GROW THROUGH WHAT YOU GO THROUGH: A QUALITATIVE DESCRIPTION OF SOUTH ASIAN IMMIGRANT MOTHERS' NICU EXPERIENCES

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A Thesis Submitted to the School of Graduate Studies in Partial Fulfilment of the Requirements for the Degree Master of Science in Nursing

McMaster University MASTER OF SCIENCE IN NURSING (2024) Hamilton, Ontario (Nursing)

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NUMBER OF PAGES: 121

LAY ABSTRACT

Existing research offers insights into the general challenges and distress often associated with mothers' experiences in the NICU. However, there is little evidence to understand the specific experiences of South Asian immigrant mothers within this context. The objective of this thesis is to describe and understand the experiences in the NICU reported by this population. Employing a qualitative description methodology, this study engaged four eligible participants. Data collection entailed semi-structured interviews alongside a demographic questionnaire. Employing qualitative content analysis, four overarching themes were identified: (1) Seeking to Understand, (2) The Impact of South Asian Culture on the NICU Experience, (3) Becoming a Mother One Step at a Time, and (4) Circle of Care.

ABSTRACT

Background: Experiences in the NICU can be profoundly challenging for parents, particularly for populations such as immigrants, underscoring the essential need for comprehensive support during hospitalization. South Asian immigrants constitute a significant proportion, approximately 25%, of Canada's visible minority population. South Asian immigrant women face unique adversities linked to gender role expectations, encompassing responsibilities such as childcare, cooking, and cleaning. Their access to vital health services may be hindered by these responsibilities, which could limit their integration into the new country. Compounded by unfavourable social determinants of health (SDoH), these challenges can exacerbate issues related to inadequate prenatal care, education, and nutrition, all of which are predictors of adverse maternal and neonatal health outcomes. While existing studies offer insights into the general experiences of mothers in the NICU, there is a notable gap in understanding the specific experiences of South Asian immigrant women. This study aims to investigate the experiences of South Asian immigrant mothers whose infants currently are in the NICU or have been admitted within the past year.

Methods: Employing a qualitative descriptive approach, we recruited four participants and employed data collection methods including one-on-one semi-structured interviews, a demographic questionnaire, and participant observation. Qualitative content analysis was completed for data analysis.

Findings: Four overarching themes were identified from the semi-structured interviews: (1) Seeking to Understand, (2) The Impact of South Asian Culture on the NICU Experience, (3) Becoming a Mother One Step at a Time, and (4) Circle of Care.

Implications: This study addresses the gap in NICU research for South Asian immigrant women, serving as a foundational platform for future nursing research and advancements in practice. It highlights the importance of clear communication and preparation for discharge delays to alleviate parental concerns. Moreover, it sheds light on culturally sensitive care practices and encourages further exploration of the impact of South Asian culture on hospital experiences. The study's unique sample offers insights into the specific needs of this demographic, potentially benefiting other ethno-racial immigrant groups.

ACKNOWLEDGMENTS

First and foremost, I wish to extend my gratitude to my supervisor, Dr. Olive Wahoush. Your guidance and support were instrumental as I navigated my first research study. You were always available when I needed your help, even on short notice and you brought so much positivity to each conversation. Additionally, you highlighted the significance of taking breaks, asking questions, and prioritizing my own health and well-being. Thank you so much for everything. Moreover, I wish to express my sincere gratitude to Dr. Michelle Butt and Dr. Ruth Chen for their invaluable support and encouragement throughout this journey. Their guidance, time, and uplifting words were instrumental in helping me reach the finish line. Dr. Butt's meticulous feedback has significantly contributed to my academic development, for which I am truly grateful. I also would like to extend a special thanks to Dr. Nancy Carter, who served not only as an exceptional professor but also as a consistent and dependable resource and support. Drs. Carter, Wahoush, Butt, and Chen have consistently served as mentors throughout my entire graduate journey, and for that, I am thankful. I would also like to sincerely thank my participants. Thank you for feeling comfortable enough to share your stories. I am hopeful that this research will help shape the lives of future South Asian immigrant mothers in the NICU.

To my parents, Ajit Singh Deol, and Kamaljit Kaur Deol. I don’t know what I would do without you. Dad, thank you for teaching me the importance of education. When I was little, you told me teachers are like “Guru’s”, and the impact they have is invaluable. Now, I hope one day I can make you proud as a teacher myself. Mom, without you this thesis would not exist. You are my inspiration, my world, my rock. Thank you for showcasing what hard work looks like. I hope my research on South Asian immigrant women reflects my deep appreciation for you and your consistent support, for our entire family. I love you both so much. I hope I’ve made you proud.

