

Shades of Care: Understanding how BIPOC mothers and children
experience paediatric care in Ontario, Canada

by

Raisa Ladha

A thesis

presented to the University of Waterloo

in fulfillment of the

thesis requirement for the degree of

Master of Science

in

Public Health and Health Systems

Waterloo, Ontario, Canada, 2021

© Raisa Ladha 2021

AUTHOR'S DECLARATION:

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

ABSTRACT:

Background: Race and ethnicity are determinants of health which play significant roles in shaping the quality of care and health outcomes for a child. In Canada's increasingly diversifying patient populations, it has been observed that definitions and experiences of health vary. Lack of understanding of these variations within the context of paediatric care can set children on a trajectory for negative health outcomes in the future, whereas their acknowledgement and active incorporation in care has the potential to orient children on a path towards holistic wellness.

Objectives: The purpose of this study was to gain an understanding of how BIPOC mothers and children experience paediatric care in Ontario. It additionally aimed to explore how BIPOC mothers perceive the provider-patient relationship and what their needs and expectations are in these encounters in order to positively engage with and receive paediatric healthcare services.

Methods: The participant sample consisted of BIPOC mothers residing in Ontario who have required paediatric care for their children (ages 0- 5). Fourteen semi-structured interviews occurred via video call or over-the-phone. Semi-structured interviews were conducted to allow participants the opportunity to authentically share their experiences, safely and without judgement. Participants' stories were inductively coded and examined through narrative analysis to discern how BIPOC mothers represent their experiences of acquiring paediatric care.

Results: Participants shared multi-dimensional definitions of health in the context of their own children, which influenced their perceptions of healthcare experiences. Provider-patient interactions were ultimately a central component of the patient experience, with needs such as respect and compassionate bedside manner being universal. Positive experiences within the provider-patient relationship tended to be as a result of individual providers' efforts and commitment to their patients. Healthcare providers were described as influencing participants' abilities to lay a strong foundation for their children's future. This is of particular significance as BIPOC mothers have expressed an increased sense of responsibility in advocating for and working towards optimal states of wellness for their children. Participants recalled building or engaging with communities of support to ensure their children's wellness, and healthcare providers were suggested to become a central part of these communities, as opposed to simply existing on the periphery.

Contribution: This study enables a comprehensive understanding of how BIPOC mothers conceptualize "health" for their children, as well as how they experience paediatric care in Ontario and how they feel about these interactions. Contributions of this research are 3-pronged: (1) enhancing cross-cultural understanding in paediatric care; (2) identifying the healthcare needs of paediatric patients and their families; and (3) informing clinical practice. This study also provides direction as to what sorts of approaches must be taken in order to sustainably implement culturally collaborative paediatric care in Ontario.

ACKNOWLEDGEMENTS:

I want to begin my thesis by recognizing and extending my gratitude to the first peoples of the land that we reside on. This thesis was written on the traditional territories of the Huron Wendat, Haudenosaunee, and Anishinaabe peoples. With that said, participants were located across what is currently known as Ontario. Although the locations of each participant at the time of interviews were not disclosed, it is essential to acknowledge that we are all hosted on Indigenous land.

This thesis could not have been written without the love and support of my family, friends, peers and mentors (you know who you are).

In particular, I want to thank my Supervisor, Dr. Elena Neiterman, for her endless guidance and empowerment. Dr. Neiterman, I am absolutely honoured to have had the privilege of receiving guidance from you for many years now and can honestly say that neither my accomplishments nor my character would be the same without you. Thank you for always being as invested in your students' wellness as you are in their success. You truly lead by example and inspire us all to bring curiosity, courage and compassion to all our endeavours.

This thesis would also not have been possible without the support of my committee members, Dr. Chris Perlman and Dr. Samantha Meyer. Your feedback has been instrumental in helping me grow as a student and researcher.

Earlier this year, I was helping one of my aunts edit a biography she was putting together about my grandfather, who was a teacher for a large portion of his life. Although he passed many years ago, I realized how many similarities we shared – a thirst for lifelong learning, a passion to teach others, and a desire to uplift ourselves and our greater communities. I would not be here today without my family, so thank you all for being such strong pillars in my life. To my parents, thank you for instilling in me the value of hard work, as well as an appreciation for higher learning. Thank you for always believing in me and ensuring that I can enter any room with confidence, yet also with humility.

Lastly, this research would not have been possible without my study's participants – the incredible mothers. Despite experiencing motherhood during the COVID-19 pandemic, which has been no small feat, these women were generous enough to share their time and their stories with me. A number of the interviews in this study took place with participants' children present – from quietly working on schoolwork to being cradled in their mother's arms. Thank you all.

TABLE OF CONTENTS:

INTRODUCTION	1
(1) BACKGROUND	2
1.1 Race and ethnicity as determinants of health	2
1.2 Experiences of BIPOC families within a healthcare context	4
1.3 Experiences of care provision to BIPOC in academia and clinical practice	7
1.4 Avenues toward an equitable standard of paediatric care in Canada	8
(2) RESEARCH OBJECTIVES	10
(3) METHODS	11
3.1 Research Design and Approaches	11
3.2 Reflexivity	13
3.3 Participants, Recruitment and Data Collection	14
3.4 Narrative Analysis	17
(4) RESULTS	19
4.1 Chapter 01: Motherhood Through a Cultural Lens	19
4.1.1 Conceptualizing “health” from the perspective of BIPOC mothers	19
4.1.2 Experiences of motherhood and supporting their children’s health	24
4.1.3 Perceived sense of belonging in healthcare as a BIPOC mother	27
4.2 Chapter 02: Provider-Patient Interactions	32
4.2.1 Duality of BIPOC patient experiences in paediatric care	32
4.2.2 Influence of HCPs in shaping the BIPOC patient experience	34
4.3 Chapter 03: Communities of Support	38
4.3.1 Reflecting on the significance of community for BIPOC mothers	38
4.3.2 Repositioning HCPs and creating sustainable communities of support	40
(5) DISCUSSION	45
5.1 Summary of Results and Reflection on Participant Narratives	45

5.2 Limitations	51
5.3 Key Takeaways and Recommendations	53
(6) CONCLUSION	55
(7) REFERENCES	57
APPENDIX A: RECRUITMENT FLYER	66
APPENDIX B: PARTICIPANT DEMOGRAPHICS	67
APPENDIX C: INTERVIEW GUIDE	71
APPENDIX D: KEY TAKEAWAYS & STRATEGIES FOR HEALTHCARE PROVIDERS	73

INTRODUCTION:

Health is influenced by a multitude of factors, which include, but are not limited to genetics, environment, health behaviour, and social determinants of health, such as education, income, housing, or access to care. A key differentiator in one's access to healthcare, in particular, is race and ethnicity – variables that ultimately have the potential to affect one's quality of care and health outcomes (Seid et al., 2003; Cheng & Goodman, 2014; Wright et al., 2019; Pachter & Coll, 2009; George & Bassani, 2018).

The influence of race and ethnicity are imperative to consider in relation to the current state of paediatric care in Ontario. Although waitlists for paediatric care services have existed for quite some time, these have been exacerbated by the COVID-19 pandemic. Between 55 and 75 percent of all paediatric surgeries at children's hospitals and over 30,000 procedures have been cancelled (Squires et al., 2020). Hence, the pandemic has created a new set of difficult circumstances which have led to families being turned away from receiving health care services. This perpetuates the already unfortunate realities for people of colour in healthcare, whose symptoms are more likely to be ignored or minimized (Asare, 2021). Access to care is but one example of how the social stratification that occurs on the basis of race and ethnicity affects families' experiences within the healthcare system. These experiences, especially if multiplied, consequentially create inequalities in health promotion, wellbeing maintenance, disease prevention, and illness recovery (WHO, 2008, p. 3). There is great urgency in ensuring that children are accessing the care they need, especially during such critical periods in their development, and no child should be left behind.

Despite the acknowledged importance of race and ethnicity as determinants of health among the general population, there remains a large gap in literature surrounding the experiences

of racially and ethnically diverse patients (Hyman & Wray, 2013; Mahabir et al., 2021; Nestel, 2012). In particular, there is an underrepresentation of the voices of BIPOC families who have received healthcare services. These families must be involved and embraced in efforts surrounding healthcare quality assurance, as service quality simply cannot be assessed without input from service users. This thesis examines how BIPOC (Black, Indigenous and People of Colour) mothers and children experience paediatric care, to clarify their needs and ultimately propose recommendations which promote culturally safe and collaborative care.

BACKGROUND:

1.1 Race and ethnicity as determinants of health

The healthcare system plays a central role in influencing a child's wellbeing, with its impacts ranging from prevention to treatment. The nature of paediatric provider-patient relationships, in particular, is quite complex, seeing as patients are often represented by their parents or caregivers. Parents and caregivers can collaborate with healthcare providers to ensure that their children are able to live a healthy life. However, experiences within the provider-patient relationship vary on the basis of race and ethnicity (Seid et al., 2003; Riera & Walker, 2010; Chen & Goodman, 2014; Wright et al., 2019; Pachter & Coll, 2009, Kelly et al., 2012). Race and ethnicity have been conceptualized as determinants of health that play significant roles in shaping the quality of care and health outcomes for a child (Seid et al., 2003; Cheng & Goodman, 2014; Wright et al., 2019; Ladha & Neiterman, 2021; George & Bassani, 2018). The large variance of these interactions has been emphasized in the current body of academic

literature as promotive of risky health behaviours and discouraging of help-seeking behaviours (Bécares et al., 2015).

Roth (2010) and Jones et al. (2008) argue that the act of racialization views race as a socially assigned and imposed classification by others, which results in a level of racial discrimination higher than how one may self-identify. Racialization is perceived to be the first step in an act of racism (Gans, 2017; Garcia & Abascal; 2016), defined by the Ontario Human Rights Commission (OHRC) as a belief that one group is superior to others – whether deeply rooted in attitudes and values or an unrealized assumption (OHRC, 2012). Many health inequities stem from institutionalized forms of structural racism, enacted both directly and indirectly on service users, which consequentially leads to individual and communal experiences of racism. Direct influences of structural racism include the apparent lack of access to adequate healthcare for BIPOC, whereas indirect influences include an imbalance of psychosocial stress load at the hands of various factors which may disproportionately affect BIPOC families (Brondolo et al., 2009). These factors include, but are not limited to, disparities in education, housing, employment, income, social or transportation infrastructure, and healthcare.

Some of the variations in experiences with the healthcare system for those who hold BIPOC identities may additionally be explained by the cultural differences between patients and providers. The study of racial variations, driven by a genetic model, has become complicated, given discoveries that there is, in fact, more genetic variation within races than between races (Cooper & David, 1986). In this sense, definitions of race and delineations of racial groups may be socially constructed, as opposed to biologically constructed. While ethnicity has more commonly been used in research concerning health disparities, it is a variable that “carries its own historical, political, and social baggage” (Oppenheimer, 2001). Culture, on the other hand,

is conceptualized as the latent construct which underlies analysis of race and ethnicity, otherwise regarded as categorical variables that enable the dissection of groups (Murry et al., 2001). It is defined as, “the learned and shared beliefs, values, and life ways of a designated or particular group which are generally transmitted intergenerationally and influence one’s thinking and action modes” (Leininger, 1985, p. 208).

The concept of culture, inherently unifying analyses of race and ethnicity, can therefore be utilized as a means of explaining the manifestation of racial or ethnic differences and broadening understanding of human development (Murry et al., 2001). It is also currently being regarded as the more appropriate explanation for variations in health behaviours and health outcomes (Egede, 2006). In this sense, addressing the cultural needs of BIPOC patients, their families and health care providers may simultaneously be a means of prevention for negative health outcomes of BIPOC children, as well as a solution to mitigating the effects of racially and ethnically rooted disparities. In fact, when provided appropriately and fairly, primary care has enormous potential to mediate the racial and ethnic inequities themselves (Wright et al., 2019).

1.2 Experiences of BIPOC families within a healthcare context

“Health” is a multi-dimensional concept that can look differently in conceptualization and manifestation, depending on which individuals or communities are being considered. Although there are predefined factors which may be indicative of health, definitions and experiences of health are also subjective. In the context of paediatric care, parents may feel some innate desire to nurture and protect their children, as well as to consult healthcare providers for support. Experiences within this parent-provider relationship vary, seeing as providers are experts on health and parents are experts on their children’s emotions and behaviours (Aarthun et

al., 2019). These variations are further compounded when we consider the variables of race and ethnicity.

Although the experiences of people of colour are largely varied, each shares the commonality of being a minority and has thus experienced some sense of difference or otherness in relation to the Eurocentrism deeply rooted in Canadian society. In seeking paediatric care within the context of Ontario's healthcare system, experiences of racial discrimination by BIPOC families are not at all uncommon. Racial discrimination at the hands of healthcare providers (HCPs) currently includes but is not limited to being exposed to the negative attitudes of HCPs, being ignored by HCPs, experiencing prolonged wait times, and dealing with hostility and disrespect of cultural beliefs of patients and their families (Pollock et al., 2015). Indigenous people disproportionately experience barriers to healthcare service access and utilization in Canada, such as racism, fear of judgement, and a lack of traditional Indigenous health services (Wright et al., 2019).

Despite these occurrences and extensive consequential scholarship that links racial discrimination to health outcomes in adults, little research is currently available regarding the impact of racial discrimination in health-related contexts on children (Pachter & Coll, 2019; George & Bassani, 2018; Bécares et al., 2015). A true understanding of the experiences of BIPOC mothers and children in acquiring paediatric care requires an acknowledgement of the vast differences even within various racial and ethnic groups, as opposed to a generalized recognition of individuals who share some cultural similarities (Banerjee et al., 2011; Fellin et al., 2013). For instance, some accounts of the paediatric patient experience in Canada have been generalized as representative of the South Asian experience, while the "South Asian" classification is, in fact, comprised of cultures from numerous different regions, including

Afghanistan, Bangladesh, India, Pakistan and Sri Lanka (Banerjee et al., 2011). These cultures each have their own variations of languages, customs, and beliefs which deserve to be acknowledged and honoured in their own regard. Similarly, while the Aboriginal Children's Health and Well-Being Measure (ACHWM) was developed to meet the need for a culturally relevant measure of health and well-being for Aboriginal children (8-18 years) in Canada, this continues to be one of the very few measures available for Aboriginal peoples despite the vast cultural diversity across Indigenous communities (Young et al., 2017). These measures must be assessed for their relevance to other Indigenous communities, which are more geographically or culturally distant (Young et al., 2017).

