children who helped their parents fill out government documents at the time. As I became a fluent speaker in English and even more so when I received a university degree, I noticed how people treated me differently. It was as if I was now on their side, instead of the other side. The side that is foreign, the side they thought was so different from their own. Having lived on both metaphorical sides, I know how false this notion is. These sides do not exist. We are all so similar, dealing with so many of the same issues.

As a child, I was concerned about my parent's health. As a nurse, I began to see how some healthcare workers viewed my dad. In the hospital, I have heard the word noncompliant many times. Medical professionals use the term "noncompliant behaviour" for a patient who refuses treatment despite being informed about the benefits of treatment (Kleinsinger, 2003). Danielle Ofri (2012), a medical doctor, wrote a piece in the New York Times on the concept of noncompliance. He describes that when a patient is named noncompliant it is "as though a black marker is branded on the chart" (n.p.). Noncompliance warns other healthcare workers that this patient is someone to watch for and is a difficult patient. What is often not noted is why the



patient is noncompliant. There is a myriad of reasons, or experiences, that are causing the patient to respond in different ways. As care providers, we are meeting the person in the midst of their lives, and there is a need to explore what contributes to their behaviour. Unfortunately, the patient is also catching the healthcare worker in the midst of their lives - often a life marked by large patient loads and time constrictions. Many things lost when we carry large patient loads and face time constraints – often times a patient’s noncompliance is left unexplored. Yet with my dad, I have explored his ‘noncompliance’ my whole life. I have seen his struggles and he has described his challenges to me. Only after years of negotiating my relationship with my dad, from a child to a nurse, have we come to a place of better understanding as to why he reacts so strongly to adhering to treatments for his diabetes.

I still struggle with trying to help my dad live a healthier lifestyle, but I have learned strategies to help him manage his diabetes. Simply telling my dad to exercise would not have any desired result. My dad was isolated from many of his family and friends when he left Kosovo. I found that if I went on walks with him, he was thrilled to get to spend time with me and spend hours talking to me, all the while getting his steps in. When deciding on diet choices, my family worked together to find compromises. Choosing breakfast and lunch dishes that were healthy and perhaps being more lenient around dinner with providing more cultural dishes was possible if supplemented with a post-dinner walk. That seemed to work. The complexity of my dad’s health cannot be reduced to making simple compromises; however, they are helping. There are challenges every day and it is only now, after many years, that I am in a position where I am finally able to intervene in a helpful way.

As a nurse in Canada, I interact with families whose stories are similar to mine every day. Our stories are similar in that we are both refugees and immigrants to Canada. Similar in that the

families I see are learning to navigate a complex and often confusing system just as I once had to. Similar in that we probably felt foreign in a country we now call home at some point in our lives. However, our relationships and identities are shaped in other ways in a healthcare context. I am a healthcare provider and they are the patient. There is this wall made up of “professionalism” that stands between us. It is not often that I disclose that I am a refugee or immigrant. I do not take the time to explain my background. It is only after many years that I have begun to wonder if disclosing more about myself would be helpful to patients.

Occasionally I have an adult inpatient on my unit who does not speak English. When their families arrive, I find myself in a situation I have lived many times. A young child is trying their best to translate for their parents, only this time I am a health care provider and not the young child I once was. I feel great empathy when I am in these situations. In these moments, I recall my experiences and it shapes my ability to provide care while integrating the patient’s experiences. As Maria Lugones (1987) would say, I could travel to their world in some ways. I could travel to the world of the child, trying their best to be helpful to their parents in a confusing situation. I could travel to the world of learning a new system for the first time. In my role as a nurse, interacting with patients of all different backgrounds, I believe my background has allowed me to travel to many of these worlds at once. Lugones (1987) states “one can inhabit more than one of these worlds at the very same time” (p.11). I inhabit the world as a refugee, the world of an immigrant, the world of a concerned daughter, and the world of a concerned health care practitioner. Recognizing these multiple worlds, I, and the people I meet, has made me a more thoughtful and conscientious nurse.

As a refugee with a parent who has health complications, I wonder: what if the situation was reversed? What happens when the child is the one with severe health problems and the

refugee parent must cope with this? How do refugee families learn to navigate the complexities of the healthcare system for their child when they are trying to learn a new language and simultaneously get accustomed to a new culture? How does the responsibility of taking care of a child with complex health needs impact one as a parent? I also wonder who the nurse is in working with refugee families and children. My experience as a refugee influenced me and my interactions with the healthcare system. Fortunately, I had the resources and support growing up to gain the skills to navigate a healthcare system that allowed me to help my parents. However, many others who are not so fortunate, and those too are stories that need to be told.

## **Turning Towards the Research Puzzle**

### **Purpose of Study**

This study aims to inquire into the experiences of Syrian refugee families who have children living with disabilities. Since 2015, due to the onset of the Syrian refugee crisis, Canada has accepted over 40,000 Syrian refugees (Government of Canada, 2017). Most families accepted for resettlement are families with young children (Houle, 2019; Oudshoorn et al., 2019). With the prevalence of refugees with disabilities, there is reason to believe some of these children may come into Canada with various disabilities (Conte, 2016; UNHCR, 2018; WHO, 2011). With the influx of young Syrian refugees with disabilities, these families have accompanying needs. The intersections of being a refugee and having a disability make individuals increasingly vulnerable, making “refugees with disabilities among the most isolated, socially excluded, and marginalized of all displaced populations” (United Nations High Commissioner for Refugees Antonio Guterres as cited in UNFPA, 2018, n.p.). Moreover, language and cultural barriers may hinder access to services or prevent Syrian refugee families from advocating for themselves. Understanding the experiences of Syrian refugee families with

children living with disabilities has the potential to influence nursing practices and policies, create supportive environments, and ensure the appropriate resources are available for families.

## **Literature Review**

### **Syrian Refugees in a Global Context**

The people of Syria have been dissatisfied with the leadership of the Syrian regime for many years (BBC news, 2019; Laub, 2021); they vocalized discontent with corruption, high unemployment rates, and a lack of political freedom under the Assad family rule (BBC news, 2019; Laub, 2021). Inspired by the *Arab Spring* uprisings (2010/2011), Syria began to partake in pro-democracy protests against their corrupt government in 2011 (Human Rights Watch, 2019; Laub, 2021; Rodgers et al., 2016). However, the Syrian government was quick to dismantle these protests by resorting to violence (Rodgers et al., 2016). Rebel groups formed to battle government forces and have persisted fighting for their beliefs (Human Rights Watch, 2019). These confrontations developed into a civil war that has elicited attention from global forces and involved many groups and countries, increasing the complexity of it (BBC news, 2019; Laub, 2021). Hundreds of thousands of Syrians have died or have fled Syria for their own safety since the initial protests (Laub, 2021). Syria is now deemed to be in a state of “refugee crisis” (Human Rights Watch, 2019). The United Nations (UN) Refugee Convention defines a refugee as a person who:

owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group or political opinion, is outside the country of his nationality, and is unable to, or owing to such fear, is unwilling to avail himself of the protection of that country. (UNHCR, 2019, n.p.)

The UN refugee agency reported that there are currently 25.9 million refugees around the world (UNHCR, 2019b). Over 50% of those refugees come from three countries: Syria (6.7 million), Afghanistan (2.7 million), and South Sudan (2.3 million) (UNHCR, 2019b). Nearly half of all refugees are under 18 years old (UNHCR, 2019b).

Syria now has the largest forcibly displaced population in the world with 6.6 million people internally displaced and 5.6 million Syrian refugees around the world (UNHCR, 2019c). It is estimated that the death toll since the civil war began in Syria in 2011 is at 511,000 as of March 2018 (Human Rights Watch, 2019). The refugee crisis in Syria has large implications for other nations around the globe. Many countries have accepted people seeking refuge from Syria. Lebanon, Turkey and Jordan have hosted the majority of Syrian refugees (UNHCR, 2019c; Human Rights Watch, 2019). Other countries around the world are closely following suit, one of which is Canada (Government of Canada, 2017).

### **Syrian Refugees in a Canadian Context**

Historically, Canada has a long record of accepting refugees, welcoming approximately 12,000 refugees a year (Government of Canada, 2019b). Canada accepts refugees through three programs: government assisted refugees (GARs), privately sponsored refugees (PSRs), and the blended refugee program (BVORs) (Government of Canada, 2019; Government of Canada 2019b). In the wake of the refugee humanitarian crisis in Syria, Canada committed to accept 25,000 Syrian refugees in 2015 (Government of Canada, 2017). This commitment included GARs, PSRs, and additional BVORs (Government of Canada, 2019b). Since the commitment in 2015, Canada has surpassed its original goal, accepting 40,081 Syrian refugees by January 2017 (Government of Canada, 2017). Syrian refugees have quickly become the largest group of refugees residing in Canada (Houle, 2019).

Canada's criteria for accepting Syrian refugees prioritizes families with young children (Houle, 2019; Oudshoorn et al., 2019). Of the Syrian refugees in Canada, 85% of families consist of couples with children (Oudshoorn et al., 2019; Houle, 2019). The 2016 census data showed 44.2% of refugees who resettled into Canada between 2015 and 2016 were in the 0 to 14 age group (Houle, 2019). Moreover, Syrian families tended to have more children (average 2.8 children per family) than refugee families from other countries (average 2.2 children per family) (Houle, 2019). The number of young children aged 0 to 14 per family is even larger for government assisted refugees (3.2 children) compared to privately sponsored refugees (2.2 children) (Houle, 2019).

Canada offers various services to their GARs and BVORs to help them integrate into their new life in Canada. Canada offers the Resettlement Assistance Program (RAP) that "helps meet the immediate and essential needs of resettled refugees" for GARs and BVORs (Government of Canada, 2019b, n.p.). PSRs rely on their private sponsors for these services (Government of Canada, 2019b). Under the RAP, income support is provided for up to one year, or until families and individuals can support themselves (Government of Canada, 2019). RAP provides integration services for temporary housing, needs assessments, integration assistance and referrals for the first four to six weeks in Canada (Government of Canada, 2019). After that time, GARs are left on their own to establish settlement in Canada. Canada provides the Settlement Program, which helps enable integration through funding for "language learning, community and employment services, path-finding, and referral services" (Government of Canada, 2019b, p.2). The Interim Federal Health Program (IFHP) provides "limited, temporary coverage of health-care benefits" for refugees, who are not eligible for provincial or territorial health insurance (Government of Canada, 2019b, p. 2). Due to the state of crisis, shortly after the

Government of Canada announced that it was accepting 25,000 refugees, changes were made to the resettlement process that the initial Syrian refugees experienced. For example, the first wave of Syrian refugees (between 2015 and 2016) had the immigration loan repayment burden waived (Government of Canada, 2019b). Subsequent Syrian refugees did not have this same exception (Government of Canada, 2019b).

### **Syrian Refugees in the Alberta and Edmonton Context**

Of the 25,000 Syrians initially accepted into Canada, about 4,500 have been resettled in Alberta (Agrawal & Zeitouny, 2017). Of those, Edmonton has welcomed 2,250 Syrian refugees (Mahaffy, 2018). More than half of the refugees accepted into Alberta are aged 17 or younger (Mahaffy, 2018). Of the accepted families, 81% had a family of six people or more (Mahaffy, 2018). Upon the influx of Syrian refugees, the vast number of newcomers surpassed the capability of one organization alone to meet their needs (Mahaffy, 2018). This prompted the collaboration of agencies, organizations, and individuals to come together to help serve the needs of Syrian newcomers (Mahaffy, 2018). Of the GARs accepted, more than 90% did not speak one of Canada's official languages (Mahaffy, 2018).

There are reports that GARs “came with more pre-existing health concerns than predicted” (Mahaffy, 2018, p. 23). In Edmonton, GARs from Syria had their initial health screening completed through the New Canadians Clinic (Mahaffy, 2018). This Clinic was a hub for refugees and provided “excellent, culturally sensitive health assessment, orientation and referrals” (Mahaffy, 2018, p.51). The excellent care provided by the clinic was, in part, attributed to the integration of Arab-speaking health care practitioners who had a keen interest in refugee health (Mahaffy, 2018). In 2017, Alberta Health Services (AHS) withdrew funding from the New Canadians Clinic, and initial health screening for newcomers was redirected to the East

Edmonton Health Clinic (Mahaffy, 2018). After the initial screening, refugees are expected to seek care from a family physician in the community. This decision was widely regarded as controversial and received criticism among refugee advocates. Among the critiques for this policy decision is that family physicians do not have the time, resources, or expertise to offer holistic, culturally appropriate, and comprehensive care to this vulnerable population (Mahaffy, 2018).

Looking backwards at the influx of refugees into Edmonton, it was evident that Syrian refugees faced many hardships as they adjusted to their lives in Canada (Mahaffy, 2018). Syrian refugees reported that the key challenges included finances, language training, employment, housing, health, mental health, family reconfiguration, and education (Mahaffy, 2018). These hardships are often interrelated; for example, unemployment is connected to the lack of English language skills. This results in financial struggles that strongly shape their lives and affect the status of their well-being. In efforts to ameliorate these challenges, Edmonton advocates call for a community-owned and operated Community Health Center (CHC) for refugees. This CHC should provide every refugee with holistic primary care and access to social services over an extended period of time (Mahaffy, 2018). Edmonton currently is the only large urban center in Canada that does not have a clinic solely dedicated to refugees despite the large influx of Syrian refugees in Edmonton (Mahaffy, 2018).

### **The Health of Syrian Refugee Children**

Since the conflict began in Syria, many children did not/do not receive core services or care, such as adequate sanitation, appropriate nutrition, safe water, and guarantee of safety, or access to healthcare (Citizenship and Immigration Canada, 2015). The United Nations High Commissioner for Refugees (UNHCR) reported on the health of Syrian refugees in Lebanon,



Jordan, and Iraq and they found that the general health conditions among Syrian refugees were: communicable and non-communicable diseases, vaccine-preventable diseases, trauma and mental illness, injuries and disabilities, and sexual violence (Citizenship and Immigration Canada, 2015). Mental health was one of the most prevalent health concerns as many Syrians dealt with the trauma inflicted by the conflict in their home country (Citizenship and Immigration Canada, 2015). Children and adolescents were noted as a particularly vulnerable group due to their high reports of mental health concerns, injuries, and disabilities (Citizenship and Immigration Canada, 2015).

To prepare for the influx of Syrian refugees into Canada, data analysis was conducted on the demographics and health of the populations accepted. The data revealed that Syrian refugees were most likely to have: hypertension, diabetes, visual or hearing impairment, and mental illness or trauma (Citizenship and Immigration Canada, 2015). When refugees arrived in Edmonton, they arrived with various health concerns, from living in war zones or refugee camps (Mahaffy, 2018). Syrian refugees in Edmonton often needed an array of health services including: immunizations, dental health work, and care for untreated chronic illnesses, among other services (Mahaffy, 2018).

The World Health Organization (WHO) recognizes migration as a social determinant of health (WHO European Region, 2018). Many migrant children are at an increased risk for not meeting their basic healthcare needs due to the state of their country of origin but and due to migration (WHO European Region, 2018). A migrant child is at increased risk for infectious diseases, dental problems, and stress-related issues because of fleeing a country for fear of persecution (WHO European Region, 2018). Moreover, armed conflict can result in disabilities from injury or trauma (Priddy, 2019). These disabilities may be exacerbated if not tended to

(Priddy, 2019). Due to the complexity of migration, newcomers must undergo comprehensive health assessments, and care is provided upon arriving in Canada to allow for successful settlement (Mahaffy, 2018).

### **Disability and Syrian Refugee Children**

The United Nations Convention on the Rights of Persons with Disabilities defines a person with a disability as “those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others” (United Nations, 2007, p.4). The disability issues literature shifted from a focus on impairment, which was reflective of a medical model, to a focus on participation, more of a social model in defining disability. For this literature review, I used the UN definition of disabilities when referring to disability. I do not include disabilities attributed to mental health illnesses as the complexity of mental health disabilities of refugee children exceeds the scope of this research project.