To my sisters, Aran, Dilpreet, and Pawan, words can never fully express the depth of my love for all of you and the gratitude I feel for sharing this experience together. Aran, you have shown me what strength and perseverance look like. That, if I am patient and dedicated, I will see the fruits of my labour. Thank you for supporting me through the highs and lows of my entire nursing career. You have been my anchor, and I always know I can rely on you. Dilpreet, your support means the world to me. You've stood by me through countless essays, assignments, and sleepless nights, and your presence alone has made me feel accompanied throughout this entire journey. You have celebrated my every milestone, big or small, and I will always cherish that. Pawan, I have always looked up to you—both literally and figuratively. You've consistently been a few steps ahead, making everything seem effortless, even though I know it requires immense effort. I feel grateful to have you as my best friend and to be able to navigate our graduate journeys side by side. I love all of you so much. Thank you so much for everything.

To my dear Rohit, I extend my heartfelt gratitude for never losing faith in me. Your patience during moments I thought were insurmountable is deeply appreciated. Thank you for telling me that I can do hard things. Your unwavering support through every difficulty and your reminders of my potential mean the world to me. The pride with which you speak about me to your friends and family is something I hope to continually live up to. This journey and the next, is dedicated to our shared future.

Finally, to my beloved late grandfather, Gurdev Singh Dhaliwal, I miss you. Every now and then, I reflect on my childhood and the overwhelming influence you had during the first and favourite decade of my life. A part of me feels like you've been watching how I got to where I am today, and I hope I have made you proud, Cha Cha ji.

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DECLARATION OF ACADEMIC ACHIEVEMENT

I, Rosie Deol, declare that this work is solely my creation, and in cases where it is not, proper acknowledgment of the original source has been provided following the guidelines of APA 7th edition. This thesis fulfills the requirements for a Master of Science degree at McMaster University. I, Rosie Deol, am the primary author, with co-authors including my thesis supervisor, Dr. Olive Wahoush, and committee members, Dr. Ruth Chen, and Dr. Michelle Butt. In my capacity as the first author, I directed the construction of the research question and purpose, design and analysis of the study, interpretation of findings, and the overall composition of this thesis. The collaborative efforts of all co-authors were instrumental in revising and approving the final version of this thesis.

Date: March 11, 2024

MSc Thesis: A Qualitative Description of South-Asian Immigrant Mothers' NICU Experiences

Signature: Rosie Deol

DEFINITION OF TERMS

Adult Women: Adult women 18 to 40 years old

Immigrant: Permanent residents who were born outside of the country and moved to Canada via the immigration process (Statistics Canada, 2017b).

South Asian Countries: India, Bangladesh, the Maldives, Nepal, Sri Lanka, Pakistan, or Bhutan

LIST OF ABBREVIATIONS

FCC: Family Centered Care

HHS: Hamilton Health Sciences

HSC: The Hospital for Sick Children (SickKids)

NICU: Neonatal Intensive Care Unit

PICC: Peripherally Inserted Central Catheter

PMHD: Perinatal Mental Health Disorder

QD: Qualitative Description

SA: South Asian

SDoH: Social Determinants of Health

WHO: World Health Organization

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CHAPTER ONE: INTRODUCTION

Background

The 2021 census revealed that South Asians constitute the largest visible minority group in Canada, accounting for 7.1% of the overall visible minority population, which corresponds to approximately 2.6 million people (Statistics Canada, 2023). According to the Government of Canada, a visible minority can be defined as a person who is non-Caucasian or non-white in colour (Statistics Canada, 2021a). Among the South Asian population are Canadian-born and immigrant South Asians. Immigrants are residents who were born outside of the country and moved to Canada via the immigration process (Statistics Canada, 2017b). Immigrants constitute 21.9% of the population in Canada, and by 2036, the proportion is projected to rise to almost 30% (Statistics Canada, 2017b). In general, newly arrived immigrants are healthier than the average Canadian-born person; however, as time passes, this advantage diminishes, and their health starts to resemble that of the native-born population of Canada (Setia et al., 2011; Zoua et al., 2015). This is referred to as the healthy immigrant effect (Setia et al., 2011; Zoua et al., 2015). A significant contributing factor to the decline in health status is poor access to healthcare as an immigrant (Setia et al., 2011; Zoua et al., 2015). Upon settlement in Canada, immigrants face challenges such as acculturative stress and navigating a new healthcare system (Chang, 2018; Setia et al., 2011). This is particularly true for South Asian immigrant women as they come from different healthcare systems and are more likely to face challenges due to their traditional gender role expectations related to childcare, cooking, and cleaning responsibilities (Ahmad et al., 2004; Setia et al., 2011; Zoua et al., 2015). As a result, this population may not have time to access health services and thus, potentially experience more difficulty integrating into their new country (Ahmad et al., 2004; Setia et al., 2011; Zoua et al., 2015). These issues