Another layer of complexity is added to the parent-provider relationship when we consider the experiences of mothers in particular. Sawyer (1999) described engaged mothering as an "active, involved and mutual process." Motherhood may be conceptualized differently across cultures, but advocacy is a variable in mothering (Sawyer, 1999), in the sense that mothers serve as an advocate for their children. As common primary caregivers, mothers tend to influence factors imperative to their children's wellbeing, such as food preparation and storage, feeding practices, psychosocial care, hygiene, and health practices (Carlson et al., 2014). A mother's agency and autonomy is relevant in this regard, seeing as their degree of autonomy at a household level, for instance, can impact their ability to make decisions in their children's best interest (Carlson et al., 2014). When agency is honoured during mothering, it can affect social change (O'Reilly, 2004), and even go as far as improving childhood nutrition or decreasing child mortality rates (Carlson et al., 2014; Boehmer & Williamson, 1996; Hossain et al., 2007). Mothers ultimately have the potential to affect the quality of care that their child receives, as well as to affect the quality of care that the next child receives. While favourable provider-patient

interactions and positive experiences of care are important in any medical practice, this topic is of particularly relevance for paediatrics, as paediatric health care providers must manage communication with their patients, as well as with the parents or caregivers of these patients. Addressing the cultural needs of BIPOC patients and their families when they communicate with the health care providers has the potential to prevent negative health outcomes in children as well as mitigate the effects of racially and ethnically rooted disparities on a broader scale.

1.3 Experiences of paediatric care provision to BIPOC families and children

Barriers in the provision of healthcare to racially and ethnically diverse patients have been reported by paediatric care practitioners across Canada at each stage of care delivery, from diagnoses to interventions (Grandpierre et al., 2019). At the stage of diagnosis, language barriers and the family's denial of diagnosis due to cultural stigma were cited as major challenges for healthcare providers (Banerjee et al., 2011, Fellin et al., 2013). The tendency to generalize across various racial and ethnic populations as opposed to establishing individual relations with each patient and their families has additionally contributed to the lack of formal processes in place to develop collaborative treatment plans (Fellin et al., 2015). In this sense, even in the cases of healthcare providers striving to provide appropriate care to BIPOC patients, there is immense difficulty as they are often unequipped to do so – whether with regards to knowledge or resources.

Canadian medical school faculty have shared that culture is primarily experienced by physicians as a phenomenon that complicates clinical practice (Macdonald et al., 2007). Consequentially, patients' culture is understood to be a deviation from mainstream and traditional medical practice (Macdonald et al., 2007). Culture is either seen by medical students

and practitioners as a strange, foreign and exotic practice, such as traditional remedies, or a strange local practice, such as anti-vaccine beliefs (Macdonald et al., 2007). Further, Henderson et al. (2015) has found that health care providers in Canada perceive the influence of cultural, ethnic, and religious practices as additive to the complexity of the care relationship. Barriers identified by HCPs in providing care to racially and ethnically diverse patients include difficulties surrounding decision making, differing norms and beliefs, and variations in communication and understanding (Henderson et al., 2015). In practice, unintentional stereotyping, time constraints to carry out intangible activities, such as communication or relationship building, and a lack of intuitive perceptions of the family's needs affect the capacity of healthcare providers to administer culturally appropriate care (Henderson et al., 2015).

1.4 Avenues toward an equitable standard of paediatric care in Canada

Currently, paediatric healthcare practitioners across Canada are employing their own strategies to foster positive provider-patient relations and to facilitate positive patient experiences, such as writing out key words, using visual aids, providing interpreters, or learning key words and phrases in different languages (Grandpierre et al., 2019). Practitioners who have been yearning to know more about different cultures have reported attending workshops and lectures, asking families about their home life, scheduling home visits, and learning how various health conditions are perceived by different cultures (Grandpierre et al., 2019). While these individual-level efforts are commendable, it is imperative to examine the structures in place within the healthcare system at large and their conduciveness to addressing the cultural needs of all patients.

The attainment of equitable standards of paediatric care – those which allow for the equal treatment of all patients, enabled by necessary practices that embody the principles of justice and fairness – has often been associated with the successful integration of cultural competency in practice. Although lacking a single agreed-upon definition, cultural competency is rooted in the belief that health care providers should be expected to possess a certain amount of cultural knowledge in providing adequate care to patients of various cultural backgrounds (Stanley, 2006). It is broadly conceptualized as the ability of healthcare providers and organizations to understand the various factors which shape the diverse identities of their patients, as well as to integrate these factors into the delivery of healthcare services (Ihara, 2004). Cultural competency, as the first major conceptualization of some standard of practice that considers cultural needs, does indeed have its merits. However, it is still susceptible criticism, such as that it portrays the solution of cultural needs as a skill that can be simply acquired by healthcare providers through training (Stanley, 2006).

A scoping review regarding the experiences of racially and ethnically diverse families with paediatric care in North America revealed the duality of the provider-patient relationship, whereby cultural discrepancies are felt on both ends (Ladha & Neiterman, 2021). Thus, a more appropriate solution in addressing discrepancies in experiences of paediatric care by BIPOC families is “cultural safety.” A concept born from efforts to address the inequities felt by Indigenous populations, cultural safety has great potential in serving as a foundation for patient advocacy. It confronts interpersonal power differences in the patient-provider relationship to consider how power can be renegotiated between the involved parties. The key differentiator between cultural competency and cultural safety is this understanding of power (Curtis et al., 2019). Whereas the concept of cultural competency tends to maintain that power is in the hands

of the healthcare provider, cultural safety seeks to redistribute power more equally between the involved parties. Cultural safety is a fairly new theoretical avenue and more research must be conducted to truly understand its efficacy in establishing an equitable standard of care. The urgency of establishing culturally safe health care practices has been explicitly noted in the 2015 *Calls to Action* by the Truth and Reconciliation Commission of Canada (HealthCareCAN, 2016).

This research helps to clarify the experiences of BIPOC families with paediatric care in Ontario. By understanding the needs of BIPOC mothers and children, as well as how they experience various facets of paediatric care, such as the service pipeline and the provider-patient relationship, this research provides direction as to what sorts of approaches must be taken in order to sustainably implement culturally safe and collaborative paediatric care in Ontario. There is a great deal that we can learn from the voices of BIPOC mothers, as they advocate for their children, as well as others, in ways that our healthcare system must seek to receive, honour and accommodate.

RESEARCH OBJECTIVES:

My research acknowledges the immense value that the voices of BIPOC mothers and their children hold in comprehensively understanding the state of paediatric care in Ontario. Whereas many facets of society have overwhelmingly silenced the voices of BIPOC women, it is a fundamental necessity to uplift them within the context of my research. The scoping review of literature on the provision of pediatric care to racially and ethnically diverse patients in North America shows lack of research which centres on the experiences of families of colour (Ladha & Neiterman, 2021). The goal of this study is to address this gap by exploring how BIPOC mothers

and their children experience paediatric care in Ontario. In particular, this research strives to answer the following questions:

- (1) How do BIPOC mothers define “health” for their children and how can they be supported in their strides towards it?
- (2) How do BIPOC mothers and their children feel about their interactions with paediatric healthcare services?
- (3) How do BIPOC mothers perceive the role of paediatric healthcare providers and what are their experiences within the provider-patient relationship?
- (4) What are the concerns that BIPOC mothers have regarding their children’s access to and experiences of paediatric care?

METHODS:

3.1 Research Design and Approaches:

This study’s design and procedures were influenced by the theory of intersectionality, which was developed by critical race theorist Kimberlé Crenshaw. This theory examines the effects of the multiple identities that people hold on their everyday experiences (Cole, 2009). “Identities” refer to the social categories in which one claims membership and associates personal meaning (Cole, 2009). Intersections, such as race and gender, can create either oppression or opportunity (Baca Zinn and Thornton Dill, 1996). While this duality has often been observed through healthcare experience or practice, these intersections were used in this study as opportunities to decenter from Eurocentric models of care and highlight the diverse needs of BIPOC mothers.

In order to address the questions posed above, a qualitative study design was selected. A qualitative approach enabled a more comprehensive understanding of how BIPOC families experience paediatric care, to ultimately help address the knowledge gap surrounding the variations of patient experience on the basis of race and ethnicity.

This study defined its population of interest as BIPOC (Black, Indigenous and People of Colour) mothers, intentionally staying away from defining potential participants as “racialized” mothers. This was done to not impose the assumption that there is an awareness or understanding of racialization by all those who have experienced it. Those who were considered to be racialized had experienced racism due to their race, skin colour, ethnicity, accent, culture or religion. This subgroup included women of colour from different minority populations and women with different birth countries to Canada who were targets of racism, as recommended by the Canadian Research Institute for the Advancement of Women (CRIA W, 2005).

Qualitative research manages data while honouring complexity and context (Atieno, 2009), which is of particular value to my interest in furthering a comprehensive understanding of the experiences of BIPOC mothers and their children. Qualitative research methods are able to do justice to participants’ perceptions (Atieno, 2009) and this is something I find to be crucial in uplifting the voices of these individuals, who have not otherwise gotten the recognition that they deserve. Qualitative research methods enable an understanding of how participants experience events, the meanings that they place on these experiences, as well as how they interpret them (Atieno, 2009). Further, qualitative research incorporates “multiple realities” (Rahman, 2016), which is necessary in recognizing the full range of experiences of BIPOC mothers.

Interviews are the most common format of data collection in qualitative research (Jamshed, 2014). In order to provide participants with an opportunity to share their thoughts and

experiences, I decided to conduct semi-structured, individual interviews. Semi-structured interviews allowed me to satisfy the aim of qualitative research: to discover participants' frameworks of meanings while avoiding the imposition of structures and assumptions as much as possible (Marks et al., 2003). By utilizing a semi-structured interview guide with broad core questions (See Appendix C), I was able to ensure that interview time was being used effectively whilst still engaging in an in-depth dialogue of sorts (DiCicco-Bloom & Crabtree, 2006). Further, inherent in semi-structured interviews is a tendency to pose open-ended questions rather than close-ended questions (Marks et al., 2003). Open-ended questions garner participants' authentic personal reactions (Marks et al., 2003), as opposed to close-ended questions, which may elicit a forced reaction between pre-defined options or impose restrictions on what participants feel welcome to share.

3.2 Reflexivity:

It was important to myself as a qualitative researcher to be mindful of how I relate to this study and its participants, as well as to consider the roles that my relationships play throughout the research process. As a BIPOC woman myself, I inevitably co-existed with participants at various intersections of identity. Although I am not yet a mother, I could relate to the stories that participants shared as they could have been my mother or aunt. Shared identities were found to be a source of comfort for participants during the interview process. For instance, if participants were to say a word in a different language or require time to construct their thoughts due to differences in language or health communication, I could understand this need and intuitively meet them where they were. With that said, it was critical that any shared identities or intersections of value resulting from my own, personal experience did not sway the valuable

views that were presented by participants. Techniques such as active listening and open-ended questions were employed to provide participants with space to share their own thoughts and experiences, with compassion and without judgement. Reflexivity was applied throughout the research process to ensure that each participant's voice and the stories that they told were honoured in this study.

3.3 Participants, Recruitment and Data Collection:

In total, 14 semi-structured interviews were conducted with BIPOC mothers to explore their experiences of acquiring or attempting to acquire paediatric care for their children. I recruited BIPOC mothers of children between birth and 5 years of age who have required paediatric care for their children. As mentioned above, BIPOC mothers not only experience the paediatric healthcare system differently on the basis of their racial or ethnic identities, but they also experience it differently than BIPOC fathers. BIPOC mothers face a multitude of barriers, which reveal an unequal balance of power, knowledge, and resources (Aarthun et al., 2019). I intentionally focused on young children (under the age of 5) because during this time, mothers tend to be the proxy for communication and to make decisions on behalf of their children. Beyond this age, children may begin to have a more active role in their healthcare and, therefore, advocate for themselves. They may serve as translators for mothers who do not speak English fluently, may become engaged in decision-making as they obtain some level of health literacy, or develop preferences with regards to health behaviours and healthcare practices. However, before the age of 5, BIPOC mothers are uniquely advocating on their children's behalf during their interactions with the healthcare system. The mothers included in the study have resided in

Ontario for a minimum of 6 months, a period of time deemed to be necessary in order to have acquired some level of familiarity with the Ontario healthcare system.

For the purposes of this research, paediatric care was defined as healthcare services provided for a child within the Ontario health care system and funded by the Ontario Health Insurance Plan (OHIP) or university health insurance plans. This included, but was not limited to, services offered by family physicians, paediatricians, emergency services provided in a hospital setting, and specialists such as therapists, psychologists or ENTs. Participants were able to take part in this study even if they were unable to successfully acquire paediatric care, as experiences of this nature were within the scope of this study and its aim of understanding the experiences of BIPOC mothers in acquiring paediatric care for their children.

Once ethics approval was obtained, a study website (<https://www.shadesofcarestudy.com/>) was developed and recruitment flyers featuring a description of this study, inclusion criteria, and contact information were circulated virtually (see Appendix A). In abiding by the guidelines set out by provincial authorities in response to the COVID-19 pandemic, recruitment occurred via social media, word of mouth, and snowball sampling. Facebook and Instagram pages with a large BIPOC following were contacted to assist in the circulation of recruitment postings. A large portion of those who were eager to assist with recruitment were accounts relating to midwifery, reproductive justice, and networks supporting mothers in different cultural communities. Word of mouth was utilized to get in touch with mothers who may not be so active on social media. This means was primarily utilized by those who had seen my flyer and who thought that someone in their personal network would be interested. Snowball sampling through word of mouth also proved to be successful, with some participants referring other participants to me.

When an individual expressed interest in the study, they were provided with a letter of information and consent form via email. In some cases, we also communicated over e-mail so that I could answer any questions related to participation in the study, prior to the participant's signing of the consent form. Once the signed consent form was received, an interview was scheduled to take place over-the-phone or over a video call – based on the participant's convenience and comfort level. Interviews were only conducted once informed consent was obtained and they were audio-recorded with participants' permission. The interviews lasted between 25 and 70 minutes, with an average interview time of approximately 45 minutes.

Prior to conducting the interviews, demographic information was collected to provide context to participants' narratives and to better situate their experiences in their personal circumstances. The demographic variables that were explored include:

- Age
- Number of children
- Race/ethnic background
- Immigration status
- # of People living in household
- Highest level of education (of mother)
- Employment status (of mother)
- Current family income

The participants interviewed were between the ages of 28 and 49. Participants were primarily of Asian, African, or Caribbean decent. It is important to note the vast diversity within these areas. For instance, Asian participants were West Asian (Iranian or Jordanian), East Asian (Korean or Chinese), as well as South Asian (Bengali, Sri Lankan, or Indian). Participants of African decent were West African (Togolese or Cameroonian), as well as East African (Sudanese or Ugandan). Caribbean participants either identified as Black or as having mixed ethnicity. A total of three participants identified as biracial or multi-racial. The majority of participants (n=10) were

Canadian citizens, most of whom (n=6) were Canadian born. Those who did not hold Canadian citizenship were either Permanent Residents (n=3) or international students (n=1). Participants had up to four children, with most having one or two children. Many participants (n=8) were first-time mothers and highlighted the novelty of motherhood throughout their interviews. The majority of participants began by speaking about their experiences with paediatric care when their children were newborns, as this was a particularly memorable time for many. Please see Appendix B for a more detailed breakdown of participants' demographics.

Following completion of the interviews, audio files were transcribed verbatim for coding and narrative analysis. Key words verbally emphasized by participants are represented by italics.