The Women’s Refugee Commission (2008) states that refugees with disabilities are “among the most isolated, socially excluded, and marginalized of all displaced populations” (p.1). They estimate that between 2.5 and 3.5 million of the world’s 35 million displaced people have disabilities (Women’s Refugee Commission, 2008). Many other organizations concur that the number of refugees with disabilities exceeds the thousands (WHO, 2011; Conte, 2016; UNHCR, 2018). Approximately one third of refugees with disabilities are children (WHO, 2011). As disabilities often go unrecognized for refugees, this number may be even higher (Women’s Refugee Commission, 2008). Basic needs such as food, shelter, and safety are most often prioritized and care and rehabilitation needs are not adequately attended (Women’s Refugee Commission, 2008). Identifying and collecting data on refugee populations with

disabilities is a great challenge. Barriers to identifying and collecting data include accurate identification of a disability, inconsistent methodology and terminology, lack of qualified staff, various criteria for what is considered “disability” (Women’s Refugee Commission, 2008; WHO, 2011). Moreover, developing countries that report low levels of disability often use measurement tools that are not comprehensive, and that overlook many people with disabilities (WHO, 2011). This is further complicated for children, as parents who report on the child’s disability may skew results (WHO, 2011). Without accurate data to identify refugees with disabilities, it becomes easy for them to be overlooked and prevents them from receiving access to necessary care (Women’s Refugee Commission, 2008; UNHCR, 2018). This often renders refugees with disabilities “invisible” (Conte, 2016, p.328).

A study completed in 2018 in Australia showed that 22.9% of surveyed Syrian refugees aged 2 years and above had a disability (Humanity and Inclusion and Humanity & Inclusion and Information Management and Mine Action Programs (iMMAP), 2018). The study also revealed that of the sampled households, 62% reported at least one member with disabilities (Humanity and Inclusion, & iMMAP, 2018). The reported high rates of disability related to illnesses or diseases are often caused by injury and malnutrition, due to the conflicts in Syria (Humanity and Inclusion, & iMMAP, 2018). Such disabilities include difficulty walking, anxiety, depression, fatigue, and challenges seeing (Humanity and Inclusion, & iMMAP, 2018). In children aged 5-17 years old, the highest disability reported included anxiety (9.7%) and depression (5.9%) (Humanity and Inclusion, & iMMAP, 2018). In children aged 2-4 years old, the highest disabilities reported were difficulties with communication and behaviours (1.5%) (Humanity and Inclusion, & iMMAP, 2018; UNHCR, 2019). In the Australian study, 80% of children with disabilities lived in low-income households, suggesting a relationship between poverty and

disability (Humanity and Inclusion, & iMMAP, 2018). This study utilized the modified Washington Group Extended Set (WG-ES) to assess the level of disability based on the level of difficulty a person faces while doing activities of daily living (Humanity and Inclusion, & iMMAP, 2018). A limitation of this study is that the modified WG-ES has never been used in a humanitarian context (Humanity and Inclusion, & iMMAP, 2018). Furthermore, children with disabilities who may have a medical condition but are in an enabling environment and therefore not considered “disabled” on the WG-ES scale, may be excluded from these numbers (Humanity and Inclusion, & iMMAP, 2018). This high incidence of disability in Syrian refugee groups is of concern if the healthcare system in Canada is not adequately prepared to accommodate these groups.

The UNHCR states that “refugees with disabilities rank among the world’s most vulnerable persons” (UNHCR, 2018, p. 3). There are reports suggesting that displaced children with disabilities are at an increased risk for violence or abuse compared to their non-disabled peers (UNFPA, 2018; UNHCR, 2018). Persons with disabilities are at heightened risk of discrimination when their disability status is compounded with other identity markers such as ethnicity or refugee status (UNFPA, 2018; UNHCR, 2018). Moreover, refugees with disabilities face greater challenges and barriers in accessing protective services (UNHCR, 2018), which increases vulnerability. The UNHCR reports that children with disabilities are at a greater risk of “abuse, neglect, abandonment, exploitation, health concerns, exposure to the risk of longer-term psychosocial disturbances, family separation, and the right to education” (UNHCR, 2018, p. 3). The United Nations Convention on the Rights of Persons with Disabilities recognizes that persons with disabilities should have the same rights and opportunities as their non-disabled peers (United Nations, 2007). Disability can lead to decreased socio-economic status and lower

social well-being (WHO, 2011). Children are particularly vulnerable to these disadvantages (WHO, 2011). As health and migration status also have implications on the well-being of children, the intersectionality of these two factors can put children at multiplied disadvantages (WHO European Region, 2018).

### **Parental Perspectives on having a child with disabilities**

There is limited research on the perspective of Syrian refugee parents who have a child living with disabilities. Of the research on parental perspectives, most is focused on immigrant populations or other ethnic refugee groups. The majority of the literature supported the idea that having a child with complex health needs can be of considerable stress to parents (Albright, 1997; Beatson, 2013; Cummings & Hardin, 2017; Hsiao, 2018; Khanlou et al., 2015; King et al., 2011; Kvarme et al., 2017). The constant demand to care for a child living with disabilities can lead to a variety of stresses that can ultimately cause a decreased quality of life for parents (Albright, 1997). High levels of stress may also decrease parenting effectiveness (Hsiao, 2018). When parents of children with disabilities are immigrants, it can create a compounded level of stress on the parents (Khanlou et al., 2015). Immigrant parents of children living with disabilities face specific challenges that other parents may not face, including language/communication barriers, lack of knowledge about the services available, and access to limited social/communal networks (Beatson, 2013; Cummings & Hardin, 2017; Khanlou et al., 2015; King et al., 2011). Furthermore, immigrant parents experience cultural barriers and a lack of culturally specific support whilst navigating health systems and understanding their child's disability (Kvarme et al., 2017). Adding to the stresses of becoming part of a new culture, and having a child living with disabilities, immigrant and refugee populations are among the most socially and economically disadvantaged members of society (Harris, 2003, as cited in King et al., 2011). The

World Health Organization (WHO European Region, 2018) states that migration in itself is a social determinant of health and can place an individual at greater risk of poor health outcomes. Moreover, immigrant or refugee mothers of children with disabilities may be particularly vulnerable as cultural gender norms may see women as the primary caregiver (Jennings et al., 2014; Khanlou et al., 2017). The intersectionality of various factors such as refugee status, disability, gender, among other things, can multiply the disadvantages faced among these groups (UNFPA, 2018; UNHCR, 2018).

Several vital concepts arose in the literature on immigrant or refugee families' perspectives on caring for a child living with disabilities. One recurring concept was related to language barriers (Beatson, 2013; Cummings & Hardin, 2017; Khanlou et al., 2015; King et al., 2011); another theme focused on cultural roles and perceptions (Beatson, 2013; Cummings & Hardin, 2017; Khanlou et al., 2015; King et al., 2011).

In one qualitative study with immigrant families who navigated disabilities and related services, researchers reported that families wanted to actively participate in meeting the needs of their children (Cummings & Hardin, 2017). Refugee parents wanted to take a more hands-on approach at home and take a more passive approach in schools or in medical settings (Cummings & Hardin, 2017). Parents saw those in schools and medical settings as being in professional roles and as being experts (Cummings & Hardin, 2017). All immigrant and/or refugee families wanted increasing and better communication with the professionals who engaged with them (Cummings & Hardin, 2017). Although there were efforts taken to mitigate communication barriers, parents were sometimes left on their own to try and interpret English; often no follow-up was provided (Cummings & Hardin, 2017).

Working with five Somali refugee mothers with children living with disabilities, researchers identified that parents were “not understanding their child’s condition” and that mothers found “managing a child with special needs” challenging (Beatson, 2013, p.144). The lack of understanding of the condition was often attributed to insufficient English language skills (Beatson, 2013). The Somali refugee mothers reported wanting increased time with and teaching by healthcare professionals to help them understand what the disabilities were and how to care for their child (Beatson, 2013).

A report completed for Citizenship and Immigration Canada, titled *Barriers to health service utilization by immigrant families raising a disabled child: Unmet needs and the role of discrimination* showed that immigrant parents of children living with disabilities had higher levels of unmet needs than non-immigrant parents of children with disabilities (King et al., 2011). The unmet needs were in regard to receiving adequate help finding services, access to care in languages spoken by refugees, advocating on their behalf, day-to-day support for their child, financial barriers for equipment and services, discrimination and cultural barriers and a lack of family-centered care (King et al., 2011).

The literature review did not yield any articles focusing on the perspective of Syrian refugee parents with children with disabilities in the Canadian or global context. Due to the lack of research and attention to this demographic, refugees with disabilities have been called the “forgotten victims of armed conflict” (UN committee as cited in Priddy, 2019, p.12). The influx of Syrian refugees into Canada highlights the importance of inquiring into the lives of Syrian refugee families with children living with disabilities. Trauma and injuries associated with armed conflict in conflict-rife areas such as Syria can cause disability (Priddy, 2019). If these disabilities are neglected, they may become exacerbated, creating more complex problems in the

future (Priddy, 2019). As Canada accepts refugees from Syria and focuses on accepting families with young children who experience health issues, it is likely that some families will have children living with disabilities. Insight into the experiences of Syrian parents with children living with disabilities can help formulate policies, and health care practices to ensure that this population is adequately cared for and become visible.

### **Research Puzzle**

In forming my research puzzle, I reflected on my experiences as a refugee and nurse. I remember my childhood and how when my parents interacted with the healthcare system it was often myself or one of my siblings who was the primary point of contact. That was because we were the ones whose English was proficient enough to translate. This made me wonder about situations where the child may not be able to act as the translator. I thought about refugee parents who had children living with disabilities. What are their experiences when they are unable to rely on their children for extra support to navigate new systems?

I continued to collect pieces of my research puzzle when I met up with staff at Catholic Social Services (CSS). CSS serves as a hub for newcomers who arrive in Canada as GARs; staff connect refugee families with health and social services to help integrate families into Canadian life. The staff described to me their experiences with the influx of Syrian refugees and how overwhelmed the system was/is. They spoke of how the majority of families they met/meet had up to five or more members. Moreover, they noted many young children, as well as children with disabilities, among these families. This posed many challenges in connecting families with different specialists and ensuring that they attended to the referrals they needed. There were also challenges in integrating children with disabilities into the school system. Syrian children with disabilities did not have opportunities to attend school in Syria. There are complex challenges for



this specific population, and it made me wonder even more about the unique experiences of this population.

CSS connected me with Dr. Bonniecca Islam from the Department of Pediatrics at the University of Alberta. She is a pediatrician who assessed many Syrian refugee children from CSS. Dr. Islam provided me with insights into her experience of working with parents of children living with disabilities from Syria. She mentioned that it was often easy to attend to the medical needs of the children, but that it was difficult to navigate cultural systems. I wonder what the families' experiences are as they simultaneously navigate medical needs and cultural systems.

The conversations I had with community members raised many questions for me. These questions formed the basis of my research puzzle. *What are the life stories of Syrian refugee parents of children living with disabilities? How do their lives as refugees impact them as parents of children living with disabilities? What are their everyday experiences with their children? In what ways has being a parent of a child living with disabilities impacted their families, their wellbeing and health, and their sense of the future?* In this narrative inquiry I inquired into the experiences of Syrian refugee parents of children living with disabilities. In doing so, I traveled to the participants' worlds and tried to understand their experiences through their told and lived stories.

### **Methodology**

Clandinin and Caine (2013) state that narrative inquiry is “a way of understanding experience” (p.165). Moreover, they assert that narrative inquiry is “an in-depth study of individuals' experiences over time and in context” (Clandinin & Caine, 2013, p.165). This is done by looking at an individual's experiences through a “three-dimensional narrative inquiry

space” composed of temporality, sociality, and place (Clandinin, & Caine, 2013, p. 167). As I interacted with the Syrian refugee families, I was interacting with them at a certain period of their lives, or as Clandinin and Caine (2013) say, “in the midst” (p.169) of their ongoing lives. They carry with them the experiences of being forced to flee their countries. Moreover, they are being thrust into a new country where they are in the midst of places and relationships shifted by new institutional, social, and linguistic narratives. They have the added complexity of being a parent to a child living with disabilities. As such, I was meeting them in the midst of their ongoing complex lives, and they were meeting me in the midst of mine.

Narrative inquiry is a relational inquiry (Clandinin, 2013). This is important as it allowed me to think narratively about my own experience in relation to the participants’ narratives. I have my own experiences of living as a refugee, which continues to shape my experiences. As I considered both the participants’ lives and my own in this narrative inquiry, I was called to constantly be reflexive and reflective on my experiences and how they affected the experiences participants shared with me. Being relational also required me to negotiate the relationships and various aspects of the research with participants (Clandinin, 2013). This means I was in ongoing dialogue with participants about the study, and as the result of the study we co-composed this work (Clandinin, 2013).

Relational ethics guides narrative inquiry and the interactions with participants must be “marked by ethics and attitudes of openness, mutual vulnerability, reciprocity, and care” (Clandinin, & Caine, 2013, p. 169). It was my responsibility to adhere to the relational and ethical responsibilities. I did this through constant “self-reflection, contemplation, openness, and uncertainty” in the process of conducting this study (Bergum 1999 as cited in Clandinin, & Caine, 2013, p.169).

## **Ontological and Epistemological Underpinnings**

Clandinin and Connelly (2000) state that humans live storied lives and that researchers should therefore attend to their lived and told stories. Narrative inquiry is a way to attend to a person's lived and told stories, that is, to their experience. Narrative inquiry is a way to study and understand experience. What distinguishes Narrative Inquiry from other research methodologies is its relational ontology (Clandinin & Connelly, 2000). Narrative inquiry works from John Dewey's ontology and epistemology of experience. Dewey (1916) states that experience "grows out of other experiences, and experiences lead to further experiences" (p.164). This philosophy is the basis of Dewey's (1916) two criteria of experience: interaction and continuity. Interaction alludes to a person's interaction with their environment, or the sociality and place in the three-dimensional inquiry space (Clandinin & Caine, 2013). Inquiring into an experience as a continuous concept means we understand people in relation to their social and personal contexts that are always evolving and building on previous and future experiences. A person's experience is shaped by their past, present, and future, or the temporality of experience (Clandinin & Caine, 2013). Dewey's (1916) ontology of experience contributes to the fundamental features of narrative inquiry, which are reflected in the three-dimensional narrative inquiry space (Clandinin & Caine, 2013). The three-dimensional narrative inquiry space is composed of temporality, sociality, and place (Clandinin & Caine, 2013). These dimensions help me to pay attention to the "imagined temporality, sociality, and places of participant's lives" (Clandinin, & Caine, 2013, p.170).

When I was contemplating potential research projects for my thesis, I considered my life experiences. I reflected on my experiences as a refugee, my experiences as a nurse, and my experience of becoming a Canadian. As I conducted this narrative inquiry, I wanted to honor my

experience as well as the experiences of participants. In order to understand the experience of the participant, I worked hard to understand their experiences in relation to their environments, communities, relationships, and social contexts (Clandinin & Connelly, 2000). The relationship created between the participants in this narrative inquiry and me was crucial and affected the stories shared in this study. Moreover, I had to consider how experience is constantly being shaped and that the thoughts and feelings of the participants and I may have changed over time. This narrative inquiry, therefore, does not have a clear beginning or end, as the experiences continue to be influential long after our interactions have ended.

### **World Travelling**

I am entering the worlds of my participants as a healthy, educated woman who is coming from a nuclear, stable family. I have lived in Canada for most of my life, and I show no indications in my English language skills or outward appearance that I may not have been born in Canada. However, I am also entering from a world as a refugee – a world of feeling strong pressure to conform to western society’s expectations. I am also entering from a world of a nurse, where I have been responsible for caring for patients with the intention to make them feel better and feel cared for. Lugones (1997) states that one can travel between worlds or cohabit one or more of these worlds simultaneously. As I enter this process, I wondered what worlds I would travel to, and how to be in multiple worlds at the same time.

Lugones (1997) writes of “being at ease” in a world (p. 12). To be at ease would mean that you are comfortable and confident with all the components of that world, or a “fluent speaker” (Lugones, 1997, p.12). The research participants entered from different worlds than my own. They are parents of children living with disabilities. I have never been a parent and I have never had a family member with a disability. Participants came from areas of conflict, where

safety was a paramount concern. I was only a young child when I experienced migrating to a new country. I do not have memories of conflict, although my parents do. However, I still have the potential to be at ease in their world through a shared history of migration (Lugones, 1997). Moreover, through narrative inquiry, I was able to travel to their worlds. Lugones (1997) states that by travelling to someone's world, you can "understand what it is to be them and what it is to be ourselves in their eyes" (p. 17). As I inquired into their worlds, I gained insight into their experiences.

### **Participants**

The target population for this study was Syrian refugee parents with children living with disabilities. More specifically, families where at least one parent was able to speak English. A translator was hired to communicate with non-English speaking families. The inclusion criteria are Syrian refugees that have at least one child living with a disability (that is not primarily a mental health disability); arrived in Canada in the past 5 years; and willing to engage in multiple conversations.

Recruitment was done through CSS. When Syrian GARs first arrived in Edmonton they were first greeted and involved with CSS. Therefore, CSS has an ongoing database of their clients and provides an opportunity to reach participants that are Syrian refugees with children living with disabilities. As the front-line staff at CSS had already met and developed close relationships with these families, they were able to inform them of my research. Convenience sampling was used in selecting participants. Participants were recruited through a networking approach done by CSS employees. Potential participants were given my contact information or agreed to allow CSS employees to have their information given to me. All elements of the study were explained to potential participants (through myself or the use of a translator) and consent

was obtained once I received verbal confirmation that the participants were aware of all elements of the study including: time commitment, confidentiality, expectations, and purpose of the study. Once I received verbal confirmation, I asked participants to sign a written consent form outlining all aspects of the study and highlighting that they are able to withdraw from the study at any time with no consequences. Of all the families I contacted I was able to recruit two families for this study. Other families contacted either did not answer or return my calls or explained that they were not interested in participating. As I only recruited two families, I was able to devote time and care to developing strong relationships with each family in order to engage in thoughtful conversations. Considering the socio-economic status of many Syrian families, and to help with recruitment, I also provided snacks and a \$20.00 gift card for every tape-recorded conversation I had with the participants' families.

### **Field Texts**

I met with each family three to five times, for one hour long conversation over the course of a few months. For each family, the designated point of contact was the father in the family as per the family request. It was the father who spoke about their experience in both families. I allowed the participant to choose the place of meeting, to facilitate comfort for the participant. Collecting field texts took place during the Covid-19 pandemic, and therefore the participant and I both adhered to public health restrictions that were in place at the time. I asked participants to move to online communication to ensure safety parameters were met, but both families refused, citing technological difficulties. Therefore, I met with each family in person during periods where public health officials permitted in person meetings. This varied and the meetings took place from November 2020 until July 2021. I negotiated with participants, and we collaborated to come up with the amount of time we would spend together (Clandinin & Connelly, 2000). I

met each family in the place of their choice. As meetings took place during the Covid-19 pandemic, at times this meant meeting in outdoor public parks or waiting for restrictions to ease to allow for meeting indoors. I began the study by listening to the stories of the participants (Clandinin, & Caine, 2013). Participants led the conversations while the questions I ask guided the conversation towards the research puzzle. The questions were open-ended to facilitate dialogue and to give participants a chance to fully describe their experiences (Streubert & Carpenter, 2011).

Clandinin and Connelly (2000) talk about the relationship between the researcher and participant as “being a tenuous one, always in the midst of being negotiated” (p.72). Therefore, in developing relationships with participants, there is the possibility that a natural, easy rapport is not established. There are accounts of a “gap between a researcher and a participant narrative” being “too great” and this has affected the nature of the participant, researcher experience (Clandinin & Connelly, 2000, p.72). In efforts to mitigate this risk, in discussions, I disclosed my experience as a refugee, and how I have come to establish a life in Canada. This undoubtedly changed the nature of our relationship, as having a conversation with someone who has experienced something similar to you may be different from discussing an experience with someone unfamiliar with the experience entirely. Negotiating relationships was an ongoing process through each of the meetings.

Clandinin and Connelly (2000) suggest that the purpose of the research often changes as the narrative inquiry progresses and there is a clearer understanding of “what we are trying to do” (p. 73). I negotiated the purpose of my research by explaining the intentions of the research project and in doing so shaped the purpose of the project (Clandinin, & Connelly, 2000).

My field texts are composed of information that includes, but is not limited to, “conversations, interviews, participant observations and artifacts” I collected during our interactions (Clandinin, & Caine, 2013, p. 172). I encouraged participants to share any artifacts they felt comfortable sharing with me. Artifacts included photographs, annals, and chronologies to help describe their experience as we co-compose field texts (Clandinin & Caine, 2013).

As part of each conversation, I created reflective field notes. The notes are meant to record what I have “heard, seen, thought, or experienced” during each conversation (Streubert & Carpenter, 2011, p. 42). The field notes were also used as a place to “describe observations, assumptions about what is being heard or observed, or personal narrative about what is experienced” (Streubert & Carpenter, 2011, p. 43). My field notes are composed of journal entries, anecdotes, and collections of artifacts. My method of field note recordings are varied depending on how I felt I could best make sense of the experiences or describe how I was feeling. The transcribed conversations, field notes, and participant observations help ensure and support me in understanding the experiences of the participants (Clandinin, J. 2016). Moreover, the fieldnotes are explored in the narrative accounts as “writing in the margins” sections woven in each account.

### **From Field Texts to Interim and Final Research Texts**

All audiotapes were transcribed verbatim. All field notes and artifacts collected were recorded and included in the data analysis. Analysis of the data began with the onset of the study on day one. The participants were active in the analysis of the field texts and as we negotiated narrative accounts (Clandinin & Caine, 2013). My first participant did not speak English and therefore required a translator to facilitate the co-composing of narrative accounts. My second participant was fluent in English and was able to co-compose the narrative account himself. Co-



composing narrative accounts gives participants the opportunity to ensure the accuracy of the accounts and enhances the credibility of the work (Streubert & Carpenter, 2011). For the duration of the study, I also participated within a response community where I shared and discussed my work (Clandinin & Caine, 2013). The response community was composed of my thesis supervisors, committee members, and field workers at Catholic Social Services or health care practitioners who work closely with refugees living with disabilities. My response community also included other graduate students engaged in narrative inquiry studies. Response communities were able to help enrich my research by providing “insights and wonders” (Clandinin & Caine, 2013, p. 174). During the writing of the interim texts, I paid attention to the three-dimensional narrative inquiry space. The narrative accounts were written in ways that are attentive to the temporality, sociality, and place of the narratives; by paying attention to these, we can “move deeper into the multiple meanings of experiences” (Clandinin, 2013, p.50).

Narrative inquirers must be able to justify, “so what?” and “who cares?” in terms of their research (Clandinin & Caine, 2013, p.174). These justifications are done in three ways: “personally, practically, and socially” (Clandinin & Caine, 2013, p.174). My personal justification is revealed through the narrative beginnings section. As a nurse and a refugee, I feel personally invested in the stories of refugees. In the practical justification, narrative inquirers must consider issues of “social justice and equity” or the “so what” of their research (Clandinin & Caine, 2013, p. 174). The Canadian government is currently accepting Syrian refugee families into Canada, many of which have health complications (Mahaffy, 2018). As such, this research may help develop programs that may meet the needs of newly arrived refugee families who care for children living with disabilities in Canada. Moreover, the theoretical justification for this area of research is that I will be contributing to the exploration of narrative inquiry in nursing, an area

where narrative inquiry is underutilized compared to education (Clandinin, & Caine, 2013). In the social justification of the proposed research, I hope in telling the stories of Syrian refugee families with children with disabilities to help others gain new insights. This research allows insight into the needs of this population and may be considered in developing policies specific to this population. Moreover, gaining insight into this population's experiences has helped develop my personal practical knowledge as a nurse by informing me on how to provide nursing care that is culturally safe.

In the final stages of composing this narrative inquiry, I considered the audiences as I questioned who would be the reader of these research findings (Clandinin, 2016). In composing a narrative inquiry, "we must stay wakeful to the multiplicity of ways that our research texts can be read and positioned" (Clandinin, 2016, p. 176). By reflecting on temporality, sociality and place throughout the research texts, the audience members can begin to see the complexity of each participant's experience. Once these complexities are revealed, readers can reflect on their own complex experiences in relation to the participants. Writing the narrative accounts was an iterative process that was negotiated with participants to best reflect the narratives of both participants and I (Clandinin, & Caine, 2013). Looking across the accounts, I looked for narrative threads that resonated between the experiences of both participants (Clandinin, 2013). The goal for this narrative inquiry was not to find an "answer" or generalize the findings of my study, but to open up new insights and wonders. As Clandinin (2013) articulates, the goal of a narrative inquiry is "to engage audiences to rethink and reimagine the ways in which they practice and the ways in which they relate to others" (p.51).

## **Ethical Considerations**

Before beginning my research, I obtained ethical approval to conduct my research from the University of Alberta Ethics Review Board. Clandinin and Connelly (2000) argue that obtaining ethical approval before initiating the narrative inquiry goes against the “relational negotiation” that is customary to a narrative inquiry methodology (p.170). In order to adhere to institutional ethical guidelines of the University, I am “imaginative and open to all the fields that, we and our participants, may eventually see as part of the inquiry” (Clandinin, 2013, p. 198).

When I was faced with additional ethical questions that I had not previously imagined, such as the Covid-19 pandemic, I returned to the University of Alberta Ethics Review Board for supplemental ethics review (Clandinin, 2013). Before initiating our meeting, I asked participants to sign an informed consent form. I explained to the participants my personal history as a refugee and a nurse, why the research is important to me, and the impact I believe this research may hold. I explained the time commitments of the study if they chose to participate. As narrative inquiry is a relational methodology, I negotiated with participants the time and frequency of the meetings – the meetings ranged from forty-five minutes to an hour and a half, with three to five meetings each over the course of seven to nine months. I informed participants at each meeting that if they feel uncomfortable or change their mind about participating, it is their right to withdraw from the study at any time without consequences. For my participant who did not speak English, the consent and information about the study were translated with the use of a translator that attended each meeting with me. All participants were given pseudonyms. My supervisor was always made aware of my itinerary and location when interacting with the participants to ensure my safety and the safety of participants.

Strong efforts were made to ensure confidentiality was upheld for the duration of the study. This includes changing the names of the participants and participant family members included in the study. I went into the meetings recognizing that there was a chance that engaging in this study may bring up stories of unresolved trauma or pain for participants. In preparation for this I had a list of counseling services or mental health resources available and referrals that could be made through CSS. Furthermore, for the duration of the study I approached traumatic or sensitive situations with great care. However, it was made clear that although I have a nursing background, the conversation between myself and the participants is not meant to be therapeutic or attempt to mend unresolved personal issues (Clandinin & Caine, 2013).

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## CHAPTER 2

### Narrative Account of Abbud

#### Introduction

I met Abbud at the Catholic Social Services (CSS) Recreation house. I was happy with this meeting choice as it was a place we were both familiar with, a neutral ground. It was a cold November evening and I had gotten to the venue early. Arriving early was my ritual any time I had a meeting I was nervous about and I admitted to myself that I was quite nervous. I sat in my car until it was closer to our meeting time. I tried to imagine how the meeting would go. I imagined if my parents had decided to participate in a meeting like this, how comfortable they would feel disclosing personal information to a stranger. I imagined they would be apprehensive, but admittedly I didn't really know. Maybe they would have felt relieved that somebody wanted to hear their story and would have been open to sharing their arduous journey. Or maybe, they would have not wanted to share the details at all because it was too difficult. My experience was so different from my parents, making it hard for me to imagine how my parents may have felt. What I went through as a child, I could never imagine doing now as an adult. I wondered if after these meetings I would somehow feel closer to my parents, more empathetic to their experiences. I wondered how it would impact my nursing practice in the future. I felt a sudden sense of pride that I was doing something important.

Abbud was learning English but still required help to completely understand my questions, so we required a translator. Our translator, Amina, was also a Syrian refugee. However, Amina had learned English in Syria. We hired Amina to help translate our conversation. I met with her before meeting Abbud. I was happy to have Amina present during my first meeting. It felt like I had a partner going through this with me and I imagined it would

help Abbud feel more comfortable having someone there who understands what life in Syria is like. Amina and I met in her car and walked into CSS together. Amina was friendly upon the first meeting and as we talked, I got the sense that she believed in the research project and was eager to help. When we walked inside CSS we were greeted by a receptionist. We quickly signed in and did the regular covid-19 protocols we had become used to; putting on a mask, using hand sanitizer, and recording our names to ensure proper contact tracing could be done should someone report getting sick. It had become a routine at this point. When we sat down at the table inside the reception house, Abbud arrived right on time. We greeted each other and I thanked him profusely for agreeing to participate. Immediately I took notice of what he was wearing. He was dressed casually in jeans and a bomber jacket that didn't look warm enough for an Edmonton winter. He had a warm smile and kind eyes that were disarming enough for me to relax. As I started talking to Abbud, I realized that the translator was going to be of much use in this situation. It occurred to me that Abbud may have never even heard of a qualitative research study. As I explained the research study to him and had Amina translate, I heard myself as I tried to emphasize the significance of his experience, and how he felt. I wondered to myself if he had ever really considered his feelings during his refugee journey, and if it would be difficult to recall when one was presumably in a prolonged state of survival mode.

Abbud stated, *thank you for having me, and I would welcome you into my home anytime you would like.* My heart felt warm at this quick act of generosity so soon after meeting someone. It was clear that Abbud was kind, and willing to help by sharing his story. That felt promising, and I had a sudden rush of relief wash over me.

## Life in Syria

Abbud was born in a small village in Aleppo, Syria. He grew up in a poor family, “I always had to depend on myself” he recalled. He described safety for his family as always being a priority. In Aleppo, Abbud described, safety is directly related to financial prosperity.

*In Aleppo there was a difference between the strong families and poor families. In strong families if you are joined with this families, you can do whatever you want. No one can talk to you or stop you, even if you was doing wrong things, no one can stop you. Even if anyone stopped you, the name of your family they are going to stop the others.*

However, for poor families like Abbud’s, if someone were to do something to him, he would have no protection. From a young age, Abbud had to leave Aleppo to go work abroad to make money to send back home. He had taken a job in Lebanon working in construction. Any income generated from his construction job was promptly sent back home. I got the sense that Abbud was seen as a protector in his family. Always working hard to protect and provide for his family. He said the money he made in Lebanon was enough to provide for his family but just barely.

What was life in Syria like before the war?

*In Syria, unfortunately, the government there are not helping the people. You need to work to support yourself. There’s nothing like here, a child benefit or welfare, or stuff like that. You need to work to support yourself or your family. As all the Syria people, we accept that. We didn’t have any problem with that. We can work. We can support ourselves, but there was peace. No one is afraid from the future. Most definitely the people they feel at peace. Definitely.*

What was healthcare like?

*For the healthcare, there was two kinds of healthcare. There were the government hospitals and there were the private hospitals too. For the most people, we can go to the local hospital and we can get the healthcare, but it's not that too much care. You need to pay and if you want that good kind or the best kind of the healthcare, you will need to go to the private hospitals or the private doctor's clinic to get what you want. For the medicine, we pay for the drugs there. There's nothing free like here. We need to pay. Just vaccine for immunize for the kids it was free, but other things, we need to pay for everything.*

Syria has a dual health care system made up of both private and public health care (International Labor Organization (ILO), 2020). The public health system in a public health care centre is regarded as weak by the Syrian people, and only gotten worse due to increases in demand that the government is unable to meet (ILO, 2020). These issues have made Syrians favour privatized health care (ILO, 2020). Despite these issues in Syria, Abbud recalls happy memories in Syria. An entire village would be composed of mostly family that coexisted in peace.

*Before the war, [I] was living in peace with [my] family. All the village, they were relatives. None of them are from the village. [I] was living [with my] family, brothers, sisters, other siblings, cousins.*

Abbud showed me a photo of one of the last encounters he had with his family on his phone. In the photo was a large group of people, mostly women (Abbud explained these were his sisters) and lots of children. The women were dressed modestly in hijabs, and most were holding a child in their arms or their hands. They all stood close to each other forming a wall that reminded me of a sports team. Abbud explained this was the last time they had all been together, he had visited Lebanon one last time to see them and say their final goodbyes. I could sense this picture made

him emotional by the faint smile on his face. He looked longingly at the photo. Abbud has eight children. The eldest is twenty-three years old and the youngest is three months old. All of his children were born healthy, and it was not until their journey for refuge started that one of his children developed a disability.

**Writing in the margins:** As Abbud told his story I was reminded of stories I had heard before from my own parents. Abbud's description of his life in Syria, working abroad to bring money back home was very common among myself and many of my friends who had immigrated. I remember my mom describing her relationship with her father. He worked abroad in Vienna, Austria to provide for their family while my mom and her siblings were left to be raised by her grandparents. My mom always spoke highly of her dad, describing him as a respectable man who was known for his integrity. He was depicted as a protector, much like Abbud was in his stories. It made me think of the burden this must be. To have the safety and security of an entire family on your shoulders. Did it ever get to be too much? I thought of the days I had not felt fit to work and called in sick. What a privilege to have the option to rest without feeling like you are compromising your families only money for the week. I could feel a sense of shame creeping up in me for complaining about work schedules that only affected me.