3.4 Narrative Analysis:

Following the data collection phase of my research, narrative analysis was conducted to make sense of the stories that participants told. This enabled an understanding of how BIPOC mothers represent their experiences of acquiring paediatric care in Ontario. Narrative analysis was selected because it does not rely on predefined variables, centring instead on the context and phenomena through which narratives are told, as well as on the meanings that storytellers assign to them (Andrews, 2019). The narratives obtained from participants were coded inductively to honour the authenticity and diversity of participants' stories while still enabling the analysis of their experiences in comparison to one another. Narrative analysis was conducted in accordance with the steps outlined by Andrews (2019):

- (1) Chronologically identifying meaningful discussion points within each narrative
- (2) Labelling these segments
- (3) Identifying themes within each segment and attaching them to quotations

(4) Constructing a core narrative based on these groupings and identifying the central statements that illustrate it

(5) Examining narratives together across interviews to uncover common patterns

When narratives were analyzed alongside each other, the meanings behind patterns and themes which emerged were contextually interpreted. There was no preconceived notion of what an ideal narrative must look like, in consideration of the fact that participants came from varying linguistic backgrounds and each expressed themselves differently. For instance, interviews with participants who were not fluent in English tended to last for shorter amounts of time. It was understandably tricky to translate medical and health-related terminology. However, regardless of how long an interview was, each participant spoke volumes in their own way, and each transcript was reviewed as such. In what follows, I present my findings summarizing key topics that were discussed across narratives: experiences of motherhood in the context of paediatric care, provider-patient interactions, and communities of support that mothers developed to help facilitate children's wellness.

RESULTS:

4.1 Chapter 1: Motherhood Through a Cultural Lens

4.1.1 Conceptualizing “health” from the perspective of BIPOC mothers

When considering BIPOC mothers’ experiences supporting their children’s health, it is also imperative to consider what they believe “health” looks like. In other words, we must understand what mothers need to see or feel in order to know that their child is growing healthily and happily. The narratives shared by those interviewed reveal concerns for their children’s wellbeing, across physical, mental, emotional, and spiritual dimensions. There was also a temporal element to conceptualizations of health, with mothers working to ensure their children’s health in the short and long term. In this sense, health was viewed on a continuum – not just a current state of being, but also a future to work towards. While culture was proven to influence certain aspects of health such as nutrition or healing remedies, it did not take precedence over what was suggested by healthcare providers. Concern about what was being suggested was only raised when there were gaps in communication or if there was uncertainty around what was being discussed.

For instance, Participant 8 is a 34-year-old mother with a 2.5-year-old son. Her and her partner are Tamil. They are both Canadian citizens and grew up in Canada. Participant 8 is currently working towards her PhD and working part-time, while her partner works full-time. She discussed how her definition of “health” for her son has been influenced by her own health-related experiences when she was a child:

“I was a really skinny kid, and I came here when I was two, and everyone felt that I was *too* skinny. And so, my parents were giving me vitamins and stuff like that. And I felt like

at *that* time, I had gained weight from that experience, and I never was able to lose that weight again. So, it was a lot of, like, there was a lot of fluctuations. I was, like, you know, I was *too* skinny... and then it was like it was *too* chubby. So, I kind of didn't want to put that pressure, weight pressure, on my son... Like, you know what? Like, he's eating... if you're full, and you're, you know, satisfied, and you're healthy, then, like, that's enough for me. Like, I don't want to give that same type of pressure of like... you're not enough weight, you're not less weight, because I felt like I had that pressure when I was growing up... not necessarily from my parents, per se, but definitely we did have it from a healthcare perspective and a societal perspective as well.”

Participant 8 ultimately did not want her son to feel as pressured by healthcare providers – and consequentially, family – as she was, to meet objective development milestones. She instead emphasized that her son’s health would be determined by his own, personal development journey.

Health was also interpreted as being beyond individual control, with some mothers viewing health as a blessing from God. For example, Participant 2 reflected on her experiences giving birth to her daughter in Canada, where there were some observations made by her primary healthcare provider via testing, which raised concerns about her daughter’s wellbeing in the womb. After giving birth, Participant 2 had to stay in the hospital for an additional week and her daughter required surgery in her head. Considering what a critical period of development her daughter was in, this experience was quite frightening and worrying for Participant 2 – also a new mother. Now that years have passed and her daughter is growing up, Participant 2 felt inclined to reflect back on that experience and give thanks to God as she defined “health” for her daughter:

“You know, maybe because at the beginning she had the surgery and we were in a hard situation... like... Alhamdulillah... I want to say, I don’t know if you know this word, but Alhamdulillah, it means like thank God... like thank God she is getting better... because I

knew, like, the baby has a problem after when I was in my 7 months of pregnancy, which is, like, late, you know? It's not the beginning... So, because they were saying she might lose some of the normal things that child get, like maybe she would not see... what I am seeing now, I am very thankful to God because she is doing well, she is walking... she doesn't have any issues! ...Like, she walks, she talks, she even learns the two languages... she speaks Arabic and English... writes both of them... she is smart, you know? ...Which is good (Laughs), like, she is smarter than me, I believe!"

In this sense, Participant 2 viewed God as instrumental in her daughter's recovery, as well as in her resiliency and ability to thrive following such a major obstacle in her life. Similarly, Participant 5, who is also Muslim (although Togolese, whereas participant 2 is Sudanese), gave thanks to God when reflecting on her children's health status:

"...They are healthy, Alhamdulillah. Thank God because it is God. I can't say it is my thing. You know what I mean?"

Although these mothers were so actively involved in their children's healthcare, they also saw their children's health as being beyond their total control and as being influenced by divine power.

Mothers additionally shared how experiences of life in a greater societal context ultimately play a role in determining their children's abilities to experience "health." For instance, Participant 13 alluded to her daughters' happiness and ability to thrive when considering what it means for them to live a healthy life. Participant 13 is a mother in her early 40s, with a 7-year-old and an 11-year-old daughter. She is married, and both her and her partner were born and raised in Canada. Participant 13 and her partner are both Indo-Persian. She has a bachelor's degree and is currently working full-time. Despite spending most their lives in Canada, Participant 13 and her partner briefly lived in the United States to pursue promising job opportunities. As a result, their oldest daughter was born in the United States. Participant 13

frequently acknowledged her socioeconomic privilege (high-income) as a factor in those of her healthcare experiences which were positive. When discussing how she would know that her children are healthy, she shared:

“Happiness is the biggest thing... that they are children who continue with a curious mind, have moments of joy in life, are happy... nothing is deterring them from having a life where they have the ability to thrive.”

Similarly, Participant 12 reflected on the numerous factors at play in her daughter’s day-to-day life and how they all collectively affect her health and wellbeing. Participant 12 is a 34-year-old mother with a 4-year-old daughter. Both her and her partner are Ugandan. Participant 12 is living with her daughter as she pursues her PhD, while her partner remains back home. When reflecting on what she would need to see in order to feel as though her daughter is healthy, she shared:

“Health for her would mean she’s living in a safe community. She has a healthy network of friends. She's in a, you know, a space where she can run, cycle, exercise... She's obviously not sick. You know, that's very important. And if she *is* sick, she has access to *immediate* care. There's no delays, she has access to medication if she needs to or a specialist if she needs to. That the information I need, because I am getting used to this context of information... the information I need to keep her healthy is available... Mentally, she's well. I mentioned that earlier in terms of, you know, discrimination and stuff like that... that she feels like she *belongs*. And she has a good support system, and she lacks support for *nothing* would be my ideal situation. Spiritually as well. Of course, she's young, but you know, spiritual aspects, for me, are important for her as well. So being able to nurture that would be critical, and yeah, access to mental health services, if she ever needs that when she grows up... And I think for me, the biggest thing is, if she did need access to services, I would prefer it to be someone from the same ethnic background just because they would relate better... Also another thing, I guess, that I need to mention about her wellness is also being connected to her roots. I think that's really important to me, because that gives her an *identity*. And identity is part of your self-assuredness, you know, your emotional stability, and whatnot. So having that cultural... knowing where she's from,

knowing that she is loved, and she has a whole community of support *back home* as well as the one we're building *here*, is very important as well.”

In describing a multi-faceted understanding of health, Participant 12 highlighted how healthcare goes beyond the stereotypical healthcare setting – relating to sense of belonging and safety in the greater community as well. She also demonstrated forward thinking by anticipating her daughter’s needs as she grows, taking more of a preventative stance rather than reactionary.

Seeing as Participant 12 mentioned social supports, cultural identity and belonging in her conceptualization of “health” for her daughter, we also chatted about what brings about feelings of “home”:

“I think home is somewhere you *love* to go to. Somewhere that gives you *peace*, somewhere where you have *community*. And so, I feel like I've built a home in Canada because for instance, during the pandemic, or even when we came back from Uganda, we had to quarantine for two weeks. And *every day* someone brought food to the door, or they asked me do you need groceries? I can go shopping for you. Or you know, on Mother's Day, bringing flowers and treats and stuff like that. So those little acts of kindness and, you know, friends and the support system... they have really made me feel at home... So, when you see yourself actually *thriving* in a space, you know, and you're *contributing*. And I think, I guess, for me feeling *accepted* in those spaces, that makes me feel at home.”

This excerpt reinforces the notion held by multiple participants, that health is also influenced by the community. The ability to know peace and be embraced by those around you, for instance, goes a long way in ensuring one’s mental health. When considering the previously identified multi-faceted nature of health, these sorts of supports ultimately promote and maintain an overall sense of wellbeing.

In order to better understand how BIPOC mothers and children experience paediatric care, as well as how the healthcare system can be shaped to better support them, it was imperative to first understand how BIPOC mothers experience motherhood, as well as how they

define “health” for their children. While participants appealed to different elements and dimensions of health, such as physical, emotional or mental health, all participants also acknowledged that they play a direct role in influencing their children’s health. Their perspectives on their perceived influence were determined by various factors that are discussed in this next section.

4.1.2 Experiences of motherhood and supporting their children’s health

While participants discussed their experiences as mothers with paediatric care, each was also experiencing motherhood in their own, unique ways. Experiences of motherhood varied based on factors such as culture, immigration status or family structure. Not only were participants recounting stories of how their children’s lives have been shaped, but in some ways, they also spoke to how their children affected their lives – particularly, their desires or decisions.

Motherhood often affected participants’ decision-making and consequentially shaped their immigration strategies. For instance, Participant 7 is an international student pursuing her PhD studies in Canada. She is a 38-year-old mother with a 6-year-old daughter. She and her daughter’s father are Bengali. However, they are no longer together. She is also working part-time to support herself and her daughter. Prior to coming to Canada, Participant 7 lived in the United States for many years. As a result, she frequently compared and contrasted Canada’s healthcare system to that of the United States and Bangladesh. She attributes her decision to come to Canada as an international student to being influenced by four key factors: the healthcare system, educational opportunities, freedom, and quality of living. These four factors, however, were primarily reflective of the future that she envisioned for her daughter. Participant

7 also discussed how the choices that she has made since her daughter was born have been with her daughter's health and wellbeing in mind:

“...Especially as a mother, it makes a huge, huge difference... When I'm just me, you don't really think about your own life. Because before I was a mom, I didn't really take my life or health as seriously as I do now, like when I cross the street... walking alone... I remember in college, I used to walk alone at night, like 2 am... (Laughter)... like, you just don't think about the safety as much. Now I wouldn't do it because, you know, someone else depends on me. So, I also do a lot of the healthcare things for my daughter, because I have to stay healthy for her. So, partially, I would say for both of our health, it makes a huge difference. For sure.”

As Participant 7 indicated, being a sole parent required her to reconsider how she engages with her own health, given the realization that her daughter “depends” on her. Similar to Participant 7, many mothers talked about rearranging their activities (and sometimes their lives) around considerations for their children's health and wellness.

While some mothers were the sole or main decision-makers for their children, others coordinated care with other family members, such as partners, grandparents, or even their children themselves. For instance, Participant 2 is a 28-year-old mother with an 8-year-old daughter. She is married, and both her and her partner are Sudanese. They moved to Canada 11 years ago and are now Canadian citizens. Participant 2 had her daughter in Canada and her husband is currently working full-time as she wraps up her postsecondary education. Although Participant 2 has been in Canada for a relatively long period of time, when discussing her parenting, she talked about utilizing healthcare practices and remedies that have been passed down in her family through generations. By employing the same care practices with her daughter that she inherited from her own mother, she is not only passing down cultural knowledge related to healing remedies, but also influencing her daughter's self-determined care practices:

“...I’m from Sudan and we use certain oil. And when I was sick, when I got cough, my mom would give me sesame oil... one or two tablespoon[s]. And I figured out that adding sugar and lemon makes it better... and little bit of salt, it will remove the thing from the chest or whatever. For my daughter, at the beginning, she was saying, ‘no’ because my husband was telling her to drink what he brought from the pharmacy, and I said, ‘no, this is better,’ and he would say, ‘no, this is better’,... and then she would be, like, ‘I don’t like the taste of the oil’... so, she wouldn’t drink it and would go to the other thing! (Laughs) ...but she is growing, right? And now I think her decision is changing and she will say, ‘yeah, I will try it.’ Before she wouldn’t try it, but now she is saying, ‘I will take it’... which is good! You know? Good for me! (Laughter) ...It’s her who makes the decision. Back home, it’s the mom who makes the decision... now the children make their own decisions, which is okay!”

This excerpt illustrates the strides for harmony that mothers make between Western culture and their culture of origin. In this example, Participant 2 adopted some values from Western culture and parenting styles, such as the child being a stakeholder in parenting decisions, while also holding onto her cultural roots by utilizing patience and wisdom to demonstrate to her daughter why there is merit in the traditional remedy.

Another participant who engaged in this type of decision making was Participant 5, a 44-year-old mother with 2 sons. Her eldest son is 11 years old and came to Canada from Togo at 8 months, while her youngest son is 9 years old and was born in Canada. Both Participant 5 and her partner are Togolese. Her partner is currently working full-time, while she works part-time as a personal support worker. Although Participant 5 and her partner both speak English, it is not their language of preference. When in Togo, they spoke French, and that is their preferred language of communication in Canada as well. Participant 5 shared similar sentiments to Participant 2 and discussed how she also engages in practices which she believes to be in the best interests of her children – particularly with regards to their diet. She prefers to cook food at

home, where she can be confident about the nutritional value of what her children are consuming. However, she does order out on special occasions so that her children do not feel as though they are missing out on common childhood experiences in Western society. Participant 5 also spoke about how she makes these choices, just as Participant 2 did, even if her children may not currently realize their benefits, as she is looking out for them and their future.

Ultimately, the cultural models of motherhood that mothers bring to parenting are critical in shaping how they experience paediatric care. Their perspectives additionally affect their expectations of the healthcare system and their comfort or satisfaction with subsequent interactions. In this next section, I explore how welcomed BIPOC mothers feel by the healthcare system, in their children's interactions with paediatric care.

4.1.3 Perceived sense of belonging in healthcare as a BIPOC mother

Partnered with participants' identified needs for connection and belonging, which was proven to be difficult to come by within systems that are not entirely inclusive, the mothers I interviewed expressed a sense of increased responsibility to oversee their children's experiences of care. This included closely monitoring the care being received, being an active advocate on behalf of their children, and uncovering or constructing the necessary pathways to secure their children's health and wellbeing.