### **Syrian War and Journey for Refuge**

In 2011, the war in Syria began. As different groups in Syria began fighting each other, the village that Abbud's family resided in was stuck in the middle. It was no longer safe for them to live there. For a short period of time, his family moved to a nearby village to seek safety. It wasn't long before that village was getting increasingly dangerous. Abbud made the decision to move his wife and children to Lebanon. Abbud was familiar with Lebanon as he had worked

there for many years but also, he feared that if he went away to work in Lebanon alone he may not have the opportunity to return to see his family again. Sticking together was the only option.

They departed for Lebanon in 2013, however, the trip to Lebanon was an arduous one.

*It was scary. [I] didn't feel safe because at any time maybe something happened, like bombs, like fighting between two sides. Especially [when] you are going in for the enormous city, big cities, maybe they choose your name, like they look your ID and maybe they want you to go to the military. It was not safe. Until [I] arrive[d] to the Lebanese border at that time that [we] feel safe there.*

The safety that Abbud and his family felt arriving in Lebanon was short-lived. Living in Lebanon presented its own set of challenges that Abbud and his family would have to face.

*As Syrian refugee [in] Lebanon, there is no respect for the Syrian people there. The situation was too bad because [I] was living in a camp. It was too poor. You need to work hard to support yourself, at least like you can just eat and stay alive. That's it. No more.*

In Lebanon, Abbud and his family lived in a refugee camp for the entire duration of his stay in Lebanon, nearly six years. At first, Abbud recalls receiving a lot of help from the United Nations (UN). The UN would provide relief for up to 75% of costs associated with food or healthcare. However, as the number of Syrian refugees in Lebanon increased the benefits decreased. The increase in refugees began to affect all aspects of his life as his salary at work also started to decrease. To make matters worse, Abbud did not feel safe living at the camp.

*It was terrible. It was a bad life. We lose everything. Nothing to protect us, no rules to protect us.*

It was in Lebanon where his son got in an accident that would render him disabled.



*One day he was playing outside and he has an accident by car, they take him to the hospital. He stay in hospital for 45 days, he was in coma. He has injury in his brain, his lungs and he was in bad situation but after 45 days, he returned to the life as they say but he return as a newborn baby. He was not talking.*

**Writing in the Margins:** I found this example of his teenage son returning to a “newborn baby” very striking. It was as if the son that he had known all his life had suddenly changed in front of his eyes to someone entirely new and he would need to get to know this new person from the beginning. I imagined myself as a child playing outside with my siblings or my cousins and going through an accident like that. What would that do to my parents? I could imagine the turmoil that would cause in my community, how I would receive all the attention and help I needed in a prompt matter. How there would be initiatives put in place to prevent other children from similar accidents. I had accessible resources and a strong support system. It would have been a traumatic experience for anyone, but I know I would have had help. I wondered how Abbud may have felt at that moment. I wondered if he felt alone.

How did you feel? How did you cope with this?

*[I was] feeling too bad. Do you know how when you see that your kids was normal and suddenly become disability and you can't do anything for him after he returned to his home he needs the treatment, you need to go to physio, and stuff like that but [I] couldn't pay anything because [I] didn't have enough money. Also, [I] [have] a family, need to support them. Until now, [I still feel] the same, feel too upset about that and about [my] son.*

How was the treatment in Lebanon?

*In Lebanon, for [my] poor situation, [I] couldn't do anything for [my] kid. There is no money, and [I was willing] to pay a lot of money. It will be very expensive and [I] [can't] do anything for him, just the physiotherapy for him. Even that, it was very expensive for [me].*

I wondered if maybe they received some compensation from the accident that could help him with the medical bills. The entire situation felt unfair.

*The person who make an accident, they couldn't judge him a criminal because [my son] he's a Syrian refugee and no one will listen to them and all the things. He just was going and take care of them just a little bit but that's it.*

I saw pain in Abbud's face as he told the story. His eyes widened and filled with emotion. His voice got quiet as he explained his story, and would sigh as if to say "what could I do?" I wondered how one could cope with the pain of seeing your child need urgent medical care that is not readily available. I asked how they have come to terms with this traumatic experience?

*When [I] compare what happened to [me], to [my] family, to [my] kids, [I] say, we believe in God, and that happened from God. Everything is coming for us or happened with us, everything is coming from God. We believe for that, and we didn't blame anyone or any person for that.*

## **Journey to Canada**

Abbud never imagined his journey as a refugee would take him farther than Lebanon. He didn't have any intention of leaving before the war and before his son had his accident. However, after the accident, he began paying closer attention to the rumours among the camp of families being sponsored to live abroad in places like Europe, America, and Canada. He began to notice

people leaving the camps. Abbud dreamed of taking his family to a safe country where he could provide the adequate healthcare needed for his son and promise safety for his family.

*It's become hope for [me] if the UN choose [my] file to be a refugee in other countries, not just especially in Canada. One time, the UN, they give [my] wife's sister a call and they asked her if she wants to be a refugee in Canada. She told them, yes, but I have also my sister and her situation was like [having a son with disabilities], and they take [my] numbers and give [me] a call and ask [me] if [I] want to be a refugee or landing in other country and [I] said yes. When they choose [my] file and they gave [me] this call, [I] was so happy because they chose [me] and they approved the file because, finally, [we] will leave everything bad for [us] and [we] will start a new life for [me] and [my] kids. For [me], this country, it's the country who [will] protect [me], and support [me] and give a good future to [my] kids.*

**Writing in the Margins:** I could sense the hope in Abbud's voice as I heard Abbud tell his stories and the familiar story of migration. Moving to Canada meant safety, and it meant a possibility to have a better life for his children. This was the same dream that brought my parents to Canada back in 1999, and it's the dream that has brought many immigrants to Canada before then. I thought to myself about how the dream for a better life can give people hope in times of immense hardship like what Abbud and his family went through. What a powerful emotion hope is.

In 2018, Abbud and his family arrived in Canada. Their flight stopped in Toronto for one night before heading to their final destination, Edmonton. I asked about his first impression of Canada.

*When we arrived in Toronto, I asked a lady if I could go outside to smoke. When I went outside and saw the freezing weather, I stopped smoking.*

This made us all laugh. I noticed how in our later meetings, Abbud was more comfortable telling humorous anecdotes. The mood didn't feel as intense and there was a sense of familiarity between all of us. I asked Abbud if he had any pictures of his arrival in Canada. He showed me a picture of his family in a small apartment, all huddled together in the dining room. They were all smiling. In the picture was his English tutor who had come to their apartment to teach them English. Abbud smiled as he looked at the picture.

### **Healthcare in Canada**

As Abbud and his family got acquainted with Canada, they quickly got acquainted with the healthcare system. To first understand their interactions, I had to try and understand the extent of his child's disabilities. I asked how his first appointments went in Canada. Abbud expressed that he felt very disappointed with the initial appointments as he wanted urgent care for his son but quickly found out that he would be waiting a long time before any interventions would begin.

*He has problem with his right side, he can't control [his] hand or use it. There is no sign from his brain to his hand or leg to move or to do what should do. They make a surgery for him to make both legs... the same length, it's because the right one it [is] shorter than the left one and now he still need to face surgery, but for COVID-19 situation, everything stopped, but [we] are still waiting. There's a new date. Then there is another surgery, he should make it. His mouth, it can't be closed, so he need surgery to his mouth to make his mouth close because even if you try to close it, it's still open. He can only eat from one*

*side and can only talk slowly. They told [me] there is nothing they can do for him. They told him there is a surgery, they can do it for him, but they didn't give [me] any hope.*

I could sense by how Abbud's sentences became increasingly fragmented that he was having a difficult time articulating the complexity of his son's situation. There were a multitude of problems that needed to be dealt with for his son to resume normalcy in his life. Even as a healthcare professional, it felt overwhelming to me. I could only imagine how this feeling was compounded by things such as language barriers, accessibility, and an ongoing global pandemic.

How do you feel about your experience with healthcare?

*There's no comparing between [my] old life in Syria or Lebanon and [my] new life in Canada. [My] experience, it was very good. Everything was new for [me]. [My] life has changed completely from since [we] live in Canada, but [I] just want[] something from healthcare. They have too slow system here, and you need to wait for emergency cases. Maybe that's this case it's become more so than before, for the waiting time. After all they do, they tried to do their best, but they taking steps until they arrive at the surgery. When they decided he needed this surgery, he need to wait for long time to give him appointment for his surgery. This appointment also it will be for a long time too.*

At the beginning of our conversations, I sensed a deep sense of gratitude every time there was mention of healthcare and his experience in Canada from Abbud. But as we got to know each other, Abbud began to reveal how long wait times were a great deal of frustration for him.

*As parents, this feeling is too hard for [us] when you know that your son needs help and you can't do anything. For example, when [we] went to the dentals, he asked them if he can get help to make his son drink food and he send them to another*

*clinic who [said] can they put the braces for teeth to make the teeth normal, but even with that help, he needs another surgery to make the two jaws more normal to chewing the food. Another thing, he needs two other surgery and for all this situation [there is a] waiting list, [I began to] feel depressed and feel [I] become more stress[ed] for all that. [I'm] always think[ing] that why they're too slow and my son need a lot of help and he's still waiting. In Canada, you don't need to pay money or a lot of money, but at the same time, there's another side. You need to wait and the waiting is more harder than to find the money.*

Maybe they noticed the surprise on my face, as I hadn't thought about it like this before because Abbud decided to explain further.

*Maybe I can give you an example. Like Syria or Lebanon, we can borrow money from our friends, families, and offer that much money how much we need and you take it to the hospital and solve all the problems, but here, we don't need to pay money, but we need to wait.*

**Writing in the margins:** I was truly surprised at hearing Abbud talk about the impact of waiting times on him. I have always been aware of the challenge wait times pose on our healthcare system. It was something you always heard when talking about Canadian healthcare. “These wait times are absurd, but that’s what you get with free healthcare” was a common phrase that circulated the hospital. However, to hear Abbud say that at least in Syria he had options for healthcare, I began to see truly how restrictive this system can be. Abbud felt a sense of urgency with his son, and in this environment those options were taken from him. He couldn’t do anything to help, he was stuck in a perpetual state of waiting. All of the waiting was contributing negatively to his mental health. He was being forced into inaction

with the hope that eventually something would come of his waiting. While he waited he had to watch his son live a life in pain. I felt terrible. I began working in healthcare with the hope of helping people and it was hard hearing how the system often fails people.

As Abbud continued, he explained that waiting times were not the only challenge Abbud and his family faced. Language barriers were also very difficult for him.

*The language is a big issue for [me] and for most of the refugees here because [we] want to understand. [We] want to explain. There is specific words, especially in healthcare, you have to use it, and this word [we] didn't have it. Now after [my] experience, [I] have these words and [I] can understand [better], but [I] have the same problem, [I] can't answer, or complete the conversation with them.*

Were there translators available to help you?

*No, sometimes not. Sometimes, but not always. The doctor, they use always- their phrases or their words are medicine words. [I] can understand the word in normal life, but when they use it, they use it in different ways so [I] can't understand what they mean.*

The use of complex medical jargon posed an understandable barrier. I thought of the people in my life who were fluent English speakers and still struggled to understand the complexities of their medical conditions. I reflected on my own practice to the times where I had to do patient education regarding specific procedures. It was always a challenge to find the right words to explain accurately what was happening but also be as simple as possible. I wondered about how to ease this burden in healthcare. To my surprise, Abbud said the one area where translation was less of an issue was in physiotherapy.

*[I] don't have a big problem [in physiotherapy] because they show [me] a picture, and they are doing it in-person for [us], so [we] see it [with our] eyes so [we] can understand.*

The use of pictures and demonstrations were the most effective in easing translation barriers for Abbud and his family. I thought about how often I incorporated this into my own practice or saw it done. For complex procedures I have seen the use of brochures with pictures but that was usually done at discharge and not before. The system puts a lot of the responsibility on the patient to ask questions, to do their research, to take notes while things get explained. But what happens when the patient can't do that such as in Abbud's family's case? The flaws in our current way of doing things began to become more apparent to me as I heard Abbud tell his story.

We ended our sessions by discussing if Abbud ever missed Syria, if he or his family ever longed to go back. Abbud explained that his younger children don't have much memory of their time in Syria or Lebanon and adjusted easily to life in Canada. For the older kids, they struggle more adapting to school and miss their families. However, when they have contact with their family, they are content living in Canada and would not want to move back. I asked Abbud how he felt about Syria. He told me that the only person left residing in Syria is his mother.

Is she safe in Syria?

*No, we can't say, but no guarantee. She refused to leave her town. She preferred to stay. She preferred to protect her family, her kids and asked them to take their families and leave the town, but for herself, she preferred to stay in the town. We can say it's her life, all her life there. It's very hard for people to leave their place. For most all people, for senior people especially, most of them they think that they will become a criminal if they*



*leave their countries or their place. They're always thinking if we pass away, where will they put us? We prefer to stay there and die there. Even if we are dying, at least we are in our country. If everyone leaves this country, this country will be empty, and this is our country. We can't leave it. We live for a long time, so if we want to die, it's better to die in our country, in our place.*

Despite the hardships, and the conflict, Abbud still felt deeply connected to Syria. He left because he was forced to, for his safety, and for the safety of his family. However, he still had aspirations to return one day to pass away in his country for the sole reason that it was his. Syria was home, and nothing would change that for him. Abbud taught me a lot about the journey a refugee may go through and the experiences they have with Canadian healthcare. I was able to reflect on my own experiences and think deeply about who I am as a daughter, a refugee, an immigrant, a nurse, and a researcher. I met Abbud in the midst of his story, and he in the midst of mine. But together, we were able to travel to each other's worlds and see each other's stories of migration from a different perspective. For that I am thankful to Abbud.

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## CHAPTER 3

### Narrative Account of Mahir

#### Introduction

I met Mahir, my second participant, through a mutual contact at Catholic Social Services (CSS). He currently works at CSS in assisting newcomers as a community support worker. Mahir spoke both English and Arabic, making him an ideal person to assist newcomers at CSS. Mahir was generous enough to agree to participate in this research project, *anything that could help the people we are ready to do* he had said when I asked him to participate. Mahir was bilingual so this would mean that a translator was not required for this meeting. Not having a translator at our meetings made me a little nervous. It meant that there would be one less barrier between us, creating a potential to connect closer but also made me feel more vulnerable. I was afraid that if the conversation didn't go well that was a personal reflection on my ability to connect and communicate with him. I tried to forget these thoughts, and instead reminded myself that he had an important story to share, and I was fortunate enough to hear it. As I explained the process of the research project, I could tell Mahir did not quite understand why I wanted to meet so many times to hear his stories. I felt tension as I explained how many times we would need to meet and why I wanted to hear about his experiences. I got the sense in the way Mahir talked about our meetings that he wondered, what made me so interested? I felt that he was apprehensive that there would be "a catch". I tried my best to explain to him the relational nature of narrative inquiry and my experience with being a refugee myself. I explained how my own experiences shape my research and tried my best to not sound like a telemarketer despite feeling that way when I recruited participants. It is in recruiting participants of my study that I began to note the differences between my role as a health practitioner and a researcher. In the former role

I was used to having a sense of trust from my patients. When a patient is admitted in the hospital, they often have a sense of trust in their nurse that they are there to help them and will not cause harm. Although there are some patients who are more suspicious of their healthcare providers, I have found that trust between patient and healthcare practitioners is expedited due to the vulnerable nature of the situation. There is a lot of trust involved when you allow a nurse to bring you your medications or perform a procedure on you or even help you to get dressed. As a researcher I quickly realized that my participant does not trust me yet and the mere nature of my job would not be enough to win over that trust. Trust would take time. I hoped I would get to that point with Mahir over the course of our meetings.

When I asked Mahir to meet to have our first conversation, we made plans to meet inside his home. This would mean I would get to meet his entire family as well. Before our first meeting I parked my car outside of his house and waited for our agreed time before walking out. It was a winter evening with fresh snow powdered onto the sidewalks and windshields of the cars parked next to me. Everything around me felt calm and still, yet as I sat there, I was getting increasingly nervous. Are you really ready for this, I thought to myself? Is this safe? What if he feels that halfway through our conversation, he cannot trust me and does not want to continue? I could feel doubt brewing inside of me but as the clock inched closer to our meeting time, I pushed my doubts away and mustered the courage to walk up to his door and knock.