For instance, Participant 9 discussed how she was perceived when she entered each interaction with the healthcare system as a single parent – even though there was never a partner in the picture, seeing as she had used a sperm donor to have a child. Participant 9 is a 42-year-old mother with a 5-month-old daughter. She is a Canadian citizen and identified as being Black (Caribbean). Her sperm donor was also Black. She stated that, “every experience is racialized in

some form,” and highlighted that she is not alarmed by particular experiences within the healthcare system because of this. Participant 9 went to college and typically works full-time, but is currently on maternity leave to care for her daughter. Participant 9 recalled in great depth how she has consistently made an effort to ensure that she is being treated fairly in her interactions with the healthcare system. The reasoning behind her concerns are multi-layered, but require further examination nonetheless, as quality healthcare experiences are closely tied with equitable healthcare experiences:

“I mean, I think it was a conscious thing for me... to ensure people understood that I was a single mother by *choice*. I did make that, I made it clear very early with my interactions with the hospital... like, first of all, there is no father. It's called sperm donor. I'm a single mother by choice... Really, I spelled that out, like... once I wrote that down, nobody ever asked again... But also, because I... my own thoughts were, like, I don't want them to think this is some sort of stereotypical situation they may have created, you know?... Like, on TV... although this would be a *great* show.”

Participant 9 demonstrated awareness not only of how her racial identity may be perceived, but also of how these perceptions would influence her treatment. Explaining her need to explicitly self-identify as a single mother by choice, this participant alluded to the stereotypes made about mothers who look like her and the consequences such stereotypes may have had on the quality of care that she and her child could receive. Participant 9 went on to discuss an evidently emotional ordeal that she went through while her daughter was staying in the NICU, and reflected on why her unwavering commitment to advocating for herself and her daughter is a necessity:

“When you *can* speak up for yourself and you are *willing* to ask questions, you find that people address you differently. Like, even with her care, she was at [Hospital] for 82 days? And around 60 or so days in, she was intubated, and it was a nurse... the nurse on shift, I had never met. And I went in at my regular time in the evening and he didn't deal with it well. He didn't notify me, and the way he did tell me when I came in was very nonchalant

and in my opinion, disrespectful and I complained to *everybody*. And then going forward, they were even... they were very clear and very informative and, like, anything, any *change*, they made sure, like, they called me and I didn't walk into any surprises after that. But I think it's also because I was willing to say, 'I did not like that. I'm not comfortable with that'."

This example demonstrates the power Participant 9 attributes to agency in influencing treatment. Although Participant 9 was initially excluded from the decisions related to her daughter's care, she made sure that her voice was heard and negotiated a role for herself, as a rightful stakeholder in her daughter's healthcare.

The realities faced by the mothers who took part in this study suggest that physical experiences in clinical settings are racialized. However, racism is not only the product of social interactions, but it is also embedded in the understanding and sharing of medical knowledge – traditionally created and interpreted from a Eurocentric lens. For instance, Participant 8, who is Tamil (as is her son), was repeatedly told by her son's healthcare providers that he was not growing properly. When searching for solutions, she booked an appointment with a nutritionist, who helped her see the situation from a different perspective:

"One of the things that I really loved about when I went to him [nutritionist] was, the first thing he did is he looked at me and my husband up and down, and he's like, oh, you guys are small people! ...and he said a very interesting thing. He said, you know, these curves that we're measuring your son on are based on WHO curves, but the majority of them are based on Caucasian individuals, so, they're not catered towards, you know, other ethnic minority groups. And so, if you looked at the curves from Sri Lanka, which I then did afterwards, he's actually *on* the curve for a Sri Lankan kid. So, it was interesting to get that *perspective*, and to be told that because it definitely alleviated a lot of anxiety. I was kind of that mom where, like, I'm, like, nothing's wrong with him. Nothing's wrong with him... but everyone, like, not everyone, but, like, every time I went to these appointments, he's not on the curve, like, you know, something's wrong... that that's what I feel like I was

being told. And when I was... when the *nutritionist* said that, I was, like, okay, you know what, so I'm not crazy. I didn't make this up. Like, you know, he's actually totally healthy and fine.”

This excerpt highlights the role that healthcare providers play in validating mothers' concerns, as well as in affirming their maternal 'instincts'. As a result of the experiences that Participant 8 had as a child with the healthcare system in Canada and her son's similar experiences, she also shared the expectations that she has of herself in her interactions with the healthcare system on behalf of her son. Participant 8 discussed how she expects herself to be knowledgeable about how to navigate the healthcare system and advocate for her family, given that it is so closely tied to her educational field of research as well. However, she also revealed that her experiences as a mother differ from her expectations as an educated professional:

“You know, sometimes I've definitely felt like we're heard and sometimes, I felt like there wasn't really enough time to even feel like we're heard in the appointment. And sometimes it's just, I don't think we ourselves have felt like we had the voice to advocate for it. ...Which is, sometimes I think back and it's a little bit scary, because I would *like* to think that I can advocate for, you know, myself or my son. But sometimes you do kind of get scared, kind of, like, okay, you know, what if, like, I'm missing something that they're telling me that I'm not understanding, or whatever. And so sometimes that power... like healthcare provider versus patient role is still present, even when *you're* the *parent* of the patient.”

In this sense, Participant 8 demonstrated how being a mother, as opposed to a professional, takes precedence when it comes to these healthcare interactions. Despite the fact that she was navigating familiar systems and had high levels of health literacy, she was not certain that she could always advocate for herself and her child.

Participants' sense of belonging in the healthcare system was largely shaped by their interactions with paediatric healthcare providers. Their reception by providers affected their

feelings of inclusion and empowerment within the provider-patient relationship. In the next section, the nature of provider-patient interactions is explored further to determine the scope of providers' influence, as well as to understand how providers can facilitate positive healthcare experiences for BIPOC mothers and children.

4.2 Chapter 2: Provider-Patient Interactions

4.2.1 Duality of BIPOC patient experiences in paediatric care

Many participants were able to speak to both positive and negative experiences with paediatric healthcare providers. Positive interactions with healthcare providers usually occurred when mothers found healthcare professionals via referrals or word of mouth through personal connections. Some sort of common ground between providers and patients, such as patients knowing other patients or even holding the same ethnic, racial or gender identities as the provider, significantly helped establish trust and increase comfort. This was harder to come by, however, in emergency and hospital settings, with participants highlighting lack of pre-established rapport as a barrier. Participants ultimately wanted to feel safe, seen and supported in the space that providers hold for them, but in situations where this was not possible, constraints that were identified included: limited availability of paediatric care providers, lack of avenues to voice concerns about care provision and treatment, restricted availability of services and resources reflective of individual or cultural needs, and a lack of consistency across care received from different providers.

One of the participants who spoke to the duality of patient experiences in great depth was Participant 1. Participant 1 is a 30-year-old mother. She has a 2-year-old daughter and is currently pregnant. She is of mixed ethnicity – her father is Jamaican/Cuban and her mother is Chinese/Portuguese. Participant 1 was born in Canada and is married. Her partner was also born in Canada and is Caucasian. Participant 1 is currently on maternity leave and is working towards a PhD while her partner works full-time. As her daughter is quite young, most of their healthcare

experiences have been with routine paediatric check-ups. Participant 1 discussed a negative experience with her daughter's paediatrician, which led her to seek a different provider.

“I guess one part of it was, so he was male, and I think... I don't know... sometimes I feel like there's a gender bias or something like that... where they kind of talk down to you or think you're not smart or something like that. So I felt that kind of domineering personality that he had, that I just don't think we clicked... so that was one part... With him, because it was an individual health practice, I felt like I constantly had to be like, “oh, I'm having these issues... can I see somebody?” He would kind of fight it, so, you'd have to keep arguing or advocating to get, like, the care you needed.”

Upon moving to a new city, Participant 1 was placed on a long waiting list for her daughter's current paediatrician. However, when reflecting on her most recent experiences with her daughter's current paediatrician, Participant 1 excitedly recalled how he goes the extra mile to ensure her daughter's comfort.

“So she's 2 and goes in for her 2-year appointment. That was fun because she's talking a lot more so it's like you prep her and stuff for the appointment, whereas before she's a lot younger so it's harder to um do those appointments... like, with vaccines and stuff... so, yeah, this appointment was very positive. Um... her doctor, he's a gay male that's Asian, so he's... I found him to be the best doctor or caregiver for her so far. So he's just really positive with her and really, like, kind in terms of how he cares for her and so she was wearing a little bunny shirt and he was like (imitates animated voice), “I'm going to check how your bunny is doing!”

This willingness to go above and beyond was described and appreciated by Participant 3 as well. Participant 3 is a 49-year-old mother. She is married and has 4 sons – a 6-year-old and three older sons who are in their teen years. Her and her partner immigrated to Canada from Sudan. They are both Canadian citizens. Participant 3 and her partner both have bachelor's degrees from Sudan. They are both currently working. Participant 3 and her sons predominantly interact with the healthcare providers during their regular check-ups. She is also appreciative of her current

family physician, who has gone above and beyond to support her family. She recalled how her family physician makes referrals immediately when needed and makes herself available in emergency situations, regardless of the time.

Overall, interviews with participants revealed that experiences with the healthcare system are influenced by a wide range of factors, such as access to healthcare services, shared identities between families and providers, and feelings of empowerment within healthcare interactions. Participants' accounts of their experiences with paediatric care highlighted how both positive and negative experiences have the potential to shift participants' existing perceptions of the healthcare system, which is why it is imperative to understand the direct role that healthcare providers play in facilitating these shifts.

4.2.2 Influence of HCPs in shaping the experiences of BIPOC mothers and children

Tone and demeanour were highlighted by participants as key determinants of their experience in paediatric healthcare settings. When recounting positive experiences, participants highlighted respect, autonomy, communication, awareness and compassionate bedside manner as key values that were most important to them.

A primary example of this is Participant 6. Participant 6 is a 37-year-old mother. She is married and has a 13-month-old son who she and her partner adopted. Both her and her partner are of mixed ethnicity. Participant 6 is Trinidadian Indian from her mother's side and Guyanese/Portuguese on her father's side. Her partner is Trinidadian Chinese on his mother's side and Jamaican Chinese on his father's side. They were both born in Canada and adopted their son in Ontario. Their son is also mixed race. His birth mother is Irish and his birth father is African American. Participant 6 has a bachelor's degree and is working full-time while her

partner is on parental leave. She has predominantly received pediatric healthcare services in the neonatal intensive care unit (NICU). She recalled how a stay in the NICU is common before adoptive parents can take their child home, especially in her case, where not much was known about the medical histories of the biological mother or father. Her son was in the NICU for 30 days, during which period both Participant 6 and her partner would frequently be present in the NICU. Participant 6 reflected on her experiences in the hospital after her son was born, and the role that communication played in helping to bring clarity to an otherwise unfamiliar experience:

“I think the healthcare system, for the most part is pretty supportive... the doctors, the nurses, and the paediatricians in the hospital, also, were really good about helping us through everything... So saying, like, you know, we're going to do a spinal tap, because we want to take some spinal fluid, and this is *why*... and you know, he has a fever and this could be *why*... and we're gonna run this test and this is *why*... they were really good about explaining everything, they were really good about giving us literature.”

Participant 4 shared similar sentiments regarding the value of a supportive and collaborative provider-patient relationship. Participant 4 is a 32-year-old mother. She is married and has a 4-year-old son. Participant 4 is of mixed ethnicity – Chinese and Caucasian. Her partner is also Caucasian. Both her and her partner were born in Canada. Participant 4 has a master’s degree and is working full-time, as is her partner. Most of healthcare experiences that her son has had so far were also in the NICU. Participant 4 was induced early, and when her son was born, his blood sugar was of concern. He was placed in the NICU within an hour of his birth, and stayed there for six days. She shared:

“...I tend to prefer to be talked to as an equal... and so when doctors communicate to me, like I understand what they're saying.... And I didn't feel like they glossed over things, which they obviously could have, given the fact that [child] wasn't advocating for himself to know more. They kind of volunteered that information, which I appreciated, as opposed to me having to probe and given that circumstance, like I'm already in a vulnerable situation

having just given birth... so the fact that I didn't have to pry, and I didn't have to... I didn't have to ask those questions... they kind of volunteer the information? That's what I, I appreciated the most. And they did have a calm and caring demeanor, which I hope is the norm for NICU... they just, they were friendly and warm and they just kind of gave off that warmth, which was appreciated.”

On the other hand, some mothers shared different experiences. For example, Participant 14 highlighted the importance of compassionate care and bedside manner when interacting with patients. Participant 14 is a 38-year-old mother. She is married and has a 5-year-old son and 8-year-old son. Participant 14 is Iranian and her partner is Jordanian. They both came to Canada before their sons were born and are now Canadian citizens. Participant 14 was trained as a medical doctor in Jordan and is now working towards her PhD while her partner works full-time. Despite being a medical doctor herself, Participant 14 said that when she is interacting with the healthcare system on behalf of her children, she sees herself primarily as a mother. She discussed the role that healthcare providers’ body language can play in creating a comfortable and welcoming environment for patients and their families:

“The family doctor, actually when she was talking, you know... to the patient, she was giving her back to the patient... She was typing on computer, and the patient was behind, you know? ...So, this is this is very bad, you know? I really don't like it. Because, yeah, you need to have like facial expression... you need to have this communication with them. Because the people here are not just tourists here or something... like a number, you know? Sometimes they just want to show like how many people you saw every day, how many patients they have... something like that. So, this is not nice, because the people here are the patients. They are not just numbers. They have feelings, emotions, and sometimes they have some difficulties...”

The passion of healthcare providers is felt immensely by participants at the point of care. When reflecting on positive experiences during healthcare interactions, participants referred to the evident passion of providers who were eager to go above and beyond for their patients – for

instance, by taking time to connect directly with the children, providing care after hours, or helping to facilitate access to necessary supports and services. While many recognized the heavy workload of healthcare providers, they also recognized when they were viewed as a burden or as someone equally deserving of support as the patient before. It is clear that patients and their families are impacted by how healthcare providers interact with them – whether through their demeanour, words or actions. For instance, Participant 6 went on to highlight how strongly cognizant she was of providers’ attitudes towards her, as well as how prominently they shaped the patient experience:

“I feel like some nurses, and, again, they experience a lot of things that we don't get to see, so you kind of, like, you do have to understand... but also, like, just because you experienced something awful that morning, that doesn't make *my* child or *my* parents or *my* sibling any less important... And I feel like if you're going to be a frontline nurse, or a doctor... you do need to have like a Masters in that... like, you need to know how to act and, like, change your tune for every family, so it's always positive, it's always helpful... I think, like, training on bedside manner is... there's never too much. You can never have too much of that for people who are in these roles.”

Overall, participants’ accounts made it clear that healthcare providers hold immense power in shaping a patient’s experiences and perceptions of the healthcare system. Just one compassionate doctor who takes the time to listen and provide genuine care can provide enormous amounts of relief and comfort to those service users who had not previously had the most favourable experiences. This sort of compassionate care has been highlighted by participants, irrespective of background, as a fundamental necessity.

4.3 Chapter 3: Communities of Support

4.3.1 Reflecting on the significance of community for BIPOC mothers

Many participants relied on their own informal community ties for support and exchanges of information in relation to the wellbeing of their children. These communities, which I entitled “communities of support,” give mothers a sense of pride and belonging. While there are some core values of “community” that were shared by participants, who that community was comprised of and what it signified varied. Family was commonly at its core, but community could expand to include other points of contact such as friends, neighbours, peers and colleagues. Communities of support are essentially mothers’ means of advocacy for their children, as well as for other mothers and children in the communities that they reside in.

Although the benefits of community in helping to maintain health were often discussed, the absence of community was also felt by some. For instance, Participant 11 is a 31-year-old mother with a 10-year-old daughter and a 9-month-old daughter. Both her and her partner are Cameroonian. Participant 11 is single and living in Canada as a permanent resident with her 9-month-old daughter. She has a college diploma and is currently on maternity leave from her job to care for her daughter. Participant 11 has most commonly interacted with the healthcare system virtually due to her daughter being born during the COVID-19 pandemic. While she appreciates how accommodating her family doctor has been, she expressed concern about how accurately physical symptoms could be conveyed in telemedicine, as well as discomfort sharing intimate information online. Participant 11 reflected on how the COVID-19 pandemic increased isolation from her communities of support, and the significant effect this has had on her daughter’s development.

“...With this pandemic, we are just stuck home... our babies don't interact with nobody. They know just us... so, like, yeah, it's really, really crazy. I think we have some resources where these kids can meet, play together... it's hard. I think she knows *me*, and my brother's kids are just all tangled up. I'm even happy that I have a brother that has kids that they can interact. If not, I would have been all by myself with her. Sometimes when she sees people, she wants me to carry her and she'll just cry because she's not familiar with these particular people. She's just with us, so we don't have that opportunity... with the pandemic, I don't think there is any solution for that. We just have to go with that but it's really, really hard like to stay just with them, without interrupting. I think if places are open, we will go to the YMCA... they can go play there... they can do all those things. But all those facilities we don't have... we really missed that opportunity now, for us, most of these pandemic periods.”

Participant 10 also shared similar sentiments. She is a 38-year-old mother with a 9-year-old son and 3-month-old son. She is married and both her and her partner are East Asian (Korean). Participant 10 is a graduate student and she is living in Canada with her family as a permanent resident. Prior to arriving in Canada, Participant 10 and her family lived in the United States, where her partner completed his studies. Her oldest son was born there while her youngest son was born in Canada. Participant 10 is currently at home with her kids while in school and her partner is working full-time to support them. Her youngest son was born during the COVID-19 pandemic – just as the daughter of Participant 11 was. Participant 10 similarly reflected on the impacts of COVID-19 on her children's mental health, and the role that community has played in aiding them through it. She discussed how communities of support are particularly necessary when considering how parents such as herself did not grow up in communities where mental health was spoken about or understood. Participant 10 expressed her appreciation for community-based supports such as a children's reading list from her local library that featured books on mindfulness and mental health, as they helped her support her

son's mental health during the pandemic, when other healthcare supports were not as easily accessible due to wait lists or restricted in-person interactions.

4.3.2 Repositioning HCPs and creating sustainable communities of support

Participants thought that, ideally, healthcare providers would be a part of these communities as well, woven into their very fabric, as opposed to simply existing on the peripheries. Participants discussed how healthcare either is or should be personal – healthcare providers should not be strangers, and “patients are not just numbers” (Participant 14). Participants frequently discussed how they feel a personal responsibility in ensuring a good quality of care for their children, as well as how they would like to see a levelling of these responsibilities whereby this load is shared between parent and provider.

For example, Participant 13, who is Indo-Persian, has primarily interacted with the healthcare system on behalf of her daughters for standard check-ups and allergy-related appointments. However, she also recalled how her youngest daughter had to see a physiotherapist due to barriers in mobility as she was transitioning from crawling to walking. This was a trying time for Participant 13 as a mother because they were put on an 8-month waitlist during such a critical period in her daughter's development. They ended up paying out-of-pocket for a physiotherapist who could see them urgently, but Participant 13 acknowledged her disappointment in this wait and how other families may not have had the privilege that she did to fund a more convenient option. Participant 13 additionally discussed how she felt a responsibility to help build communities of support and actively advocate for her children so that they can thrive. In fact, she attributes her children's health to her constant dedication tapping into networks, researching, and staying on top of their care. She believes that continuous

collaboration is needed with these networks to attain her definition of what health looks like for her children:

“...We now know health isn’t just nutrition, it’s about mindfulness and there’s an entire ecosystem we’re working with here as they grow and develop.”

Participant 13 additionally recalled how when she was on maternity leave for her second daughter, she made it a point to expand the network of mothers that she was a part of. She prioritized that work as an obligation, and because, as she explained, “you don’t leave a mother behind.” Participant 13 ultimately exemplifies the dedication of participants in not only seeking out existing pathways and links in this “ecosystem,” but also constructing pathways which make support more accessible to those mothers and children who need it. She acknowledged values from her cultural and religious upbringing as factors affecting her desire to help other mothers – just as mothers from her community supported her, she was eager to support new mothers that came after her.

Participant 9 echoed Participant 13 in acknowledging her privilege compared to others who share similar cultural identities, because of her close proximity to communities of support. In particular, she highlighted how fortunate she was when it came to her childbirth experiences, as well as her ability to ensure her daughter was healthy. In reflecting on her experiences with her daughter in a neonatal intensive care unit (NICU), she shared:

“... The whole time I thought of all the advantages I might have over someone else... I drove there every day, I had the means to pay for parking at a hospital every day. Those advantages weren't lost on me, or the fact that my whole my whole community *is* here... my mom, my dad, my siblings, my friends are all within half an hour of me... I met couples that were some *hours* away and they had to stay in the city. Or I met a couple that lived in the city but they had *no* family in Canada. They recently immigrated here. So I think that the Parent Mentor Program probably is the best thing? If they had more of those, like paired with a social worker... because I thought of all the ways where I didn't feel as though I

needed it as much. I didn't *need* it as much, but I *did* appreciate it. I had a doula and she came once or twice and was like you seem to have it under control... of course I do! My mom's here like every day, my older sister's here a couple times a week... like I have so much support *already*."

While communities of support are evidently of great significance for participants, their value for newcomers to Canada was also highlighted. For example, Participant 12 spoke in great depths about how communities of support allow newcomers to not only settle, but also to thrive. They allow newcomers to find comfort and solace in the company of those who share similar cultural identities. Participant 12 went on to explain how community can help newcomers engage with the healthcare system, as well as with positive health behaviours in general:

"I think the biggest adjustment was, of course, the community aspect. I find that Canadians are very much to themselves, and it's very odd to just say 'hi' to a stranger... or get to know your neighbors, or stuff like that ... I had to make an extra effort to make those connections, and I found that it was easier to make those connections with folks who are not *from* here, and I'm thinking that's because they faced the *same* isolation, or maybe their cultures were a bit similar... and so once I was able to do that, we created our own community *here*. And you know, these are, of course, the folks who... if your child is sick, and you don't know what remedies are available *here*, they can advise you... or have you tried this, you should go *here*... or go to the walking center, and so on, and so forth. So, I think that's how we were able to *adapt*... we have a supportive community *now* and so that has helped us really settle in. The only challenge I find *now* is where...we're African, right? And so, I worry oftentimes about the skin colour issue. Because where I'm from, we're the majority... so, skin has never been a conversation (Laughs), in *my* life anyway... of course, is, it's great that she's being exposed, we're being exposed to consuming different cultures, but then it draws attention to who she is... And I think part of who I *am*, is because I grew up in a country where we're the majority, so I was... you know, my abilities, and my intelligence was never questioned based on my colour. And so, that's the only thing I worry about being here is confidence in who she is, you know?"

These experiences of racialization and feelings of “otherness” are ultimately experienced in interactions with the healthcare system as well, which is why Participant 12 explained how communities of support can aid BIPOC mothers in navigating the healthcare system:

“I think for people who are *new*, especially for *moms*, this can be so isolating when you're new in Canada... And so if you can tap into a community, where they maybe understand your background or where you're coming from, and they're able to help you navigate the system, or even your own personal decisions... for instance, even in giving birth, and so on... just because you might be keen on a natural birth in a certain way. Because culturally, not every culture gives birth laying on the bed. You know, that's not normal in certain cultures. Certain people are more comfortable giving birth in different positions, and so if you can advocate for that, if you can go in with someone who can say, look, this is the way she prefers... so that even while you're going to... that someone is also making sure that your needs are being communicated to the health team... those are, like, little things that, culturally, people do for one another as they're navigating the system.”

Participant 12 also described communities of support as a vessel for preventative health measures. Essentially, while they are helpful during interactions with the healthcare system, they also have potential to protect the health of BIPOC mothers and children – as well as their communities. Rather than solely existing on the periphery, Participant 12 positions healthcare providers and the healthcare system as a whole *within* communities of support:

“Culturally speaking, for many cultures, the healthcare provider... they go into the *community*, to provide information, to provide support... whatever it might be. The challenge here is *you* have to *go into* a hospital, *into* a clinic, whatever it is, to get the information you need. The problem is people go when the problem is already *there*... And for foreigners, especially maybe from Africa or Asia, even South America, we go when it's *too* late. Simply because culturally back home, you only go to the hospital when you feel *pain*... So there needs to be a more community-centered way of having this information trickle down to these parents... So what services are they accessing more of? ...Are they going, for instance, to the YMCA, so their kids can play? You know, maybe that's a good

place to provide this information... Because that's where they *are*, and you found them in an environment that they're more likely to *frequent*... How can we get those resources *there*? It's the same thing with antenatal back home. Instead of requiring moms to go into an antenatal clinic, of which transport and so on might be difficult... and I'm talking about, of course, not affluent families... so what do you do for mom with five whose husband is working... I don't know, so many hours... and culturally for them, the man doesn't stay home with the kids. You know? How do you reach that mom? Aside from waiting for her to, you know, to show up at the healthcare facility if at all she ever comes?"

Overall, participants demonstrated great awareness of their positionality and experiences within the healthcare system, as well as of how other mothers experience the healthcare system. Participants had clear direction for how the healthcare system can be more supportive of BIPOC mothers and the communities that they reside in. They have taken on an active role in defining support and constructing communities of support, which must be utilized when imagining the future of paediatric care.

DISCUSSION:

5.1 Summary of Results and Reflection on Participant Narratives

Utilizing semi-structured interviews and narrative analysis, this study has enabled a more comprehensive understanding of how BIPOC mothers and children experience paediatric care in Ontario. In particular, this study clarified how BIPOC mothers define health for their children, their feelings about their interactions with paediatric healthcare services, their perceptions of the provider-patient relationship, their concerns regarding their children's health, and how they can be supported in their strides toward it. The contributions of this research are 3-pronged: (1) enhancing cross-cultural understanding; (2) identifying the healthcare needs of paediatric patients and their families; and (3) informing clinical practice. Cross-cultural understanding is necessary in consideration of Ontario's increasingly diversifying patient population, seeing as healthcare providers' training and practice has traditionally been informed through a Eurocentric lens (Baker & Giles. 2012). The experiences of BIPOC mothers are particularly unique given that race and gender identities intersect to affect experiences of the same reality. As a result, BIPOC mothers each have their own sets of needs and concerns regarding their children's healthcare. Comprehensive understanding of these needs and how they can be satisfied, as developed through this study, lend well to informing equitable and collaborative clinical practice that is inclusive of patients' diverse perspectives and identities. Currently, there is minimal literature that explores the effects of race and ethnicity on the health outcomes of children (Pachter & Coll, 2019; George & Bassani, 2018; Bécares et al., 2015). This study identifies and honours the potential of mothers to support the wellness of their children and other children in their communities, which compliments those few researchers who have identified mothers'

agency as a tool to enable positive health outcomes and affect social change (Carlson et al., 2014; Boehmer & Williamson, 1996; Hossain et al., 2007; O'Reilly, 2004).

The Canadian society within which healthcare practitioners operate is described as “the product of many years of colonial systems,” alienating communities and forcing conformity to Eurocentric standards (Baker & Giles, 2012). Despite the now widespread understanding of race and ethnicity as determinants of health which shape the quality of care and health outcomes for patients (Seid et al., 2003; Riera & Walker, 2010; Chen & Goodman, 2014; Wright et al., 2019; Pachter & Coll, 2009, Kelly et al., 2012), there is still a significant lack of understanding regarding how experiences of healthcare vary. Considering that this large variance of experiences has been emphasized in academic literature as promotive of risky health behaviours and discouraging of help-seeking behaviours (Bécares et al., 2015), ultimately setting BIPOC children on a trajectory for negative health outcomes in the future, the identification of their needs is absolutely imperative. This research study clearly identified the needs of BIPOC mothers and children to inform efforts focused on fostering positive experiences with healthcare providers.

Although participants' perceptions of motherhood involved a shared affinity for nurturance and protection of their children's wellness, definitions of “health” and experiences of it varied. Participants appealed to different elements and dimensions of health, such as physical, social or mental health. The narratives of participants also revealed maternal concern for their children's wellbeing across these dimensions, both in the short and long term. These findings paralleled those discussed by Sawyer (1999), who saw how mothers tend to serve as advocates for their children yet engage in this advocacy differently due to varying cultural influences. Health was viewed on a continuum by participants, whereby health was more than just a current

state of being – it was a future to work towards. In this sense, participants viewed preventative measures as also being helpful in influencing their children’s health and wellness.

Culture must inevitably be considered when working towards a more collaborative healthcare experience, as BIPOC patients and their families understand and experience health, as well as the healthcare system, differently. This finding is supported by literature that conceptualizes culture as unifying analyses of race and ethnicity, to ultimately explain the manifestation of racial and ethnic differences in health behaviours and health outcomes (Murry et al., 2001; Egede, 2006). Participants commonly denoted variations of experience with distinguishing phrases such as “here” versus “there” or “back home.” Experiences with the healthcare system were described to be influenced by a wide range of factors such as access to healthcare services, shared identities between families and providers, and feelings of empowerment within the interactions.

The provider-patient relationship and experiences within it were determined to be a central component of the patient experience. Positive experiences in the provider-patient relationship tended to be as a result of individual providers’ efforts and commitment to their patients. These providers appeared to view culture not as something which complicates clinical practice – the more common belief as described in literature (Macdonald et al., 2007) – but rather, as something that compliments it. Many participants, however, were able to recall positive and negative experiences with the healthcare system, which emphasizes the need to ensure that components of positive patient experiences are understood to be a consistent standard across healthcare providers. Despite there being variations in patient experiences, certain needs expressed such as respect and compassionate bedside manner were universal. These needs

reflected those factors which enable engaged mothering (Sawyer, 1999), allowing mothers to be actively involved in their children's care.