The first thing that I noticed about Mahir's home was that it was a house. In my mind I had imagined them to be living in an apartment just as I had with my family for the first few years we lived in Canada. I caught myself as I had made that assumption and tried to remind myself to not make any more assumptions going forward. Mahir and his family are going to have different experiences from what my family experienced, and I must keep an open mind, I

reminded myself. Mahir opened the door and greeted me kindly. As I walked in and got myself positioned to begin our interviews, I took in the place around me. The house was very clean with no clutter noted anywhere. The space was minimal, and it appeared to me that they made an effort to only keep things that were essential such as couches, dining tables, and chairs. There wasn't much art on the walls aside from pictures of what I assumed was family. There was one desk in the living room with a computer. I wondered how often Mahir used the computer and if he felt comfortable using technology. I thought about how my parents always asked for my help with technology whether it was online banking or starting a facetime call with family and wondered if he asked his daughters for help with the same. Despite the minimalistic aesthetic, the home felt warm and cozy. An ideal space for raising children I decided.

As I sat down and got comfortable, Mahir's family slowly trickled into the living room to greet me. Mahir lives with his wife and six daughters ranging in age from twenty years old (the eldest) to three years old (the youngest). The eldest daughters were proficient in English and were the first to start talking to me. They asked me about what I did and where I went to school. They were interested in the path I took as they were both thinking about attending University and had questions about how the school system works here. The oldest was currently taking Sciences in university with aspirations to become a doctor and wanted to know how she would go about applying. I shared with her what I know of the medical system based on the paths my friends and family had taken. The second oldest daughter revealed she was thinking about becoming a nurse and wanted to know what it is like. I was able to tell her about my experiences and what nursing has been like for me. Talking to them eased my nerves, I was happy to be helpful. The entire family was very polite and shortly after I sat down, they began serving me an arrangement of foods and drinks. It reminded me of the culture I had grown up in where the host's family served

the guests whenever they came over. It was polite to offer food and drinks multiple times to the guest even if they declined your offer the first time. Finding these unspoken connections between Mahir's family and my own made me feel more comfortable. As we shared food and drinks, Mahir asked me if I wanted to meet Abia who was not in the room with the rest of us. Abia is thirteen years old and was born with a disability. Some doctors have stated she has cerebral palsy however Mahir insists that it is not as the doctors in Syria had initially predicted she would walk within 5 years with the appropriate treatment. In his description of events, I could sense a distrust of the healthcare system as he explained multiple versions of events he had been told by multiple doctors. She is wheelchair bound and requires total care for any activities of daily living. She cannot verbalize words and has difficulty swallowing which requires her to have and feed through a Gastric tube. Her motor movements are not controlled and often sporadic. When I went to meet Abia, she was sitting in her wheelchair in her room. Her siblings gathered around her protectively. Her room was spotless, much like the rest of the house. I could see by the way her sister gently held her hand and touched her shoulder they were very caring towards her. *Everyone helps take care of her* he told me. I immediately thought about all the instances of caregiver burnout I'd witnessed with family members of patients in the hospital. I wondered if it helped to have a big family in this situation. The care for Abia could be dispersed between many people. It was clear they loved and cared for one another. The bond between family members would help them overcome much adversity I thought to myself. Shortly after I said hi to Abia, we returned to the living room, and it wasn't long before we began to talk about Mahir's life in Syria.

## **Life in Syria**

Mahir and his family are Kurdish, originally from Kobani, a city in northern Syria where most of his family still resides. Family plays a big role in Syrian culture and means a great deal to Mahir which emphasized to me.

*The relationships between the families are very strong. It is not like here in Canada. No, but in that time, very strong. For example, my sister now is a grandma. I'm still responsible if there is anything happened on their family. They call my father if there is a problem. This is the relations. Yes, the relation is really stronger there. Even though I make friends here, I know my neighbors well, but it is not the same. The families are very big. For example, the members of the family, each family maybe have 5 children, 6 children, 10 children, 12, sometimes 20.*

Mahir was a teacher who taught English literature in Syria. There were not many jobs in Kurdish areas and therefore he and his immediate family had to live in the nearby city Al Raqqa. As Mahir spoke about his experiences in Syria, I got the sense being Kurdish played an important role in his story. I soon learned that Kobani is a predominantly Kurdish city in Syria, lying south of the Turkey-Syria border. Mahir explained to me the struggles that Kurdish people have faced in Syria. Kurdish people represent 9% of the population in Syria and are a separate ethnic group from the majority which are Arab Syrians (Library of Congress, 2005). Being a minority population, the Kurdish population have faced much oppression out of government fear that they will one day demand more independence (Library of Congress, 2005). Mahir explained that the Syrian government treated Kurdish people as “foreigners”, never allowing them to feel welcome on their land. As long as Kurdish people decided to reside with the Kurdish community they were considered as having “no-identity” Mahir explained. This made things such as travel

extremely difficult. Every time Mahir wanted to travel he would have to visit the security intelligence agency to receive documentation that gave him legal rights to travel. This was not the only way Kurdish people were mistreated. Another example is the Syrian regime suppressed Kurdish people from advancing in their careers. For Mahir this meant that he was allowed to be a teacher, but he would not be allowed to advance to become a principal.

*When I was at school, my director has experienced two years, I was nine years, we are not participate with their meetings. We all the time under the control, under the eyes of intelligence security, even though we didn't do anything.*

As I listened to Mahir's story, I wondered how that must feel to be ostracized from your own country in that way. I felt myself getting increasingly angry as Mahir told his stories of mistreatment for being Kurdish. It all felt very unfair. I wondered if it made Mahir angry or if he had come to accept that as the way of living in Syria. I wondered if he ever truly felt at home while living in Syria.

Did Syria feel like your home, or do you feel more like your home was with the Kurdish people?

*Syrian?*

Yes.

*Is my home?*

Yes.

*You mean my belonging?*

Yes.

*For me, I don't believe in Syria or any place. I believe if I live in any place who give me my humanity, give me my dignity, I believe that I belong to that location.*



That is very powerful.

*This is why I don't believe the information which are in the ID, let's say, that he's Syrian or so. No, I don't believe. I believe that where I live, I get my humanity. There has to be equality with the people. No difference, all people are equal under the law. They have duty and responsibilities. I believe in such things. I don't believe that, yes, I spend most of the time in Syria that I belong to Syria. No, because I didn't find the things that we are looking there. This is my identity.*

*Yes, this is the reality. If you live all your life submissive, how could you say that I'm Syrian? No, I'm not Syrian. The Syrian is land where I live. When I belong to something, when there is equality between all the people, I get my dignity. There is equality. All the peoples are in one level under the law. This is what I believe in. If I look at my information, I'm Syria, I don't believe it. This is just information.*

**Writing in the margins:** I was moved by Mahir's account of identity. The honesty in which Mahir spoke about his country sounded poetic to me. "I can tell he is a literature teacher" I thought to myself. Mahir had been pushed to his limits so far that he could no longer identify with the country he resided in. I tried to understand the weight of what this meant. I thought of how identity is so intrinsically tied to nationality. This concept spearheads celebrations, sports, even wars. I recalled how in my own family I had heard my dad tell me many times growing up "never forget where you came from". As if my identity is rooted in the place I was born simply from being born there despite spending most of my life living in a different country. People have died and killed for their country and continue to do so. It seemed to me that the thing that almost everyone on the planet had in common was a feeling of unity for the very

thing that divides us, borders. However, Mahir's perspective of not believing the information on his ID, that his country was merely information to him, resonated with me. It made me think of where or what I consider home to be. Being born and having most of my family in Kosovo instilled in me a patriotism for the country ever since I was a little kid. This was nurtured by my parents, and I was often encouraged to speak Albanian (the native language) at home and visit Kosovo frequently. My parents wanted me to "never forget where I came from". The significance of this was always emphasized to me. However, I had only lived in Kosovo until the age of four. I had spent most of my childhood, adolescence and now adulthood in Canada. To my parents' dismay, by the time I was eight years old I could speak English more fluently than Albanian. This often left me feeling confused about my own identity. If I lived in two drastically different places, who was I really and where was home? Neither place, not Kosovo nor Canada felt entirely my own. I felt like I was stuck in a floating space of "in-between" with no geographical location I could land on. When Mahir spoke of not belonging to any geographical place but rather belonging to where he was accepted as a human, it made me feel at ease. That was how I felt too. Who I am, where I belong, where I believe home is...Those weren't tied to geographical location for me, but rather to where the people I love are. It made me realize some of the similarities I shared with Mahir despite having such different stories.

As an English teacher, Mahir taught from the year 2000 to 2012. The revolutions began to erupt in Syria in 2011 but the schools did not close until 2012 with invasions through the city, Mahir recalled. When the revolutions began, Mahir and his family did not participate in hopes of avoiding getting into trouble.

*When ISIS came, they said we will not do anything wrong to any people who didn't carry guns or fight. I was very careful about the future of my daughter[s]. I did everything to make the family be safe. After passing a year, because there were the ISIS attacked the Kurdish area.*

Unfortunately, Mahir and his family were not able to ignore it for long. Members of Islamic State of Iraq and Syria (ISIS) soon invaded their homes despite promises that they wouldn't if they stayed quiet.

*After passing a year, they announced that the Kurdish people should leave the city within 24 hours. Anyone who will not leave, they will be headed off.*

When ISIS invaded their area, the struggles that Mahir and his family encountered were only compounded by the fact that he was trying to find care for his daughter with a disability. Before the attacks, Abia was getting support and even showing signs of improvement before the revolutions erupted. She had a diligent healthcare team that was confident in her progress. When Syria became increasingly dangerous, healthcare workers left. There was no healthcare support for Abia, and she began to get worse.

*During this period of time, this year, when ISIS came, we were living in Al Raqqa about a year. Abia is my special need daughter. Abia was good and Abia received physical training three times a week. Abia has got better, but when ISIS came, people left the city. Doctor escape, fled away because nobody can live this life. It's very dangerous. If we have any chance to escape, we were dead. We didn't have any chance with special need. The condition became very bad, no schools, no money, supporting life is very difficult. Abia has choking and get seizures.*

Mahir explained to me a particularly difficult night with Abia.

*Once we didn't [know] how long Abia got-- when we woke up in the morning, we found that Abia has foam on the mouth, weak eyes, fever. She become very faint. We took her to the hospital, there is no doctor, nothing. There is an injection. They gave it to Abia just to let her sleep. It took about four or five hours and Abia situation became bad. We know that bad. We no longer could took Abia to the specialist in Damascus because ISIS didn't allow people to leave because ISIS notes that the civilians are escaping from the city. There are detainers around. There are guards. There are soldiers all around the city and didn't allow people to escape. They didn't like me to take her to the doctor. Even once or twice, when I went looking for permission, they have to give me a permission that it is written that this family allowed to leave to go to the Damascus and go back within three days. Every time they gave me this permission, they force me to give them a bag of blood. If I didn't give them, they said within three days, if you didn't come back, we will take your house, your car, and everything. The situation becomes very bad. Abia's got worse, very worse. If we want to go to the doctor, we have to go all the family because I couldn't leave the girls alone home.*

**Writing in the margins:** When Mahir mentioned that he had to give a bag of blood as compensation for permission to travel I felt my stomach turn and like I was going to be sick. He had to give a part of himself to ensure the safety of his family even though it could kill him. I imagined the struggle Mahir must have faced deciding between getting help for his sick daughter and feeling weaker from giving blood. I wondered how it felt to have to be stopped

from helping your daughter by the limitations of your own basic needs. To hope for more blood in your body to gain basic rights in your country. It made me feel extremely uneasy. It made me begin to understand the lengths that Mahir would go to protect his family.

Syria became increasingly violent, and Mahir and his family were forced to move to the South of Turkey to the regime area. They began their journey by Taxi only to be told they could only be taken halfway. The rest of the journey they had to do on foot, in Syria's blistering heat.

*Even my special need daughter's wheelchair, we couldn't take with us because there was no space, and we leave. They don't allow us to take anything with us just with our dress that we are dressing. It was very hot. I think it was in July or June. July June, I don't remember exactly what month, but it was very hot. We walked and within two nights and three days, we arrived at Kurdish area.*

In 2014 Mahir and his family made it to Turkey. Unfortunately, their fate in Turkey was not much better.

*In Turkey, the situation is also bad, but safer than Syria. We took Abia to the hospitals. Do you know there was no much care? Once or twice when I take her to the doctor, then one professor, he said, "We couldn't help your daughter. There is no cure for your daughter. She has cerebral palsy." The medication is not changed. Everything the same, no supporting. We were taking Abia by bus. It's very hard. Finally, they gave me a report that "We couldn't help you. Go home."*

*Abia's situations all the time becomes bad. Abia was controlling her neck. There was no saliva from the mouth. Now Abia couldn't control her neck. All the time dropping from*

*the mouth. Even feeding was very, very difficult. Every time a very small piece of bread or food and swallowing is very difficult. The situation was really, very difficult. This lasted about two years [In Turkey], when I received a call, said, "Would you like to go to Canada?" I said, "Yes, of course," without any hesitation.*

### **Arriving in Canada**

On November 11th, 2016, Mahir and his family arrived in Canada. They were welcomed by Catholic Social Services and were able to get housing, food, and clothing. They had support in accessing healthcare services for Abia, and regular school for the rest of the children. The children are doing well in school Mahir explained, they all are very enthusiastic to learn. I recalled all the questions his daughters asked me about university when I had first arrived. Mahir got a job with Catholic Social Services to help other refugees that were in his situation before him. His life in Canada has been good, he says, but his greatest challenge here has been with the healthcare system. It has not lived up to the needs of his child. When Mahir first got acquainted with the healthcare system in Canada, he was initially happy and impressed with the care Abia received.

*We see a specialist. We go to the neurologist. Abia was in the hospital. They make to Abia a surgery. Surgery was for G- tube, I think. Now the feeding became very, very, very, very easy. Before, it was very difficult. Every time when she swallow, she choking, and the situation is dangerous. This helped us too much. We go to the Glenrose many times. The situation, the problem here with that, after passing a year Abia has been neglected.*

I wondered what kind of neglect Mahir could be referring to. I inquired further about this. As Mahir explained the gaps in the Canadian healthcare system, I noticed he made frequent comparisons to the care he received in Syria. Abia was showing signs of improvement in Syria, Mahir explained.

*Abia was good and Abia received physical training three times a week. Every three months we were taking Abia the capital city, to Damascus. The distance between Al Raqqa and Damascus is about 500 kilometers. Each three month or two month, we visit the specialist. The specialist, all the time said to us that Abia is going to walk when she become five years old. Abia was good, nothing happened. We see that progress Abia's condition, Abia's health, everything we note that's going do better. The physical therapy or the training, the support, the man who did to Abia, every two months was writing a summary. There is two doctors. One therapist and the other is neurologist. The one who make training every two, three months write a summary, what kind of exercise you did to Abia? Is there any progress? We take this report to the specialist and he will read. He also will give his advice, either to continue the same exercises or add another exercises, like this. By this way, Abia has got better. The physical therapy who comes about a month or two month, her training is completely different [in Canada], that what was doing in Syria. There is no report here, and Syria every three months there is a report. The specialist read the report. He add another exercises or deleting other exercises. By this way, ....the neurologist, this is two years we didn't see the neurologist. The nutrition, this is four months this we didn't see him. Last time I call it, I said to my wife, "We have to change the nutrition." I call it all the time here. Every time I ask them that Abia need physical training. Abia need exercises. They said, yes. Once you sends us*

*physical therapist, she is just playing with Abia. What the physical therapist in Syria was doing all the training, moving hands. My wife would make every day about one hour and a half. When Abia, she got longer, taller, and heavier and my wife couldn't do as usual, as before. We ask if there is physical therapy, nothing done. They didn't send us a physical therapist here. If you see Abia's leg, the muscles now are short. She cannot stretch her leg like this. The leg is like this. This is because we stopped physical training. This is big problem...This muscle has becomes short. Now she couldn't. When I try to stretch her legs like this she feels pain...He said that as long as we do this visit training, her leg will be as normal, but because we stopped.*

I could sense the frustration arising from Mahir. He spoke with conviction and his tone became noticeably louder. Hearing his story of his journey to Canada and what lengths he went through to protect his family; I could sympathize with his frustration. I imagined he had hopes that a developed and peaceful country would offer him options and opportunities to help Abia. Instead, he found himself comparing the healthcare to what he received in Syria, and longing for what he had. The way Mahir formulated his arguments, I could tell he put a lot of thought into this.

*The problem here in Canada, most of the Syrian are not able to deal with the technology. This is number one. This number two. If you want that house, if you want the nurse, if you want to talk the receptionist, dialing, most of them make mistakes. For me, a little bit, "Okay, she said just recording and we will call you." I call it three days and I record. After three weeks, I called her, I said, "She said, 'Record your daughter's name and your phone numbers and Alberta health card, and we will call you back as soon as possible.'" Three days I'm calling and after two, three weeks I call it, she answered. I said, "I left my voice. I left a message for you. Why you didn't answer?" Oh, we are sorry. We're sorry.*



*We were busy. I said, "Yes, Abia has two appointments at the same day. Could you please change Abia's appointment?" She said the changing will take three months to six months, and Abia has seizures. These seizures...Abia takes seizures medication. This medication is given according to the weight. If the weight, it should increased, increased, increased. Until now, Abia has seizures. What we are doing, we buy ourselves, we increase the dosage.*

By yourself?

*Yes. We increase the dosage. Last time I called the nurse. She said we didn't have any available appointments until December, six months.*

Wow.

*I don't know why children [have to] wait, children like this condition, such situation have to wait six months to see a doctor. This is not okay at all. This child need to be under the control. She is all the time our under control. We couldn't her leave her. We couldn't her leave her because we don't know any time she got seizures.*

It was clear that to Mahir, Abia needed urgent care and to be under the guidance of health professionals. However, the system did not treat it as such. I recalled my experiences in the hospital where I encountered families that would confide in me that they did not feel ready to go home. They were afraid that they would be sent home to feed their child with a nasogastric tube before they felt comfortable. Or that they were concerned that their child was more sick than the team thinks. I remember trying to navigate those situations and feeling caught in the middle. I can recognize the pressure put on the healthcare system to discharge patients. A hospital bed is

very costly and lucrative. It is reserved for patients that cannot be managed at home. Oftentimes this is patients with deteriorating or complex health problems that need to be monitored.

Children with disabilities can often be managed outside of the hospital with community support such as homecare, and other auxiliary services. Therefore, parents are asked to learn how to manage the healthcare of their children from home with the help of supportive systems. I would encounter parents who have never had any healthcare training before and would confide in me that they feel unqualified to take it on. Unfortunately, they don't always have the choice of staying in hospital indefinitely and therefore enroll in the training programs offered and take on these roles to help their child. Healthcare providers are constantly assessing who can stay in hospital and who can go home. I imagined the scenario with Abia. I imagined they saw that she was not actively deteriorating and did not need continuous monitoring and sent her home to be put on a waitlist for referrals with other patients that needed homecare. However, Mahir did not see it that way. It was clear to him Abia needed urgent care, however that was not what he received. Mahir continued to express his concerns regarding Abia but continued to be met by lengthy wait times.

*As a Syrian, they're big families. They have children. They couldn't wait or leave their children alone at night for a long time. The same thing for Abia. I will not take Abia to the emergency, no. The specialists took this long time and this is very, very critical period to wait. We need every month, at least once every two months, the neurologist, the physical therapist, the nutrition to know what is happening. Now, we are just sitting and we didn't do anything. We didn't do anything. This is the situation. In Syria, if you go to the emergency, there are all the specialists, neurology, cardiology. If anyone has any problem, they will go to the specialist within maximum waiting no more than 20 minutes.*

*This was before the war, but here, why do I go to the emergency if I want to wait 15 hours? Once I go at 12:00 at night and next day at 12:00. I can't wait, no. Many times me and my wife go there, wait, wait. We got boring and come back without seeing the doctor. We are happy here in Canada. My daughters are achieving very good at schools. Everything is very good, but our concern is Abia. This is to be realistic, to be frank. I think it is parent's right to see many doctors. To see many doctors because not all the doctors have the same experience, but here you didn't have any choice to choose.*

This idea of the “choice to choose” struck me as very important to Mahir. He was clearly very interested in being involved in Abia’s care, but he was continuously met with barriers. These barriers Mahir described presented themselves in various ways. Mahir spoke about technology and language impeding his ability to connect with healthcare workers over the phone to book appointments. Then there were the long wait times in Emergency rooms that were so long Mahir no longer sees the point of going. He told me of a time that he went to the Emergency and was forced to wait so many hours he began to get concerned about Abia’s muscles cramping from sitting in her chair all day. He had asked the nurses at the front if it was possible to get a bed for Abia to have temporarily to stretch her limbs. They told him no. At that moment Mahir felt as if the healthcare system was causing him and his family more harm than good. When I heard his stories, I could not help but feel ashamed. I was always proud of the universal healthcare system in Canada. What I did not reflect on as often were the flaws in the system. Mahir had said the healthcare system was neglecting Abia, and as he sat there telling his stories, as a healthcare worker, I couldn’t help but feel that we have. As Mahir explained his experiences with healthcare in Canada there were clear attempts from the healthcare system to care for Abia. Mahir explained to me that he had met many times with case managers and occupational

therapists that would come to see Abia and take her measurements for supportive equipment. However, Mahir would try and ask to be involved in the process for choosing her equipment as he felt he could help choose the most appropriate equipment for her. He knew his daughter best after all. However, Mahir was continuously met with rejection. When Abia received her wheelchair, it was the wrong size. When they did receive the appropriate chair, it had a tray with sharp edges. With Abia's sporadic and uncontrollable hand movements she was frequently hitting the sharp edges and cutting her arms.

*For the equipment, like wheelchairs, I always ask. During five years, we changed two wheelchairs. This is a big mistake. If I show you the situation now Abia, I explained to them, "Why you didn't take us, for example, to the shops and show us these wheelchairs? We are the parents, and we can help you to choose which one. "This is hers, because she cannot control herself, she spontaneously moves her hands and she hurts and cut everything. I said that the tray should not have edge because she cannot to control her hands and slide the tray. They bring up very, very, very- the edge is very, very blade, like a knife. When she move her hand, all this becomes [cuts]... knew the situation. I know the situation of my daughter. I'm living with her.*

The stories where Mahir felt he was not being listened to continued. Abia is incontinent and requires total care so she uses diapers. They are allotted many diapers, and Mahir admitting to having much more than they needed. However, the diapers they have been sending to them are too small and cause leaking. These in turn cause irritation for Abia as well as additional work for the family in cleaning Abia. Despite their concerns they have been unable to change the sizing for months leaving them with a surplus of diapers that are too small. Well intentioned initiatives from healthcare workers continued to miss the needs of a child living with disabilities. Mahir

went on to explain how when they received their housing, they were given a house with stairs that connect to the living room. This made it very difficult for Mahir and his family to take Abia out on walks as the wheelchair is very heavy.

*You know these stairs; we would like every day to take Abia and walk her and at these times. Really, we do it a week once or twice because of the wheelchair. This is regarding the health.*

Mahir had asked for a ramp to assist them with rolling Abia's wheelchair outside but have no heard back. I could hear the sadness in Mahir's voice when he discussed the barriers that prevented him from providing Abia with the best possible care. His role in his family has been to protect them and ensure the best possible future for them. This hope had brought him to Canada. Mahir expressed how grateful his family is for the care they received and the safety they feel here in Canada to me many times in our meetings. However, not feeling that his daughter is getting everything she needs continues to cause him considerable stress. After hearing about his experiences in Syria, and of his difficult journey to Canada, I admitted to myself that I was hoping for a happy ending. I wanted to hear that once arriving in Canada, their troubles vanished, and they were rewarded with a new life filled with a happiness that they had never known before. This was not the reality of the situation. The reality of the situation was that this family was unwillingly forced to flee their home and are now adapting to a new culture that is presenting many barriers to receiving the proper support for their daughter.

Speaking to Mahir opened my eyes to the journey of a refugee family in Syria with a child living with disabilities. As a refugee, I have my own stories that I carry with me in whatever I do. However, I have been able to move forward and gain new experiences because I received support from everyone in my community. I felt listened to and heard. Mahir is still

fighting to be heard and even more so fighting for Abia to be heard. Refugees face many challenges migrating to a safer destination. However, Mahir explained to me that when you have a child with disabilities those challenges do not stop once you reach safety, they are ongoing. Mahir's stories provoked a lot of self reflection in me. I left thinking about how just because the healthcare system is free does not mean it is inclusive. I wondered what I would do to help families like Mahir's when I step back in the hospital.

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## **Chapter 4**

### **Publication**

A Narrative Inquiry into Experiences of Syrian Refugee Families with Children Living with  
Disabilities.

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## **Abstract**

Children with disabilities are among the most at-risk groups for marginalization due to compounded disadvantages from the intersection of risk factors such as refugee status and disability status. Despite this high risk, there is no systematic data collected on this group and scant literature on the topic contributing to a feeling of invisibility. We conducted a narrative inquiry on the experiences of two Syrian refugee families with children living with disabilities. Narrative inquiry is a way to understand experience as a storied phenomenon. In order to understand the complexities of the experience as a refugee with a child living with disabilities, attending to the lived and told stories is essential. In hearing the narration of these experiences across time, place, and social contexts various narrative threads emerged. The narrative threads that resonated across the experiences of two families included waiting and a struggle for agency, as well as disruption and continuity.

## **Keywords**

refugee, disability, children, families, Syria, narrative inquiry

There are currently 25.9 million refugees around the world; over 50% of refugees come from three countries: Syria (6.7 million), Afghanistan (2.7 million), and South Sudan (2.3 million) (UNHCR, 2019). Nearly half of all refugees are under the age of 18 years (UNHCR, 2019). Beginning in 2016 Canada has accepted over 40,000 Syrian refugees for resettlement in Canada (Government of Canada, 2017). There are records that the population accepted into Canada was primarily young and that many came with health concerns of which disabilities are prevalent (Houle, 2019; Oudshoorn et al., 2019).

The World Health Organization (2017) recognizes that historically people with disabilities have been marginalized. When disability status is combined with other identity markers such as refugee status or ethnicity, there is an increased risk of vulnerability (King, et al., 2011; McKay, 2019; UNHCR, 2018). Others have acknowledged that “refugees with disabilities are among the most isolated, socially excluded, and marginalized of all displaced populations” (Women’s Refugee Commission, 2008, p.1). Given the growing number of young refugees in Canada and the prevalence of children with disabilities, more information is needed to guide health care workers and policymakers on how to meet the needs of families with children living with disabilities (King et al., 2011). The purpose of this study is to better understand the experiences of Syrian refugee families with children living with disabilities.

### **Background Information**

In 2011, Syria saw the eruption of protests against their government that quickly turned into a revolution that progressed into a civil war (CFR, 2021). Hundreds of thousands of Syrians have died or have fled Syria for their own safety since the initial protests (Laub, 2021; Human Rights Watch, 2019). Syria now has the largest forcibly displaced population in the world with 6.6 million people internally displaced and 5.6 million Syrian refugees around the world

(UNHCR, 2019). Syria is now in a state of “refugee crisis” (Human Rights Watch, 2019). The onset of the Syrian refugee crisis attracted attention from across the world with various countries accepting refugees from Syria for resettlement. Refugees from Syria have quickly become the largest group of refugees residing in Canada (Houle, 2019). Of the Syrian refugees in Canada, 85% of families consist of couples with children (Houle, 2019; Oudshoorn et al., 2019). The 2016 census data showed 44.2% of refugees who resettled in Canada between 2015 and 2016 were in the 0 to 14 age group (Houle, 2019). Moreover, Syrian families tended to have more children (average 2.8 children per family) than refugee families from other countries (average 2.2 children per family) (Houle, 2019).

### **A Focus on Disability**

The Women’s Refugee Commission (2008) estimates that between 2.5 and 3.5 million (7% to 10%) of the world’s 35 million displaced people have disabilities. Many other organizations concur that the number of refugees with disabilities exceeds the thousands (Conte, 2016; Humanity and Inclusion, & iMMAP, 2018; WHO, 2011). Approximately one-third of refugees with disabilities are children (WHO, 2011). As disabilities often go unrecognized for refugees, this number may be even higher (Women’s Refugee Commission, 2008). Basic needs such as food, shelter, and safety are most often prioritized and care and rehabilitation needs are not adequately attended to (Women’s Refugee Commission, 2008). Identifying and collecting data on refugee populations with disabilities is a great challenge. Barriers to identifying and collecting data include lack of accurate identification of a disability, inconsistent methodology and terminology, lack of qualified staff to identify disabilities, and varied criteria for what is considered a disability (WHO, 2011; Women’s Refugee Commission, 2008). Moreover, some countries use measurement tools that are not comprehensive and overlook many people with

disabilities (WHO, 2011). This is further complicated for children, as there is an over-reliance on parents to report on their child's disability (WHO, 2011). Without accurate data to identify refugees with disabilities, it becomes easy for them to be overlooked and access to necessary care becomes limited (Women's Refugee Commission, 2008). Often refugees with disabilities are rendered 'invisible' (Conte, 2016).

Research involving refugee families with children living with disabilities shows that this demographic is "at an increased risk for unmet healthcare needs" (Mckay, 2019, p.1). Refugee families with children with disabilities face barriers to accessing healthcare services, including language, knowledge, and economic barriers (Arfa et al., 2020; King et al., 2011). The stories of refugee families with children who are labeled disabled are often not told. There is a void in the literature in relation to the experiences of Syrian refugees with children with disabilities published in Canada. Moreover, there is scant research on refugee children with disabilities in general (King et al., 2011; King et al., 2013; King et al., 2016). Of the literature available, most is concentrated on refugees with mental health disabilities (King et al., 2016).

### **Turning to the Research Puzzle**

In the current study, we are interested in the experiences of Syrian refugee families with children living with disabilities in western Canada. A narrative inquiry study design was chosen in order to understand more about the experiences of people who are often silenced. We were interested in the experiences of families who had a child with physical disabilities.

### **Methodology**

Narrative inquiry works from an understanding that "humans are storytelling organisms who, individually and collectively, lead storied lives" (Connelly & Clandinin, 1990, p. 2). Clandinin and Caine (2013) state that narrative inquiry is "a way of understanding experience"

(p.165) which allows for “an in-depth study of individuals’ experiences over time and in context” (p.165). Narrative inquirers explore people’s experiences through a three-dimensional inquiry space composed of temporality, sociality, and place (Clandinin & Caine, 2013). Narrative inquirers recognize that participants’ experiences are always unfolding, always in the midst (Clandinin & Caine, 2013). Narrative inquiry is a relational inquiry (Clandinin, 2013) which makes visible that the researcher is also part of what is under study. Narrative inquirers think narratively about their own experience in relation with participants’ narratives and, in this way, become visible in the interim research texts.

In this narrative inquiry, relationships and various aspects of the research were negotiated with participants through an ongoing dialogue. Narrative inquiry is guided by relational ethics (Clandinin & Caine, 2013) and interactions with participants must be “marked by ethics and attitudes of openness, mutual vulnerability, reciprocity, and care” (Clandinin, & Caine, 2013, p. 169). Relational and ethical responsibilities through constant “self-reflection, contemplation, openness, and uncertainty” were critical when meeting with participants, and composing field texts and research texts (Clandinin, & Caine, 2013, p.169). Ethical approval was obtained from the University of Alberta Ethics Committee.

Participants were recruited through a networking approach that involved an agency that served newcomers, including refugees. Inclusion criteria included: Syrian refugees with at least one child living with a disability; arrival in Canada within the past 5 years; and willingness to engage in multiple conversations. Participants were asked to sign a written consent form outlining all aspects of the study and highlighting that they were able to withdraw from the study at any time with no consequences. All participants were assigned pseudonyms.

Two families were recruited. Both participants and their families arrived in Canada within the last five years. Snacks and a \$20.00 gift card were provided for each tape-recorded conversation. Conversations typically lasted one hour with four conversations with each participant. Each conversation was audiotaped and transcribed verbatim. Abbud has a child who was diagnosed with a disability during their migration journey. This family did not speak English and a translator joined for each conversation. Abbud's words are his translated words. Mahir spoke English and has a daughter who was born with a physical disability.