Findings from this study suggest that healthcare providers greatly influence the patient experience, as well as patients' perceptions of the healthcare system as a whole. The space that healthcare providers hold for patients and their families affect the care that they receive, their comfort levels, and their trust towards them. In situations where participants did not feel safe, seen or supported by healthcare providers, constraints included: limited availability of paediatric care providers, an inaccessibility of avenues to voice concerns about care provision and treatment, restricted availability of services and resources reflective of individual or cultural needs, and a lack of consistency across care received from different providers. These findings paralleled literature which explored experiences in the provision and receipt of healthcare in culturally diverse populations (Pollock et al., 2015; Hendson et al., 2015).

When reflecting on positive provider-patient interactions, however, participants recalled providers who were eager to go above and beyond for their patients by taking time to connect directly with the children, providing care after hours, or helping to facilitate access to the necessary supports and services. The impact of providers who generously give their time and care, beyond what has been asked of them, speaks to the potential of cultural safety and emphasizes the limits of cultural competency in clinical practice. Whereas cultural competency portrays the solution of cultural needs as a more static acquisition of knowledge (Stanley, 2006), cultural safety is a more engaging practice which requires the activity and collaboration of both healthcare providers and recipients (Curtis et al., 2019). Positive provider-patient interactions ultimately have the power to orient patients on a path of wellness, as well as to support parents in laying a strong foundation for their children's future. This is of particular importance in the

context of paediatric care due to mothers' strong desires to influence factors imperative to their children's wellbeing and to make decisions in their children's best interests (Carlson et al., 2014). The mothers interviewed in this study expressed an increased sense of responsibility in advocating for and working towards optimal states of wellness for their children, for instance, by closely monitoring the care being received, and by uncovering or constructing the necessary pathways to secure their children's health and wellbeing. Although providers are experts in health and medicine, it is the parents who are the experts on their children, the patients (Aarthun et al., 2019). This was a belief that was firmly held by participants, with some believing that the healthcare providers who directly involved them in their children's care were also in agreement. The mothers interviewed viewed themselves as being – or wanting to be – collaborators with providers, who are respected and valued for the insights that they bring regarding their own children and their health. Healthcare providers played critical roles in validating mothers' concerns and affirming their maternal instincts, such as when assessing their children's development or wanting to become more informed about the care being received by their children.

There is much to learn from the stories of these mothers and their ceaseless commitment to advocating for their children, as well as to supporting those around them. Although feelings of confusion, dismissal, frustration, and powerlessness have been expressed in past literature exploring the paediatric healthcare experiences of mothers (Aarthun et al., 2019), it is crucial to understand that those feelings are symptoms of their experience, as opposed to reflections of intrinsic qualities that they hold. The experiences of BIPOC mothers are largely shaped by intersectionality, with variables such as gender and race playing prominent roles in affecting how they are viewed and received by the healthcare system. For instance, participants recalled being

belittled by some male providers or having to prepare for interactions beforehand to increase the possibility of being viewed as capable and valued in the provider-patient relationship. However, those same participants recalled securing their children's wellbeing by finding a healthcare provider that was a better fit for them and getting multiple opinions to ensure that their concerns were being heard.

Going beyond the appointment room, the mothers interviewed also discussed taking it upon themselves to pave the way for support networks and systems which promote belonging and are conducive to their children's ability to thrive. Communities of support allow mothers to do just this, and serve as an example of the vast potential for our future when medicine is magnified using a public health lens. Not only do they tell a story of community members who are eager to play a role in their community's wellness, but they serve as a reminder that community members can be effectively mobilized for sustainable change. Participants commonly discussed the benefit of community in helping them navigate unfamiliar health concerns regarding their children, such as where to take their child when they are ill or how to support their mental health. Discussion of mental health, in particular, highlighted the efficacy of communities of support. When existing supports (i.e. elders, extended family, networks from "back home") could not support mothers and their children as they would have hoped, participants grew their communities of support or consequentially helped others to do so. As Participant 13 explained, "you don't leave a mother behind."

Healthcare and advocacy, although seemingly two separate concepts, go hand-in-hand in supporting patients and the communities that they reside in. While healthcare may focus on treating the patient's physical body more urgently, it is through patient advocacy that we can actively prevent harm – on a physical level, as well as mentally, emotionally and spiritually.

Advocacy has the power to heal and must therefore be at the core of clinical practice. However, as advocacy begins to have a more prominent presence in healthcare, it must be acknowledged that the necessity for advocacy is a reality that patients – especially those holding marginalized identities – know all too well. Whether utilizing existing networks or building their own, communities of support allow patients and their families to share in their experiences together and ultimately support one another on a path towards wellness. As we seek ways to promote patient empowerment and collaboration in clinical practice, one must consider where healthcare providers exist with relation to these communities of support. Participants in this study determined that it is ideal for healthcare providers to become a central part of these communities, as opposed to simply existing on the periphery. The ways that healthcare providers are positioned (i.e. whether paternalistic models of care can be reframed as participatory) will be telling of the future of our healthcare system.

5.2 Limitations

This research study had a number of limitations. In wanting to hear the stories of a diverse group reflective of what paediatric healthcare practitioners in Ontario commonly see, this study inherently focused on breadth as opposed to depth. In this sense, it was a priority to include participants from a wide range of cultural backgrounds, as opposed to focusing in on a particular population. While interviewing participants of a common racial or ethnic group may have allowed for clearer patterns to emerge, broadening my search allowed for wider representation. It also uniquely allowed me to ascertain how the largely varied experiences of BIPOC women actually connect back to some of the same core needs, such as compassion, respect and collaboration. BIPOC women share the commonality of being largely underrepresented and

underserved within the healthcare system, and this study sought to rectify the impacts of subjecting BIPOC families to “otherness” within the healthcare system, whilst honouring the truth and validity of each of their experiences.

Considering the severity of the COVID-19 pandemic for the duration of this study, recruitment and interviews took place virtually. Although a wide range of individuals, groups and services circulated recruitment information in hopes of reaching a diverse patient sample, those participants which were successfully recruited inevitably had safe and secure access to internet connection or a phone line. As face-to-face interviews could not safely be conducted, I was not able to meet participants where they are, which was what was initially planned for. Not only was this restrictive in terms of getting in touch with distant communities, but it also served as a barrier to potential participants who were mothering through the pandemic. Not being able to meet participants where they were meant that participants had to carve out a specific timeslot in their schedule to share with me. A virtual research process was also restrictive as recipients of recruitment information may have been weary engaging in research whose origins they were unfamiliar with. This research study was recruiting members of marginalized populations, from communities who may not have previously had comfortable interactions with research or the healthcare system as a whole. As a result, existing networks which spanned these communities were utilized and I provided constant reassurance to participants that they have the power to determine how their stories are expressed, understood and subsequently shared.

Unfortunately, due the aforementioned factors, this study was unable to include Indigenous voices. Indigenous communities have particularly distinct experiences within the context of the Canadian healthcare system – historically and currently – which must be explored. Prior to COVID-19, a major goal for this study was to build these necessary

relationships in person. Although Indigenous social media profiles were involved in recruitment, the unpersonal nature of virtual recruitment made it difficult to build strong enough rapport. This unfortunate gap, however, serves as a reminder of how we are not entitled as researchers to communities. We have a responsibility to actively initiate and maintain these relationships.

It became clear during the analysis phase how complex it is to define and evaluate narratives, given that participants had varying levels of English proficiency, as well as constructed and expressed their narratives differently. For instance, those participants with limited use of the English language apologized on multiple occasions when they were unsure of how to communicate a particular word or concept. I took these moments as an opportunity to step back, reassure the participant, and be certain of their comfort before moving forward. It is important that research is conducted from a place of gratitude, as participants are entrusting us with their stories and they deserve to feel safe and comfortable in doing so. Throughout this research study, it was a goal of mine to ensure that participants were viewed as holding power and that I was constantly expressing my appreciation for their time and words.

5.3 Key Takeaways and Recommendations

Notwithstanding these limitations, the information obtained from this research study can be applied to inform appropriate and effective interventions for sustainable change. It is imperative that those efforts intended to improve experiences of paediatric care for BIPOC families, are in fact tailored to and successfully accessible by them. This requires a decentring from Eurocentric models of care and comprehensive consideration of the views and values held by increasingly diversifying patient populations. In this sense, there is a level of humility which is necessary – becoming attuned to patients’ cultural needs is an ongoing process that goes

beyond a pre-defined level of competency. These findings parallel those in literature which propose cultural safety as being a more appropriate approach in comparison to cultural competence (HealthCareCAN, 2016; Stanley, 2006). With cultural safety, patients are being empowered and engaged by healthcare providers to have an active role in their care.

In centring my research on the upliftment of BIPOC voices, the strategies and recommendations produced are reflective of their needs and indicative of actionable work that can be undertaken by healthcare providers to improve the experiences of BIPOC families with paediatric care in Ontario. Seeing as collaboration was identified as a key healthcare need in the majority of interviews, it is recommended that this is regarded as a priority for healthcare providers and those who affect their ability to practice. When providers are equipped with the necessary tools and resources, they can feel supported in providing compassionate and collaborative care that respects the identities of their patients. The narratives shared by participants were analyzed to develop key takeaways and strategies which can be applied in clinical practice by healthcare providers (Please see Appendix D). Healthcare providers have enormous potential to play central roles in the wellness of their patients and their communities, but it is important to note the duality of their existence in these communities as both knowledge sharers and acquirers. The sharing and acquisition of knowledge within this context is not static, but dynamic, and ultimately facilitated through cultural collaboration. This requires an active presence of healthcare providers in their patients' communities and an acknowledgement of the potential to strengthen them from within.

CONCLUSION:

While families seek support from the healthcare system and appreciate the expertise of healthcare providers, the healthcare system simultaneously has much to gain from these same families. The voices of the BIPOC mothers interviewed hold great value in understanding the current state of the healthcare system, as well as what the healthcare system must become as we work towards a brighter future. In particular, they enable a more comprehensive understanding of how “health” is conceptualized across varying cultural groups, as well as how BIPOC mothers experience the provider-patient relationship and the healthcare system when interacting with it on behalf of their children. Participants shared multi-dimensional definitions of health for their children, which subsequently influenced their perceptions of healthcare experiences. Provider-patient interactions were ultimately a central component of the patient experience, with positive experiences within the provider-patient relationship tending to be as a result of individual providers’ efforts and commitment to their patients. Seeing as healthcare providers were described as influencing participants’ abilities to lay a strong foundation for their children’s future, each component of the positive healthcare experiences which were recounted must be replicated consistently.

These findings were ultimately applied to clarify the healthcare needs of paediatric patients and their families, enhance cross-cultural understanding, and inform clinical practice. In looking to the future of an equitable healthcare system, inspiration can be drawn from the communities of support that were highlighted in this study. These communities, while traditionally supporting members’ wellness beyond the appointment room, aspire to include care providers in addition to care recipients. As healthcare providers enter these communities, decentering from traditional models of care and demonstrating cognizance of cultural diversity

will allow for a more comprehensive understanding and honouring of BIPOC in healthcare. Future efforts are recommended to focus on actively supporting BIPOC mothers in their children's healthcare journeys and advocacy efforts, as well as to determining how the healthcare system can become more engaged in providing equitable healthcare experiences which are reflective of mothers' hopes for their children. Coretta Scott King once said, "the greatness of a community is most accurately measured by the compassionate action of its members." There is much to be taken from the courage and commitment of BIPOC mothers in advocating for their children and maintaining communities of support, in the hopes of protecting and uplifting those who come after them. This study affirms the importance of patient advocacy, empowerment and collaboration with healthcare providers to imagine equitable practices that inspire a brighter future for paediatric care.

REFERENCES:

- Aarthun, A., Øymar, K. A., & Akerjordet, K. (2018). Parental involvement in decision-making about their child's health care at the hospital. *Nursing Open*, 6(1), 50-58.
doi:10.1002/nop2.180
- Aday, L. A., & Andersen, R. M. (2004). Health Care Utilization and Behavior, Models of. *Encyclopedia of Biostatistics*. doi:10.1002/0470011815.b2a4a010.
- Andersen, R.M. (1995). Revisiting the behavioural model and access to medical care: does it matter?. *Journal of Health and Social Behaviour*, 36, 1-10.
- Andersen, R.M., Davidson, P.L. (2001). Improving access to care in America: Individual and contextual indicators. Changing the U.S. health care system: Key issues in health services, policy, and management. San Francisco, CA: Jossey-Bass; 3-30.
- Andrews, S. (2019). Thematic and Narrative Analysis in the Context of Courtroom Examinations With Alleged Victims of Child Abuse. *SAGE Research Methods*.
doi:10.4135/9781526498878.
- Asare, J.G. (2021, Jul 2). How One Woman's Story of Medical Neglect Highlights the Pervasive Issue of Racism in Healthcare. *Forbes*.
<https://www.forbes.com/sites/janicegassam/2021/07/02/how-one-womans-story-of-medical-neglect-highlights-the-pervasive-issue-of-racism-in-healthcare/?sh=4184c0bc270b>
- Atieno, O. P. (2009). An analysis of the strengths and limitations of qualitative and quantitative research paradigms. *Problems of Education in the 21st Century*, 13, 13-18.

- Babitsch, B., Gohl, D., & VonLengerke, T. (2012). Re-revisiting Andersen's Behavioral Model of Health Services Use: A systematic review of studies from 1998–2011. *Psycho-Social-Medicine*, 9(11), 1-15. doi:10.3205/psm000089.
- Baker, A. C., & Giles, A. R. (2013). Cultural Safety: A Framework for Interactions between Aboriginal Patients and Canadian Family Medicine Practitioners. *International Journal of Indigenous Health*, 9(1). doi:10.18357/ijih91201212390.
- Banerjee, A.T., Watt, L., Gulati, S., et al. (2011). Cultural beliefs and coping strategies related to childhood cancer: The perceptions of South Asian immigrant parents in Canada. *Journal of Paediatric Oncology Nursing*, 28(3), 169-178. doi: 10.1177/1043454211408106.
- Beatson, E. (2013). Engaging Empowered Mothering: Black Caribbean Diasporic (M)othering Under Patriarchal Motherhood. *Journal of the Motherhood Initiative*, 4(2), 74-88.
- Bécares, L., Nazroo, J., Kelly, Y. (2015). A longitudinal examination of maternal, family, and area-level experiences of racism on childrens socioemotional development: Patterns and possible explanations. *Social Science & Medicine*, 142, 128-35.
doi:10.1016/j.socscimed.2015.08.025.
- Boehmer, U. & Williamson, J. (1996). The impact of women's status on infant mortality rate: A cross-national analysis. *Social Indicators Research*, 37, 333-360.
- Brondolo, E., Gallo, L.C., Myers, H.F. (2009). Race, racism and health: Disparities, mechanisms and interventions. *Journal of Behavioral Medicine*, 32, 1-8. doi: 10.1007/s10865-008-9190-3.
- Brown, C., Barner, J., Bohman, T., & Richards, K. (2009). A Multivariate Test of an Expanded Andersen Health Care Utilization Model for Complementary and Alternative Medicine

- (CAM) Use in African Americans. *The Journal of Alternative and Complementary Medicine*, 15(8), 911-919. doi:10.1089/acm.2008.0561.
- Carlson, G.J., Kordas, K., Murray-Kolb, L.E. (2015). Associations between women's autonomy and child nutritional status: A review of the literature. *Maternal and Child Nutrition*, 11, 4520482. doi: 10.1111/mcn.12113.
- Cheng T.L., Goodman E. (2014). Race, Ethnicity, and Socioeconomic Status in Research on Child Health. *Paediatrics*, 135, 225-237. doi:10.1542/peds.2014-3109..
- Cole, E. R. (2009). Intersectionality and research in psychology. *American Psychologist*, 64(3), 170-180. doi:10.1037/a0014564.
- Commission on Social Determinants of Health. (2008). Closing the gap in a generation: Health equity through action on the social determinants of health (Final Report). World Health Organization.
http://apps.who.int/iris/bitstream/handle/10665/43943/9789241563703_eng.pdf;jsessionid=3894E1DBEA255631781C953BE5C73739?sequence=1
- Cooper, R., David, R. (1986). The biological concept of race and its application to public health and epidemiology. *Journal of Health Politics, Policy and Law*, 11(1), 97-116. doi: 10.1215/03616878-11-1-97.
- Curtis, E., Jones, R., Tipne-Leach, D., Walker, C., Loring, B, Paine, S.J., Reid, P. (2019). Why cultural safety rather than cultural competency is required to achieve health equity: A literature review and recommended definition. *International Journal for Equity in Health*, 18(174), 1-17. doi: 10.1186/s12939-019-1082-3.