During the conversations, participants created annals to list the significant events in their lives. Clandinin and Connelly (2000) describe an annal as the composing of a "list of dates of memories, events, stories and the like" (p.112). Participants also shared photographs and observations as they told their stories. Annals, photographs, participant observations, audiotapes, and field notes were used as field texts. Field notes were records of what the researcher has "heard, seen, thought, or experienced" during each conversation (Streubert & Carpenter, 2011, p. 42). The field texts became the basis for the interim research texts, called narrative accounts. Narrative accounts are "a way to make sense of multiple and diverse field texts" (Clandinin & Caine, 2013, p.172). The creation of narrative accounts is an iterative process where field texts are "read and re-read" with attention paid to temporality, sociality, and place (Clandinin & Caine, 2013, p.172). The accounts are co-composed with participants. By co-composing the narrative accounts, each participant was afforded the opportunity to negotiate the accounts to ensure they are comfortable with the representation of their experiences (Clandinin & Caine, 2013). By making the three-dimensional space visible, the complexity of each participant's experiences also become visible (Clandinin & Connelly, 2000).

Once the narrative accounts were composed, the researcher metaphorically laid the accounts side by side to identify resonances. Resonances were used to form narrative threads across the two accounts. The resonant threads represent participants' experiences across temporality, sociality, and place.

### **Narrative Accounts of Abbud and Mahir**

As a part of this paper, we included select excerpts of the narrative accounts of participants. ["I" in these accounts refers to Vanesa Beka, the first author, who engaged directly in conversations with participants].

#### **Coming to know Abbud**

I met Abbud at a community agency who served refugees when they first arrived in Canada and was joined by Amina, a Syrian refugee, who acted as a translator. Despite Abbud's limited English, he was kind and expressed his gratitude to us for taking the time to hear and inquire into his story. Abbud was born in a small village in Aleppo, Syria to a poor family. He recalls working to provide for his family from a young age. Abbud and his wife have eight children. The eldest is 23 years old and the youngest is three months old. All of his children were born healthy, and it was not until their journey for refuge started that one of his children developed a disability.

***Leaving Syria for Lebanon.*** When war erupted in Syria in 2011, Abbud and his family found themselves in an increasingly dangerous warzone. It was not long before they had to make the decision to leave Syria and migrate to Lebanon for their safety. Once they arrived in Lebanon the conditions were precarious.

*As a Syrian refugee [in] Lebanon, there is no respect for the Syrian people there. The situation was too bad because [I] was living in a camp. It was too poor. You need to work hard to support yourself, at least like you can just eat and stay alive. That's it. No more.*

***Becoming disabled later in life.*** In Lebanon, Abbud and his family lived in a refugee camp for nearly six years. It was in Lebanon where his son was in an accident that left him disabled.

*One day he was playing outside and he has an accident by car ...*

As Abbud told this story I heard the sadness in his voice. I was starting to understand what a jarring experience this was for him. Abbud did not have the ability to access the appropriate treatment for his son despite his best efforts. He did not get any form of compensation for the accident or validation for the great injustice that had occurred. I tried to imagine how isolating this experience must have felt. I wrote down in my field notes *I wonder if he felt alone?*

*In Lebanon, for [my] poor situation, [I] couldn't do anything for [my] kid. There is no money, and [I was willing] to pay a lot of money. It will be very expensive and [I] [can't] do anything for him, just the physiotherapy for him. Even that, it was very expensive for [me].*

Abbud had to learn to live with his new reality of having a child with disabilities. After the accident, Abbud began to seek other opportunities for his son. He sought sponsorship to live in countries abroad. To Abbud's surprise, the United Nations heard about Abbud and his family and offered them an opportunity to become refugees in Canada. This was a chance for Abbud and his family to gain safety and help for their son.

***Arriving in Canada and experiences of waiting.*** In 2018, Abbud and his family arrived in Canada. Abbud's life in Canada still poses challenges for him.



*There's no comparing between [my] old life in Syria or Lebanon and [my] new life in Canada. [My] experience, it was very good. Everything was new for [me]. [My] life has changed completely from since [we] live in Canada, but [I] just want[] something from healthcare. They have too slow system here, and you need to wait for emergency cases. Maybe that's this case it's become more so than before, for the waiting time. After all they do, they tried to do their best, but they taking steps until they arrive at the surgery. When they decided he needed this surgery, he need to wait for long time to give him appointment for his surgery. This appointment also it will be for a long time too.*

**Language Barriers.** Wait times were not the only challenges. Abbud and his family also struggled with language barriers every time they interacted with the healthcare system.

*The language is a big issue for [me] and for most of the refugees here because [we] want to understand. [We] want to explain. There is specific words, especially in healthcare, you have to use it, and this word [we] didn't have it. Now after [my] experience, [I] have these words and [I] can understand [better], but [I] have the same problem, [I] can't answer, or complete the conversation with them.*

### **Coming to know Mahir**

I met Mahir through a mutual contact at a community agency serving refugees, where he currently assists newcomers as a community support worker. Mahir speaks both English and Arabic. When I invited Mahir for our first meeting, he graciously asked me into his home. This meant I got to meet his entire family in the process. Mahir and his wife, have six daughters ranging in age from 20 years to 3 years old. Most of his daughters were quick to greet me as I entered, engaging me in friendly conversation. The only daughter not in the room was Abia. Abia was in her wheelchair in her room, and Mahir asked if I wanted to be introduced to her.

***Born with a disability.*** Abia is 13 years old and was born with a disability. Some doctors have stated she has cerebral palsy. Mahir insists she does not. Mahir insisted that doctors in Syria predicted she would walk within 5 years with appropriate treatment. Mahir explained that Abia is wheelchair-bound and requires total care for any activities of daily living. She cannot verbalize words and has difficulty swallowing which requires her to have a Gastric tube. Her motor movements are not controlled and are often sporadic.

***Meeting Abia in Canada.*** When Mahir told me about Abia he invited me to go see her. She was in her wheelchair in her room with some of her siblings around her. Her room was spotless, much like the rest of the house. I could see by the way her sister gently held her hand and touched her shoulder that they were very protective of her. *“Everyone helps take care of her,”* he told me.

***Questions of Identity.*** Family was important to all of them, which was evident in the way they interacted with one another. Mahir and his family are Kurdish. They are originally from Kobani, a city in northern Syria where most of his extended family still resides. Mahir was a teacher who taught English literature. Mahir explained that the Syrian government treated Kurdish people as *“foreigners”*, never allowing them to feel welcome. As a result, the Kurdish people of Syria faced many challenges in their day to day lives. When the revolutions began to erupt in Syria in 2011, Kurdish people faced many difficulties. For Mahir, this was compounded by the fact that he had a child living with a disability. The city became increasingly dangerous and Mahir no longer had access to their doctors as most had fled the country. Mahir described how severe the situation became for Abia,

*Once we didn't [know] how long Abia got-- when we woke up in the morning, we found that Abia has foam on the mouth, weak eyes, fever. She become very faint. We took her to*

*the hospital, there is no doctor, nothing. There is an injection. They gave it to Abia just to let her sleep. It took about four or five hours and Abia situation became bad.*

***Moving to Turkey.*** In 2014, Mahir and his family were forced to move to Turkey for their safety and with hopes of finding appropriate healthcare for Abia. Unfortunately, life in Turkey did not provide them with the help they needed.

*In Turkey, the situation is also bad, but safer than Syria. We took Abia to the hospitals. Do you know there was not much care? Once or twice when I take her to the doctor, then one professor, he said, we couldn't help your daughter. There is no cure for your daughter. She has cerebral palsy. The medication is not changed. Everything the same, no supporting. Abia's situations all the time becomes bad. Abia was controlling her neck. There was no saliva from the mouth. Now Abia couldn't control her neck. All the time dropping from the mouth. Even feeding was very, very difficult. Every time a very small piece of bread or food and swallowing is very difficult. The situation was really, very difficult.*

The deterioration in Abia's health prompted Mahir to seek alternatives. He spent months speaking to officials, applying for permission to seek refuge elsewhere. After nine months of persistent attempts, Mahir finally got the call that Canada would accept him and his family.

***Moving to Canada.*** In 2016, Mahir and his family arrived in Canada. His life in Canada has been good, he says, but his greatest challenge remains finding the best possible healthcare for Abia. Initially, Mahir was thrilled with the care they received. They were able to undergo surgery for Abia to have a Gastric Tube inserted to mitigate her risks for aspiration. For the first year after arriving in Canada, Mahir felt that he was getting all the required attention from his healthcare team. However, after a year the attention decreased, he explained.

*The physical therapy who comes about a month or two month, her training is completely different, than what was doing in Syria. There is no report here, and Syria every three months there is a report. The specialist read the report. He add another exercises or deleting other exercises. By this way,....the neurologist, this is two years we didn't see the neurologist. The nutrition, this is four months this we didn't see him.*

**Experiences of Waiting.** Mahir expressed his frustration with waiting for healthcare. He explained that when they did get appointments, he would struggle with technology and advanced medical jargon. One struggle that Mahir spoke of, however, was not being listened to. Often when providing rehabilitative support devices for Abia such as a wheelchair or bedframe, Mahir was excluded from the conversation despite constantly advocating to be included in the process.

*For the equipment, like wheelchairs, I always ask. During five years, we changed two wheelchairs. This is a big mistake. If I show you the situation now Abia, I explained to them, Why you didn't take us, for example, to the shops and show us these wheelchairs? We are the parents, and we can help you to choose which one.*

Mahir acknowledges he and his family have come a long way in the treatment and care provided for Abia. However, he continues to fight for the best possible care.

### **Resonant Threads**

When carefully looking across the narrative accounts, two resonant threads emerged that provided insights into the experiences of Syrian refugee families with children living with disabilities.

## Thread 1: Waiting and a Struggle for Agency

Both Mahir and Abbud are waiting: first, they waited in Syria before they fled as the revolutions erupted; then they waited to be granted refugee status in Canada; and now they are waiting in Canada in the context of healthcare. Mahir learned quickly that getting care for Abia involved waiting for many appointments, but he was surprised that an emergency department had such long wait times for emergencies.

*In Syria, if you go to the emergency, there are all the specialists, neurology, cardiology. If anyone has any problem, they will go to the specialist within maximum waiting no more than 20 minutes. This was before the war, but here, why do I go to the emergency if I want to wait 15 hours? Once I go at 12:00 at night and next day at 12:00. I can't wait, no. Many times me and my wife go there, wait, wait. We got boring and come back without seeing the doctor.*

In a comparison between his experience with healthcare in Syria and Canada, Abbud said,

*In Canada, you don't need to pay money or a lot of money, but at the same time, there's another side. You need to wait and the waiting is more harder than to find the money.*

Abbud's frustration in waiting was his inability to help. He couldn't do anything to make the waiting go faster.

*Like Syria or Lebanon, we can borrow money from our friends, families, and offer that much money how much we need and you take it to the hospital and solve all the problems, but here, we don't need to pay money, but we need to wait.*

Attending closely to Abbud's and Mahir's words made visible their lack of relational agency. Edwards (2005) describes relational agency 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). Working with Edwards’ idea of relational agency, we see the barriers that prevent Abbud and Mahir from having a sense of agency. In Syria or Lebanon, Abbud felt that he had some form of agency because he could go out and find money for his son to receive treatment. In Canada, he was unable to make the system work faster. There was nothing he could do.

*As parents, this feeling is too hard for [us] when you know that your son needs help and you can't do anything. For example, when [we] went to the dentals, he asked them if he can get help to make his son drink food and he send them to another clinic who [said] can they put the braces for teeth to make the teeth normal, but even with that help, he needs another surgery to make the two jaws more normal to chewing the food. Another thing, he needs two other surgery and for all this situation [there is a] waiting list, [I began to] feel depressed and feel [I] become more stress[ed] for all that. [I'm] always think[ing] that why they're too slow and my son need a lot of help and he's still waiting.*

A key concept of relational agency is the “capacity for working with others to strengthen purposeful responses to complex problems” (Edwards, 2009). Abbud and Mahir both expressed the desire to work with their healthcare practitioners in developing their children’s healthcare plans but both faced exclusion in the process. This absence of working with others, in the ways Edwards (2009) suggests, contributed to the lack of agency Abbud and Mahir felt in Canada. They faced challenges in collaborating with others to respond to the complex health issues of their children. For Mahir, this was a change from what he had experienced in Syria. Mahir described feeling agentic in Syria. As a teacher, he had the health care benefits that supported high-quality treatment for Abia. Moreover, he felt equipped to advocate for his daughter’s treatment. The healthcare team which included Abia’s medical specialists, dieticians,

physiotherapists etc., included Mahir in their healthcare plans for Abia. The team developed reports every two or three months with Abia's history, updates, and future plans while asking for Mahir's input on what he noticed about Abia's progress. Mahir was satisfied with this system and felt it was contributing to Abia's progress in getting better.

In Canada, Mahir had a very different experience. Mahir felt that the concerns he had for Abia were not addressed with the urgency they required. Despite his advocating for Abia, he was constantly told to wait.

*The specialists took this long time and this is very, very critical period to wait. We need every month, at least once every two months, the neurologist, the physical therapist, the nutrition to know what is happening. Now, we are just sitting and we didn't do anything. We didn't do anything. This is the situation.*

Mahir asked to be involved in the process of choosing Abia's equipment as he felt he could help choose the most appropriate equipment for her. He felt he knew his daughter well. However, Mahir was continuously met with rejection. They did not include him when choosing a wheelchair for Abia and, when she received her wheelchair, it was the wrong size. When they received the appropriate chair, it had a tray with sharp edges. With Abia's sporadic and uncontrollable hand movements, she frequently hit the sharp edges and cut her arms, rendering the tray useless.

*I explained to them, "Why you didn't take us, for example, to the shops and show us these wheelchairs? We are the parents, and we can help you to choose which one...I know the situation of my daughter. I'm living with her."*

The struggle for relational agency was only compounded by language and technology barriers for Mahir.

*The problem here in Canada, most of the Syrian are not able to deal with the technology.*

*This is number one.*

Mahir explained a time when a referral was made on the same day as another appointment. He had called to reschedule but was met with no answer. After 3 weeks of calling, he finally received a response.

*I said, "I left my voice. I left a message for you. Why you didn't answer?" Oh, we are sorry. We're sorry. We were busy. I said, "Yes, Abia has two appointments at the same day. Could you please change Abia's appointment?" She said the changing will take three months to six months".*

Mahir was extremely frustrated with this situation. Mahir was trying to book this appointment urgently because Abia was having seizures. He felt he couldn't wait for another three to six months to have her assessed. This prompted his family to increase the dosage themselves. By increasing the dosage himself, Mahir displayed a sense of agency. He felt he knew the needs of his daughter and acted upon them in that moment.

It was surprising how much Mahir and his family struggled to receive care. While the pressures on the healthcare system to provide care in a timely manner are well known, it was evident that certain groups of people were excluded. Mahir's account of his experiences highlighted the challenge of making appointments and phone calls when everything is online, and he has multiple appointments for his daughter. In a qualitative study conducted in Norway, immigrant families with children with disabilities described what was interpreted as "accessing help as a battle" (Arfa et al., 2020, p. 9). Families described the challenge to access care through relentless advocating for their children and requesting help to obtain access to specialists; this often took a toll on their mental and physical health (Arfa et al., 2020).



Despite the barriers Mahir experienced, and continues to experience, he tries hard to regain the agency he once felt he had in Syria through advocating for better care for Abia. Edwards states relational agency “is a capacity which involves recognising that another person may be a resource and that work needs to be done to elicit, recognise and negotiate the use of that resource in order to align oneself in joint action on the object” (2005, p. 172). In order for relational agency to be obtained, the health care team needs to make an effort to ensure that patients and their families are involved in decisions that impact care.

### **Thread 2: Between Disruptions and Continuity**

*He has injury in his brain, his lungs and he was in bad situation but after 45 days, he returned to the life as they say but he return as a newborn baby.*

The above quote is how Abbud described seeing his son after the accident that rendered his son disabled. Abbud endured seeing his son change from one body into another, change into a body that he did not recognize. Disruption is defined as a change or interruption to the normal course or continuity of some activity (Merriam-Webster, n.d.). For Abbud, the disruption he experienced, when his son became disabled, caused ripples of change throughout Abbud’s life. He had to learn how to provide care for his child that required advanced medical attention in an area where healthcare was scarce. It was his son’s accident that prompted him to seek refuge in a country, like Canada, where he believed healthcare services would be accessible. Seeking continuity despite, or in spite of, the disruption was important for Abbud.

Dewey (1938) describes continuity as a fundamental aspect of experience. All experiences are carried forward and influence future experiences (Dewey, 1938, p.35). Continuity is essential to the understanding of experience and therefore experiences must be assessed across temporality as “experience has temporal continuity” (p.245). With the use of

annals, that were composed by participants, continuity of their experiences became visible. As Abbud and Mahir told their stories there were threads of continuity in two forms; continuity through their lived experience, and continuity through the narrating their experiences as they struggled to create coherence. Carr (1991) speaks of narrative coherence and states “[o]ur lives admit of sometimes more, sometimes less coherence; they hang together reasonably well, but they occasionally tend to fall apart. Coherence seems to be a need imposed on us, whether we seek it or not. Things need to make sense” (p. 97).

Abbud has always been the protector for his family. As the male of the household, as is typical in Syria, he was the one who protected and ensured the livelihood of his family. When his family resided in Syria, Abbud commuted to Lebanon to work and sent money back to his family. Later, when civil war erupted in Syria and Abbud and his family found themselves as refugees in camps in Lebanon, Abbud continued to find work to provide for his family. There is continuity in Abbud’s past experiences as a protector that continues to influence his future experiences. When Abbud experienced the greatest disruption of his life, seeing his son change into someone he did not recognize, he struggled to find continuity as a grieving father. All the disruptions that come with being a refugee were compounded by the disruption of having a child living with a disability.

How did you feel? How did you cope with this?

*[I was] feeling too bad. Do you know how when you see that your kids was normal and suddenly become disability and you can't do anything for him after he returned to his home he needs the treatment, you need to go to physio, and stuff like that but [I] couldn't pay anything because [I] didn't have enough money. Also, [I] [have] a family, need to*

*support them. Until now, [I still feel] the same, feel too upset about that and about [my] son.*

Becker (1997) states that when disruption occurs, people make sense of their past through finding continuity in their lives from what remains unchanged. Abbud could no longer find continuity through his geographical location, his daily routine, and how he remembered his son. However, what remained unchanged was his devotion to his family that was there with him. Abbud's son's accident created an urgency for Abbud to find refuge in a safe country to provide protection to his family. Abbud's stories always centered around his family and the actions he took to ensure their safety.

*The reason [I moved] to Canada was [my] kids.*

In every story Abbud told, from the beginning in Syria to making a life in Canada, his commitment to his family was central. Abbud rarely spoke of his own feelings except in relation to feeling like he was not doing enough for his family. When he felt he could not provide for them that changed his story of who he was. Abbud's account of his experiences displayed just how closely he was intertwined with his family. When Abbud described his struggles in Canada, it was his inability to provide the best possible healthcare for his son that caused him distress. The long wait times and language barriers excluded him from feeling like he could maintain continuity, that is, by providing for his family.

Like Abbud, Mahir also had stories of various disruptions occurring in his life. Mahir was also the sole provider of his family however he came from a high socio-economic class. As a teacher in Syria, he was well educated and had benefits that helped him provide for his daughter when she was born with a disability. Mahir was able to adapt to being a father of a child with a disability and act as an advocate for his daughter from the very beginning of her treatment. He

was included in all of the discussions with the healthcare professionals that provide care for his daughter and received periodic comprehensive reports on her care plan. In telling his story, Mahir emphasized his role in the health care process, he was always taking part in her care. When Abia (his daughter) was born, Mahir explained that he was told that with the right treatment, she would improve and become “normal”. Mahir’s commitment to helping Abia become “normal” demonstrated his search for continuity in his life. When the revolutions erupted in Syria, Mahir experienced one of the largest disruptions to his life; becoming a refugee while also caring for a child with a disability.

*Abia has got better, but when ISIS came, people left the city. Doctor escape, fled away because nobody can live this life. It's very dangerous...We didn't have any chance with special need.*

Mahir was forced to try and find care for his daughter when there was no healthcare available. Mahir went to great lengths to provide for his daughter, even donating bags of his own blood in exchange for receiving permission to travel in Syria. He spent months calling the United Nations in attempts to secure refugee status to Canada. In Canada, Mahir continues to be involved in Abia’s care. He makes appointments for her and communicates with specialists. When there are long wait times, Mahir continues to try. Through these disruptions, it is his devotion to caring for his family that remains unchanged. All of his stories are centered around protecting and providing for his family, and it is through family that he finds continuity in his stories.

Archambault (2012) states that “in the case of refugee families, their trajectory, as a group, is likely to have been broken many times, but there is still a thread linking their everyday life to the memories of the past, to their family habits and values, and to their family narratives” (p. 29). For Abbud and Mahir this thread was their family. Clandinin and Connelly (2000) state

that experience is continuous because it grows “out of other experiences, and experiences lead to further experiences” (p. 2) Through the conversations had with both Abbud and Mahir, as they wove their disruptive life experiences together, their experiences in the past informed their experiences in the future. Abbud’s son getting into a car accident that rendered him disabled is the disruption that leads Abbud to seek refuge outside of Lebanon. Mahir’s experience being involved in the healthcare process for Abia in Syria allowed him to become a strong advocate for Abia in Canada. This is continuity through lived experiences.

However, continuity can also be assessed through the way in which Abbud and Mahir chose to tell their stories. In allowing Abbud and Mahir to narrate their lives, the way they choose to weave their experiences across temporality, sociality, and place creates continuity. In narrating their stories, both Abbud and Mahir created coherent stories from their beginnings in Syria to their lives in Canada. How each participant interpreted their own experiences and chooses to narrate them creates continuity. For Abbud,

*There’s no comparing between [my] old life in Syria or Lebanon and [my] new life in Canada. [My] experience, it was very good. Everything was new for [me]. [My] life has changed completely from since [we] live in Canada...*

### **Study Limitations**

Narrative inquiry does not produce results that are meant to be generalizable but rather gives insight into the unique experiences of individuals (Clandinin & Connelly, 2000). Abbud and Mahir both had distinct stories in their accounts and experiences as Syrian refugees with children living with disabilities. They came from different geographical, socioeconomic, and language backgrounds. Moreover, they had unique experiences in their migration journeys and the disability that their child lived with. Abbud came from a poor background and the disability

his son now lives with was a direct result of their journey for refuge. Mahir was educated and lived an established life in Syria where he had hopes that his daughter who was born with a disability would recover. Both families were able to escape Syria however continue to experience unique challenges in their transition to life in Canada. These experiences shaped their perception of their experience and how they told their narratives and are not necessarily representative of all Syrian refugee families with children living with disabilities.

Furthermore, the conversations taking place occurred during the COVID-19 pandemic. All precautionary measures were taken to ensure the safety of the participant and the researcher, and all government restrictions were followed. As narrative inquiry is a relational methodology, wearing masks and abiding by social distancing rules may have contributed to tension or limitations on relationships formed. These restrictions must be taken into account when considering the stories that the participants felt comfortable sharing.

### **Conclusion**

With the increase of refugees to Canada following the Syrian refugee crisis, there are now many new families with children living with disabilities. Despite this, there is a void in the research with refugee children living with disabilities. This narrative inquiry created a space for the stories of families from Syria to begin to fill this gap. In narrative inquiry, research participants and researchers meet in the midst of their stories. As resonances across the participants' stories were heard two narrative threads were discerned. The first narrative thread highlighted participants' experiences of waiting and their struggles for agency over their lives. The second narrative thread highlighted participants' struggles for narrative coherence that were disrupted by their experiences. The experiences of Abbud and Mahir are not generalizable. However, attending closely to their experiences illuminated how healthcare

professionals, and others who interact with refugee families with disabilities, need to work with them to create safe spaces where they can feel agency in their lives, agency that was disrupted by their flight from Syria. The research also makes visible how frequently, and how deep, the disruptions are for refugee families as they work to build continuity and coherence in their lives. Creating safe spaces and including them in the conversations around their health and the health of their families are possible starting points for considering forward looking stories.

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## CHAPTER 5

### A Reflective Turn

A key component to narrative inquiry is justifying a study in three ways: personally, practically, and socially (Clandinin & Caine, 2013). These justifications help answer the questions of “so what” and “who cares” about this research (Clandinin & Caine, 2013, p.174). In this chapter I draw on the resonant threads as I highlight the personal, practical, and social justifications for this research.

#### Personal: Looking Backwards

I began this narrative inquiry by formulating my narrative beginnings. Narrative beginnings are where “our research interests come out of our own narratives of experience and shape our narrative inquiry plotlines” (Clandinin & Connelly, 2000, p. 121). By reflecting on my past experiences, I was able to “position [myself] in relation to the phenomenon under study” (Clandinin & Caine, 2013, p.174). By positioning myself, I reflected on who I am and who I am becoming as the research progressed in relation with the participants and their families (Clandinin & Caine, 2013). Looking back, I see how in my narrative beginnings, I told stories of yearning for belonging. Coming to Canada to escape an unsafe country was a huge disruption in my young life. This disruption was further compounded by the noticeable differences I experienced between my peers and me in Canada in every aspect of our lives. It took me many years to begin to make sense of these disruptions and learn to feel comfortable in this new country. These disruptions in my life intrigued me in the stories of other refugees and their journeys. As I heard the stories of Abbud and Mahir’s experiences, they disrupted my stories of disruptions in my life. I began to be awake to disruptions I had never considered. I saw similarities in how Abbud and Mahir struggled with belonging as they searched for homes.

However, the disruption to parenthood that caring for a child living with a disability caused was something I had not considered.

### **World Travelling**

Meeting Abbud and Mahir gave me the chance to travel to their worlds (Lugones, 1987). By traveling to their worlds, Lugones (1987) contends you can begin to understand “what it is to be them and what it is to be ourselves in their eyes” (p.17). I was entering this narrative inquiry from my world as a nurse who worked in an acute care setting but also from the world of a refugee and newcomer. As a nurse, I always wanted to help patients I interacted with. As I travelled to the worlds of Abbud and Mahir, I began to see how the healthcare system can fail patients. It was difficult for me to contend with these relational tensions (Clandinin, 2016). Relational tensions are “shaped by our ethical stance” (Clandinin, 2016, p. 210). Abbud and Mahir both prefaced their stories by stating that they are grateful for the care they have received. I sensed they did not want to offend me when they explained their troubles with the Canadian healthcare system. I felt dis/ease in Lugones’ (1987) sense when they told me stories of nurses who disregarded their feelings or made them feel invisible. It was a powerful feeling and made me aware of my understanding of relational commitments. Clandinin (2016) states “by attending to these [relational] tensions we learn from them, even when there is no intention to resolve them; rather, our intentions are to learn and live-in ways that make visible our commitments” (p.210). Although I could not resolve the problems Abbud and Mahir have encountered within the healthcare system, their struggle for agency resonated with me. In my narrative beginnings, I spoke of how when my dad was diagnosed with Diabetes when I was a young child, I yearned to be helpful. Becoming a nurse was a way I created agency for myself. I could be in a position where I felt helpful. Hearing Abbud and Mahir speak of trying to help their families, and their

longing for a sense of agency made me reflect on who I am and how that shapes my nursing practice. How could I be a better nurse in the future? How could I work with patients to help them create agency in their lives?

### **Practical: Reconsidering Practice**

In pondering the practical justification of this research, I reflect on my nursing practice often. Nursing is often thought of as a dichotomy between two types of care, “technical care and humanistic care.” (Mateo-Martínez, et al., 2021, p.1). The technical care aspect of nursing I have refined over many years through reading many textbooks and long hours of clinical practice. The humanistic care aspect of nursing is something that can not be learned so easily. Engaging in a narrative inquiry helped me further develop the humanistic care aspects of nursing as narrative inquiry requires me to be wakeful to the person I am and the person I am becoming. Through this research I began to pay closer attention to experiences that shift my practice. In reflecting on my professional experiences, I see how the experiences in my personal life shape my practice just as my practice shapes my personal life; the personal and practical are intrinsically connected (Clandinin & Connelly, 2000). Lindsay (2008) articulates this as she builds on Dewey’s theory of experience, “each and every experience informs every subsequent experience, we understand that who we are as persons is who we are as professionals” (as cited in Lindsay & Schwind, 2016, p. 15). With every conversation with Abbud and Mahir, I carried my experiences from our meetings into my professional life and into reflections on past personal experiences.

Abbud and Mahir both told stories of feeling dismissed and excluded by the healthcare system. When Mahir explained his issues with receiving a wheelchair that did not fit his daughter, and as he exclaimed in desperation to the healthcare workers, “*why not let me come with you to choose the wheelchair? I know my daughter*”, I found myself agreeing with him.

Why not? Abbud and Mahir's struggles for agency made me think critically about the ways in which healthcare systems can silence the voices and engagement of patients and their family members. Making unilateral decisions regarding care is costly and inefficient and can take away any sense of agency from patients and their families. Now I, and others in nursing practice, might ask "how can we create environments where patients and their families are included in the process"? I also began to wonder if there are certain groups that are more excluded than others? Why are certain groups excluded? Have I given enough time to hear their stories? Nursing, as well as other healthcare professions, work within time constraints. Yet, rarely do we talk about the time patients spend waiting. As Abbud and Mahir articulated, they are always waiting - waiting to be seen, waiting to be heard, and waiting to be included. Despite not being able to change their waiting time, how can we make the time we do have with them significant?

### **Social: The Bigger Picture**

Historically, there has been very little attention paid to refugees with disabilities; as a group of people they have been invisible (Straimer, 2011; United Nations, n.d.). Straimer (2011) states this invisibility of refugees with disabilities is "is not due to their absence, but due to the discrimination" they may face in their host country (p. 538). There are estimates that the number of refugees with disabilities is in the millions, with one third of those being children. This suggests that children living with disabilities who are refugees are a very prevalent subgroup (WHO, 2011). The invisibility is heightened as minimal data is collected; there is currently no systematic collection of data on refugees with disabilities (Ernst et al., 2013; King et al., 2011; WHO, 2018). A literature scan conducted on Syrian refugee families with children with disabilities yielded almost no results. King et al. (2011) describe this gap in research and advocate that "a full-scale qualitative study with immigrant parents of children with disabilities

would be an important next step, to obtain detailed information about their experiences as caregivers, and their experiences with accessing and using services for their child” (p. 46). This narrative inquiry contributes to filling this gap and begins to illuminate the experiences of Syrian refugees with children living with disabilities.

Refugee children with disabilities face a compounded disadvantage through the intersection of disability status, minority ethnic status, and other social markers such as poverty or discrimination (Crock, et al., 2013; King et al., 2011; Strainer, 2011). In conversations with participants, the social significance of this compounded disadvantage was apparent. Mahir and Abbud spoke of feelings of exclusion and lack of agency. They had issues accessing care due to the complexity of navigating healthcare systems with different appointments to meet the needs of their child. Often decisions were made where Mahir and Abbud felt their voices were not heard. Both Abbud and Mahir compared the care they received in Canada to care available in Syria before the war, expressing areas of dissatisfaction with the Canadian healthcare system. They were primarily dissatisfied with long wait times and poor communication which often made them feel excluded. Their primary concern was getting high quality, timely care for their children. Access to high quality, equitable healthcare is a foundation of Canada’s healthcare and within the human rights for all, including refugees and migrants (WHO, 2018).

### **Future Research**

Canada has accepted thousands of Syrian refugees since the onset of the Syrian refugee crisis. Many of these families came with children living with disabilities (King et al., 2011). In order to minimize the marginalization of Syrian refugee families and specifically families of children with disabilities, research that pays attention to the unique experiences that each family may have needs to continue. Through hearing their stories, the experiences of people who are



living with children with disabilities can inform policies that aim to best meet their needs and minimize inequality. Narrative inquiry is a useful methodology to provide insight into the experiences of families who are living with children with disabilities. Furthermore, it is important to recognise that narrative inquiry holds the potential to enhance the nursing practice of the researcher. Wang and Geale (2015) state “narratives help nursing researchers understand patients, nurse patient relationships or other nursing issues such as personal identity, life-course development and the cultural and historical worlds of the narrators” (p.196).

### **Conclusion**

Narrative inquiry is not meant to produce generalizable results. “Narrative inquiry is not simply story-telling; it is a method of inquiry that uses storytelling to un-cover nuance” (Wang & Geale, 2015, p. 198). The nuances revealed through this study provide important insights into the experiences of Syrian refugee families with children living with disabilities. The complexity of Abbud and Mahir’s experiences become visible with regard to temporality (the timelines of their migration journeys as they sought coherence in their lives), sociality (the conflicting political and social contexts that informed how they felt and what they endured), and place (the various settings in which they composed their lives). All experiences are unique and by giving the time and space for Abbud and Mahir to tell their stories, we give them and their families a chance to make their struggles, possibilities, dreams, and needs visible.

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