- De Boer, A. G., Wijker, W., & De Haes, H. C. (1997). Predictors of health care utilization in the chronically ill: A review of the literature. *Health Policy, 42*(2), 101-115.
doi:10.1016/s0168-8510(97)00062-6.
- DiCicco-Bloom, B., & Crabtree, B. F. (2006). The qualitative research interview. *Medical Education, 40*, 314-321.
- Egede, L. E. (2006). Race, ethnicity, culture, and disparities in health care. *Journal of General Internal Medicine, 21*(6), 667-669. doi: 10.1111/j.1525-1497.2006.0512.x
- Fellin, M., King, G., Esses, V., Lindsay, S., Klassen, A. (2013). Barriers and facilitators to health and social service access and utilization for immigrant parents raising a child with a physical disability. *International Journal of Migration, Health and Social Care, 9*(3), 135-145. doi: 10.1108/IJMHSC-07-2013-0024.
- Fellin, M., Desmarais, C., Lindsay, S. (2015). An examination of clinicians' experiences of collaborative culturally competent service delivery to immigrant families raising a child with a physical disability. *Disability and Rehabilitation: An International, Multidisciplinary Journal, 37*(21), 1961-1969. doi: 10.3109/09638288.2014.993434.
- Gans, H. J. (2017). Racialization and racialization research. *Ethnic and Racial Studies, 40*(3), 341-352. doi:10.1080/01419870.2017.1238497.
- Garcia, S. (2020, June 15). Where Did BIPOC Come From? Retrieved August 06, 2020, from <https://www.nytimes.com/article/what-is-bipoc.html>.
- George M.A., Bassani C. (2018). Influence of Perceived Racial Discrimination on the Health of Immigrant Children in Canada. *Journal of International Migration and Integration, 19*, 527-540. doi:10.1007/s12134-018-0539-3.

- Grandpierre V., Nassrallah F., Potter B.K., Fitzpatrick E.M., Thomas R., Taylor J., Sikora L. (2019). Examining cultural competence in paediatric hearing loss services: A survey. *Deafness & Education International*, 21(4), 174-194. doi: 10.1080/14643154.2019.1589075.
- The Truth and Reconciliation Commission of Canada: Health-related recommendations* [PDF]. (2016). HealthCareCAN.
- Hendson L., & Reis M.D., Nicholas D.B. (2015). Health care providers' perspectives of providing culturally competent care in the NICU. *Journal of Obstetric, Gynecologic, & Neonatal Nursing: Clinical Scholarship for the Care of Women, Childbearing Families, & Newborns*, 44(1), 17-27. doi: 10.1111/1552-6909.12524.
- Hossain, M.B., Phillips, J.F., Pence, B. (2007). The effect of women's status on infant and child mortality in four rural areas of Bangladesh. *Journal of Biosocial Science*, 39(3), 355-366. doi: 10.1017/S002193200600143X
- Ihara, E. (2004). *Cultural competence in health care: Is it important for people with chronic conditions?* (Ser. 5). Washington, D.C., WA: Center on an Aging Society.
- Jones C.P., Truman B.I., Elam-Evans L.D., et al. (2008). Using "socially assigned race" to probe White advantages in health status. *Ethnicity & Disease*, 18(4), 496-504.
- Kelly Y., Becares L., Nazroo J. (2012). Associations between maternal experiences of racism and early child health and development: Findings from the UK Millennium Cohort Study. *Journal of Epidemiology and Community Health*, 67, 35-41. doi:10.1136/jech-2011-200814.

- Ladha R., & Neiterman, E. (2021). Shades of care: Understanding the needs of racially and ethnically diverse patients, their families, and health care providers in North America. *Journal of Child Health Care*, 1-17. doi: 10.1177/13674935211041863
- Leininger, M. M. (1985). Transcultural care diversity and universality: a theory of nursing. *Nursing & Health Sciences*, 6(4), 208-12.
- Macdonald M.E., Carnevale F.A., Razack S. (2007). Understanding what residents want and what residents need: The challenge of cultural training in paediatrics. *Medical Teacher*, 29(5), 444-451. doi: 10.1080/01421590701509639.
- Mackian, S., Bedri, N., & Lovel, H. (2004). Up the garden path and over the edge: Where might health-seeking behaviour take us? *Health Policy and Planning*, 19(3), 137-146.
doi:10.1093/heapol/czh017.
- Mahabir, D.F., O'Campo, P., Lofters, A., Shankardass, K., Salmon, C., Muntaner, C. (2021). Experiences of everyday racism in Toronto's healthcare system: A concept mapping study. *International Journal for Equity in Health*, 20(74), 1-15. doi: 10.1186/s12939-021-01410-9.
- Marks, D. F., & Yardley, L. (2004). Qualitative Data Collection: Interviews and Focus Groups. *Research Methods for Clinical and Health Psychology*. doi:10.4135/9781849209793.n3.
- Mays V.M., Cochran S.D., Barnes N.W. (2014). Race, Race-Based Discrimination, and Health Outcomes Among African Americans. *Annual Review of Psychology*, 58, 201-225.
doi:10.1146/annurev.psych.57.102904.190212.
- McIntosh, P. (1989). *White Privilege: Unpacking the Invisible Knapsack* [PDF]. Peace and Freedom.

- Murry V.M.B., Smith E.P., Hill N.E. (2001) Race, ethnicity, and culture in studies of families in context. *Journal of Marriage and Family*, 63(4), 911-914. doi: 10.1111/j.1741-3737.2001.00911.x.
- Ng-See-Quan K. (2013). *Racialized and Immigrant Women in Cities* [PDF]. Women and Urban Environments. 1-7.
- Nyqvist, M. B., & Jayachandran, S. (2017). Mothers Care More, But Fathers Decide: Educating Parents about Child Health in Uganda. *American Economic Review*, 107(5), 496-500. doi:10.1257/aer.p20171103.
- Racial Discrimination* [PDF]. (2012). Ontario Human Rights Commission.
- Oppenheimer, G.M. (2001). Paradigm lost: race, ethnicity, and the search for a new population taxonomy. *American Journal of Public Health*, 91(7), 1049-55. doi: 10.2105/ajph.91.7.1049.
- Pachter, L.M., Coll, C.G. (2009). Racism and Child Health: A Review of the Literature and Future Directions. *Journal of Developmental & Behavioral Paediatrics*, 30, 255-63. doi:10.1097/dbp.0b013e3181a7ed5a.
- Pollock, G., Newbold, B., Lafrenière, G., & Edge, S. (2015). *Perceptions of discrimination in health services experienced by immigrant minorities in Ontario* [PDF]. Citizenship and Immigration Canada.
- Priest, N., Slopen, N., Woolford, S., Philip, J.T., Singer, D., Kauffman, A.D., et al. (2018). Stereotyping across intersections of race and age: Racial stereotyping among White adults working with children. *Plos One*, 13. doi:10.1371/journal.pone.0201696.
- Rahman, M. S. (2016). The Advantages and Disadvantages of Using Qualitative and Quantitative Approaches and Methods in Language “Testing and Assessment” Research:

- A Literature Review. *Journal of Education and Learning*, 6(1), 102.
doi:10.5539/jel.v6n1p102.
- Riera, A., Walker, D.M. The impact of race and ethnicity on care in the paediatric emergency department. (2010). *Current Opinion in Paediatrics*, 22, 284-289.
doi:10.1097/mop.0b013e32833973a5.
- Roth, W.D. (2010). Racial mismatch: The divergence between form and function in data for monitoring racial discrimination of Hispanics. *Social Science Quarterly*, 91(5), 1288-1311.
- Sawyer, L. M. (1999). Engaged Mothering: The Transition to Motherhood for a Group of African American Women. *Journal of Transcultural Nursing*, 10(1), 14-21. doi: 10.1177/104365969901000110
- Seid, M., Stevens, G.D., Varni, J.W. (2003). Parents Perceptions of Paediatric Primary Care Quality: Effects of Race/Ethnicity, Language, and Access. *Health Services Research*, 38,1009-1032. doi:10.1111/1475-6773.00160.
- Squire, C. (2008, February). *ESRC National Centre for Research Methods Review Paper* [PDF]. National Centre for Research Methods.
- Squires, B., Moran, K., Churchill, J. (2020, Sept 21). Ontario's kids are back to school, let's get them back to good health. *Toronto Star*.
<https://www.thestar.com/opinion/contributors/2020/09/21/ontarios-kids-are-back-to-school-lets-get-them-back-to-good-health.html>
- Tolera, H., Gebre-Egziabher, T., & Kloos, H. (2020). Using Andersen's behavioral model of health care utilization in a decentralized program to examine the use of antenatal care in rural western Ethiopia. *Plos One*, 15(1). doi:10.1371/journal.pone.0228282.

- Van Enk, J. G. (2002). *Determinants of use of health care services in childhood: The literature*. Dissertation Abstracts. Rijksuniversiteit Groningen, The Netherlands, May 15th.
- Vingilis, E., Wade, T., & Seeley, J. (2007). Predictors of adolescent health care utilization. *Journal of Adolescence*, 30(5), 773-800. doi:10.1016/j.adolescence.2006.10.001.
- Wright, A.L., Jack, S.M., Ballantyne, M, Gabel, C., Bomberry, R., Wahoush, O. (2019). Indigenous mothers' experiences of using primary care in Hamilton, Ontario, for their infants. *International Journal of Qualitative Studies on Health and Well-Being*, 14. doi:10.1080/17482631.2019.1600940.
- Young, N.L., Wabano, M.J., Blight, S., et al. (2017). Relevance of the aboriginal children's health and well-being measure beyond Wiikwemkoong. *Rural Remote Health*, 17(2), 1-10. doi: 10.22605/rrh3941.
- Zinn, M. B., & Dill, B. T. (1996). Theorizing Difference from Multiracial Feminism. *Feminist Studies*, 22(2), 321. doi:10.2307/3178416.

APPENDIX A: RECRUITMENT FLYER

This study has been reviewed by, and received ethics clearance through
a University of Waterloo Research Ethics Committee (#42608)



CALLING FOR RESEARCH VOLUNTEERS!

Shades of Care: Understanding how BIPOC* mothers and children experience pediatric care in Ontario, Canada

*Black, Indigenous and People of Colour

What can you expect as a participant?

- A 45-60 minute interview to share you and your child's experiences with pediatric care in Ontario, Canada
- You will also be asked about how you feel your child's needs must be met in order to feel seen & supported within the healthcare system

Who can participate in this study?

- (1) BIPOC mothers who have required pediatric care for their child(ren) between the ages of 0-5 years **and**
- (2) Have resided in Ontario for at least 6 months

For more information about this study, please contact:

Raisa Ladha

School of Public Health and Health Systems,
Faculty of Applied Health Sciences at

E-mail: rladha@uwaterloo.ca



www.shadesofcarestudy.com

APPENDIX B: PARTICIPANT DEMOGRAPHICS

**The information presented in the table below is communicated using the same language that participants shared during their respective interviews.*

Participant 1:	<p>Age: 30 Number of children: 1 daughter (2 years old) and pregnant Race/ethnic background (mother): Mixed – Dad is Jamaican/Cuban, mom is Chinese/Portuguese Race/ethnic background (father): White Immigration status: Canadian citizen (Canadian-born) Marital status: Married # of People living in household: 3 Highest level of education (mother): PhD student Employment status (mother): Maternity leave Highest level of education (father): PhD Employment status (father): Full-time Current family income: ~ \$125,000 per year</p>
Participant 2:	<p>Age: 28 Number of children: 1 daughter (8 years old) Race/ethnic background (mother): Sudanese Race/ethnic background (father): Sudanese Immigration status: Canadian citizen Marital status: Married # of People living in household: 3 Highest level of education (mother): College student Employment status (mother): Currently stay-at-home mom Highest level of education (father): College diploma Employment status (father): Full-time Current family income: Middle income</p>
Participant 3:	<p>Age: 49 Number of children: 4 sons (University age, Grade 12, Grade 8, Grade 1) Race/ethnic background (mother): Sudanese Race/ethnic background (father): Sudanese Immigration status: Canadian citizen Marital status: Married # of People living in household: 5 (husband is not living at home currently) Highest level of education (mother): Bachelor’s degree Employment status (mother): Full-time Highest level of education (father): Bachelor’s degree Employment status (father): Full-time Current family income: Low-middle income</p>
Participant 4:	<p>Age: 32 Number of children: 1 Son (4 years old) Race/ethnic background (mother): Half Chinese/Half Caucasian Race/ethnic background (father): Caucasian</p>

	<p>Immigration status: Canadian citizen (Canadian-born) Marital status: Married # of People living in household: 3 Highest level of education (mother): Masters Employment status (mother): Full-time Highest level of education (father): College diploma Employment status (father): Full-time Current family income: ~ 160,000 per year</p>
Participant 5:	<p>Age: 44 Number of children: 2 sons (11 years old, 9 years old) Race/ethnic background (mother): Togolese Race/ethnic background (father): Togolese Immigration status: Canadian citizen Marital status: Married # of People living in household: 4 Highest level of education (mother): Graduate (PSW) Employment status (mother): Part-time Highest level of education (father): College diploma (electricity, car) Employment status (father): Full-time Current family income: Undeclared</p>
Participant 6	<p>Age: 30 Number of children: 1 son (13 months) Race/ethnic background (mother): Mom is Trinidadian Indian, Dad is Guyanese/Portuguese Race/ethnic background (father): Mom is Trinidadian Chinese, Dad is Jamaican Chinese Immigration status: Canadian citizen (Canadian-born) Marital status: Married # of People living in household: 3 Highest level of education (mother): Bachelors Employment status (mother): Full-time Highest level of education (father): College diploma Employment status (father): On parental leave Current family income: Middle income</p>
Participant 7:	<p>Age: 38 Number of children: 1 Daughter (6 years old) Race/ethnic background (mother): South Asian (Bengali) Race/ethnic background (father): South Asian (Bengali) Immigration status: International student Marital status: Divorced # of People living in household: 2 Highest level of education (mother): Masters, PhD candidate Employment status (mother): Part-time Highest level of education (father): N/A Employment status (father): N/A Current family income: Undeclared</p>

Participant 8:	<p>Age: 34 Number of children: 1 Son (2.5 years old) Race/ethnic background (mother): Tamil (Sri Lankan) Race/ethnic background (father): Tamil (Sri Lankan) Immigration status: Canadian citizen Marital status: Married # of People living in household: 3 Highest level of education (mother): Masters, PhD candidate Employment status (mother): Part-time Highest level of education (father): Bachelors Employment status (father): Full-time Current family income: Moderate</p>
Participant 9:	<p>Age: 42 Number of children: 1 Daughter (5 months) Race/ethnic background (mother): Black (Caribbean) Race/ethnic background (father): N/A Immigration status: Canadian citizen Marital status: Single (used sperm donor) # of People living in household: 2 Highest level of education (mother): College Employment status (mother): Not currently (Independent contractor) Highest level of education (father): N/A Employment status (father): N/A Current family income: \$80,000</p>
Participant 10:	<p>Age: 38 Number of children: 2 Sons (9 years old and 3 months old) Race/ethnic background (mother): Korean (East Asian) Race/ethnic background (father): Korean (East Asian) Immigration status: Permanent resident Marital status: Married # of People living in household: 4 Highest level of education (mother): Masters (MSc) Employment status (mother): Homemaker Highest level of education (father): Masters Employment status (father): Full-time Current family income: Moderate</p>
Participant 11:	<p>Age: 31 Number of children: 2 Daughters (10 years old and 9 months old) Race/ethnic background (mother): Cameroonian Race/ethnic background (father): Cameroonian Immigration status: Permanent resident Marital status: Single # of People living in household: 2 (participant and youngest daughter) Highest level of education (mother): Diploma Employment status (mother): Maternity leave Highest level of education (father): N/A Employment status (father): N/A Current family income: Middle-income</p>

Participant 12:	<p>Age: 34 Number of children: 1 Daughter (4 years old) Race/ethnic background (mother): African (Ugandan) Race/ethnic background (father): African (Ugandan) Immigration status: Permanent resident Marital status: Married # of People living in household: 2 (participant and youngest daughter) Highest level of education (mother): PhD candidate Employment status (mother): N/A Highest level of education (father): Bachelor's Employment status (father): N/A Current family income: Low-income in Canada, but high-income in Uganda</p>
Participant 13:	<p>Age: Early 40s Number of children: 2 Daughters (11 years old and 7 years old) Race/ethnic background (mother): Indo-Persian Race/ethnic background (father): Indo-Persian Immigration status: Canadian citizen Marital status: Married # of People living in household: 4 Highest level of education (mother): Bachelors Employment status (mother): Full-time Highest level of education (father): Masters Employment status (father): Full-time Current family income: Combined top 1% (Canada)</p>
Participant 14:	<p>Age: 38 Number of children: 2 Sons (5 years old and 8 years old) Race/ethnic background (mother): Middle Eastern/Persian (Iranian) Race/ethnic background (father): Arab (Jordanian) Immigration status: Canadian citizen Marital status: Married # of People living in household: 4 Highest level of education (mother): MD, PhD candidate Employment status (mother): Part-time Highest level of education (father): PhD Employment status (father): Full-time Current family income: Middle-income</p>

APPENDIX C: INTERVIEW GUIDE

Research Aims:	Interview questions and prompts:	How interview questions achieve aims:
<p>(1) Develop a better understanding of the experiences of BIPOC mothers and their children who have required paediatric care in Ontario</p>	<p>a) Why have you required support from the healthcare system? What were you looking for? b) Does your child have a paediatrician or see a family doctor? c) Can you tell me about your most memorable experience seeking paediatric care for your child? Walk me through the whole process.</p> <p><u>Prompts:</u></p> <p>i. <i>How did you feel during your interaction(s) with the healthcare system?</i> ii. <i>How did you feel after your interaction(s) with the healthcare system?</i> iii. <i>How do you feel you and your child's needs have been met in your interactions with the healthcare system?</i></p>	<ul style="list-style-type: none"> ▪ Assessing the prevalence of BIPOC mothers acquiring care for their children through the healthcare system ▪ Understanding the motivations of BIPOC mothers in doing so and how they feel their interactions aided in affecting the health outcomes of their children
<p>(2) Conceptualize the provider-patient relationship from the perspective of BIPOC mothers</p>	<p>d) Were you able to access and meet with a paediatric healthcare provider for the situation you just described? e) (If yes) What were your interactions with them like? f) How do you feel when you interact with your paediatrician or family doctor?</p> <p><u>Prompts:</u></p> <p>i. <i>How do you feel you are able to share your concerns with your paediatrician or family doctor?</i> ii. <i>What about you and your child do you wish, if anything, that your paediatrician or family doctor would understand?</i></p>	<ul style="list-style-type: none"> ▪ Understanding the views of BIPOC mothers with regards to health care personnel and the healthcare system itself ▪ Understanding the nature of the provider-patient relationship from the perspective of BIPOC mothers, as well as the space they occupy within it
<p>(3) Clarify the needs of BIPOC mothers in acquiring positive experiences with paediatric health care services</p>	<p>g) In that moment, what did you and your child need from your healthcare provider? h) How do you feel those needs were met?</p> <p><u>Prompts:</u></p> <p>i. <i>Do you feel like your voice has been heard in your interactions with the healthcare system?</i> ii. <i>How do you feel your paediatrician or family doctor understands your needs?</i></p>	<ul style="list-style-type: none"> ▪ Assessing how BIPOC mothers feel their needs and their child's needs have been met by the healthcare system ▪ Understanding what BIPOC mothers think must be done in order to better satisfy these needs, as well as what BIPOC mothers believe would be conducive of comfort and safety for them and their children

	<p>iii. <i>How do you find the experiences of other families of your same background to be?</i></p> <p>iv. <i>What do you think could be done differently?</i></p> <p>v. <i>What resources or services might be helpful regarding your child's health?</i></p> <p>vi. <i>What do you look for in a health care provider or service to make you and your child feel comfortable and safe?</i></p>	
<p>(4) Develop recommendations on how paediatric health care providers can enable improved healthcare experiences for BIPOC mothers and children at the point of care</p>	<p>i) How would you define “health” for your child?</p> <p>j) What would your child need for you to feel they are “healthy?”</p> <p><u>Prompts:</u></p> <p>i. <i>What health concerns do you have, if any, about your child?</i></p> <p>ii. <i>What health concerns, if any, have made you require healthcare for your child?</i></p> <p>iii. <i>How do you feel this interaction with the healthcare system affected your child's health?</i></p>	<ul style="list-style-type: none"> ▪ Understanding BIPOC mothers’ conceptualizations of “health” and what they believe it looks like for their child ▪ Understanding the nature of health concerns among BIPOC mothers regarding their children, as well as how these concerns are addressed by the healthcare system

APPENDIX D: TAKEAWAYS & STRATEGIES FOR PROVIDERS

Shades of care: Understanding how BIPOC mothers and children experience paediatric care in Ontario, Canada

Amplifying the participant's voice:

01 - Cultural Mothering



How do mothers of colour **define "health"** for their children?

The narratives shared by those interviewed reveal maternal concern for their children's wellbeing, **across dimensions** (i.e. physically, mentally, emotionally and spiritually), as well as temporally - in the short and long term.



"Health" as being beyond individual control

ex. A blessing from God or in relation to the communities they reside in.



"Health" as strong sense of belonging and identity

ex. Being welcome & able to thrive, or having closeness to cultural roots.



"Health" as safety in their environment

ex. Proximity to networks & supports, or access to physical resources.



"Health" as feelings of happiness and love

ex. Moments of joy or being surrounded by loved ones (family, friends, e.t.c.)



What are their **experiences** of mothering?

- Experiences vary based on factors such as culture, immigration & family structure.
- Mothers feel that their children influence their lives (i.e. their health and happiness) just as much as they shape their children's.
- "Home" is understood to be a place where their children can thrive.
- Care coordination can be multi-generational.



How do mothers of colour perceive their **sense of belonging** in the healthcare system?

The realities experienced suggest that **racialized experiences exist in clinical practice, as well as in the ways that we understand and share knowledge**. This understanding of knowledge goes on to shape societal health expectations such as developmental milestones.

- **Connection and belonging** can be hard to come by within systems that were not initially designed with inclusion for all in mind.
- Participants felt as though regardless of the credentials or positions they hold, they are a mother of colour first and foremost, and that this **awareness accompanies them** through their healthcare interactions.
- Mothers of colour feel an **increased sense of responsibility** to oversee their children's experiences of care. This includes:



Closely **monitoring** the care received



Actively **advocating** on behalf of children



Discovering pathways to **secure** wellbeing

Applications for clinical practice:

02 - Provider-patient interactions

What has become astoundingly clear overall is the **immense power that healthcare providers hold in shaping a patient's experiences and perceptions** of the healthcare system. Just one compassionate doctor who takes the time to listen and provide **genuine care** can provide **enormous amounts of relief and comfort** to those service users who had not previously had the most favourable experiences.



Tip #1:
Welcome mothers into your **shared** space.

- **Tone and demeanour** were highlighted as key determinants of patients' experiences.
- It is clear that patients and their families are very **receptive to the energy** that healthcare providers are exhibiting towards them.
- Both positive and negative experiences have the **potential to shift** participants' existing perceptions of the healthcare system.

"...People here are not just tourists here or something, like a number... you know? ...People here are the patients. They are not just numbers. They have feelings, emotions, and sometimes they have some difficulties..."

– Participant 14

"...I feel like if you're going to be a frontline nurse, or a doctor... you do need to have like a Masters in that... like, you need to know how to act and like change your tune for every family so it's always positive, it's always helpful... I think, like, training on bedside manner is... there's never too much. You can never have too much of that..."

– Participant 6



Tip #2:
Seek to **understand** mothers' perspectives and **amplify** their voices.

- Positive experiences within the provider-patient relationship tended to be as a result of individual providers' **efforts and commitment to patients.**
- When recounting positive experiences, participants highlighted the following as contributing factors:



Respect



Communication



Autonomy



Awareness



Compassion

*“I think it's kind of... middle ground? You know, sometimes I've definitely felt like we're heard and sometimes, I felt like there wasn't really enough time to even feel like we're heard in the appointment. And sometimes it's just, I don't think we ourselves have felt like we had the voice to advocate for it. ... Which is, sometimes I think back and it's a little bit scary, because I would like to think that I can advocate for, you know, myself or my son... And so sometimes that power... like healthcare provider **versus** patient role is still present, even when you're the parent of the patient.”*

– Participant 8



Tip #3:

Encourage mothers to **ask questions** and take initiative to **collaborate** with them.

- **Positive provider-patient interactions ultimately have the power to orient patients on a path of wellness, as well as to support parents in laying a strong foundation for their children’s future.**
- This is of particular importance in paediatric care as BIPOC mothers feel a **duty to advocate** for and work towards optimal states of wellness for their children.

- In efforts to ensure a comfortable experience for patients and their mothers, **allow mothers to ask questions** so they can better understand providers' backgrounds and perspectives, care plans being discussed, e.t.c.

“We now know health isn’t just nutrition... there’s an entire ecosystem we’re working with here as they grow and develop.”

– Participant 13

Directions for an equitable future:

03 - Communities of Support



What is the **significance of "community"** for mothers of colour?

Communities of support **allow families to not only settle** in new environments, whether to a city or Canada as a whole, **but also to thrive**. They **allow families to find comfort and solace** in the company of those who share similar identities or experiences.

- Mothers viewed the creation and maintenance of communities of support as their **maternal responsibility** in supporting their children's wellness.
- **"Community" means and looks differently for mothers**. Although family was commonly at its core, community expanded to include: friends, neighbours, peers, colleagues, and service providers.



Friends



Neighbours



Peers



Service providers



Colleagues



How can we use communities of support to work towards **holistic wellness**?

- Communities of support serve as an example of the **vast potential for our future** when medicine is magnified using a **public health lens**.
- They tell a story of community members eager to play a role in their community's wellness, and remind us that community members can be **effectively mobilized for sustainable change**.

“The whole time I thought of all the advantages I might have over someone else... I drove there every day, I had the means to pay for parking at a hospital every day. Those advantages weren't lost on me, or the fact that my whole my whole community is here... my mom, my dad, my siblings, my friends are all within half an hour of me... where you get a lot of people... I met couples that were some hours away and they had to stay in the city. Or I met a couple that lived in the city but they had no family in Canada. They recently immigrated here. So I think that Parent Mentor Program probably is the best thing? If they had more of those like paired with a social worker, because I thought of all the ways where I didn't feel as though I needed it as much. I didn't need it as much, but I did appreciate it. I had a doula and she came once or twice and was like you seem to have it under control... of course I do! My mom's here like every day, my older sister's here a couple times a week... like I have so much support already.”

- Participant 9



How can we **reposition** HCPs as a part of communities of support?

- Ideally, healthcare providers would be a **central part of these communities**, as opposed to existing on the peripheries.
- Participants discussed how healthcare either is or should be **personal**. Providers and patients are both community members **collaborating** with one another.

"My daughter fell one time on the playground from the swing... and she had, like, bleeding from the mouth... so I decided to take her to the walk in clinic... the doctor there was leaving, like he's actually locking up, right? So when I was, like, with the baby... he actually opened... I don't think he's even supposed to do that. But he opened and he checked her to make sure and then he told me no, there's no damage... and so he gave a freezie. Even he's like, if she's still bad tomorrow, you can just come here. He was like if you don't have insurance, because that time I wasn't sure it was updated... he actually gave me his number and said like if I can't pay, then it would go to his account."

- Participant 7

- Within the context of pediatrics, while providers occupy the role of medical **knowledge sharers**, it is the mothers who ultimately hold the most knowledge about their child, the patient.
- Participants frequently discussed how they feel a **personal responsibility** in ensuring a good quality of care for their children, as well as how they would like to see a **levelling** of these responsibilities whereby this **load is shared** between parent and provider.

*“For many cultures, the healthcare provider... they go into the community, to provide information, to provide support... whatever it might be. The challenge here is you have to go **into** a hospital, into a clinic, whatever it is, to get the information you need... and for foreigners, especially maybe from Africa or Asia, even South America, we go when it's **too late**... simply because culturally back home, you only go to the hospital when you feel pain... So there needs to be a more community-centered way of having this information trickle down to these parents. So what services are they accessing more of? ...Are they going to the YMCA, so their kids can play? ...Maybe that's a good place to provide this information... because that's where they are, and you found them in an environment that they're more likely to frequent... How can we get those resources **there**?”*

– Participant 12

- There is much to be taken from the **courage and commitment** of mothers to build and maintain communities of support, in **hopes of protecting and uplifting** those who come after them.
- Just as families seek support from the healthcare system and appreciate the expertise of HCPs, the voices of these mothers and children hold **great value** in understanding the current state of our systems and imagining best, equitable practices which **inspire a brighter future for paediatric care.**