may be worsened by poor social determinants of health (SDoH), to which immigrants are particularly vulnerable (Chang, 2018; Setia et al., 2011).

The World Health Organization (WHO; WHO, 2022) defines Social Determinants of Health (SDoH) as elements influencing the health and well-being of individuals. Factors such as poverty, instability in food and housing, limited educational proficiency, and challenges in accessing healthcare consistently have adverse effects on the immigrant population (Chang, 2018; Setia et al., 2011; WHO, 2022). Furthermore, immigrant groups encounter prejudice, marginalization, integration difficulties, and deportation fears (Chang, 2018). Additionally, suboptimal SDoH serve as predictors of unfavorable maternal and neonatal health outcomes, including insufficient prenatal care, educational gaps, and nutritional inadequacies (Cutland et al., 2017; WHO, 2022). These predictors often contribute to significant maternal and neonatal complications necessitating NICU admission (Cutland et al., 2017; Ilyes et al., 2022).

Furthermore, numerous developments in NICU medical care have improved outcomes for high-risk neonates born with life-threatening conditions (CCSO, 2022; American Academy of Pediatrics [AAP], 2012). A notable development is the division of NICU levels to offer NICU-specific thresholds and enhance the clarity of specialized neonatal care to better support the various complexities of critical diagnoses seen in newborns (CCSO, 2021).

In Ontario, there are 44 Level II NICUs and 8 Level III NICUs (CCSO, 2022). Each level corresponds to the population it serves (e.g., acute care criteria) and the availability of the necessary personnel, equipment, space, and technology (AAP, 2012; CCSO, 2021). To begin, Level II NICUs, further divided into Level IIA, IIB, and IIC, provide sub-specialty care (AAP, 2012; CCSO, 2021). Level IIA NICUs care for infants born at ≥ 34 weeks' gestation and weighing >1800 grams (CCSO, 2021). Next, Level IIB NICUs care for babies with a gestational

age of ≥32 weeks and a birth weight >1500 grams, as well as infants with a corrected age of ≥30 weeks (i.e., chronological age minus the number of weeks born prematurely) and a weight of >1200 grams who do not require ventilation or advanced treatment (CCSO, 2021). Subsequently, Level IIC NICUs provide care for newborns born at ≥30 weeks and a birth weight of >1200 grams and babies with a corrected age of ≥ 28 weeks and a weight of ≥ 1000 grams, stable on Continuous Positive Airway Pressure (CPAP) for 48 hours and do not require advanced treatment (CCSO, 2021). Beyond this, Level III NICUs provide long-term complex care and interventions for high-acuity neonatal patients of any gestational age or weight, including ventilation and on-site surgeries to manage unstable respiratory or cardiac complications (CCSO, 2021).

The human resource requirements within NICUs vary based on the level of NICU care and neonate acuity. Currently, it is advised that pediatricians in Level II NICUs take the position of medically responsible provider (MRP), while neonatologists assume this role in Level III NICUs (CCSO, 2021). MRPs are physicians who assume the responsibility to oversee, coordinate and direct a patient's care (Canadian Medical Protective Association [CMPA], 2019). NICU registered nurses, in addition to physicians, are an essential component of neonatal care at all NICU levels; however, the depth of clinical skills required varies for different NICU levels (CCSO, 2021; Mirlashari et al., 2016). For instance, in a Level III NICU, a registered nurse would need advanced knowledge and skills in managing a tracheostomy tube and maintaining airway patency (CCSO, 2021). However, this level of expertise would not be necessary for a registered nurse in a Level II NICU (CCSO, 2021).The interdisciplinary team may also include but are not limited to respiratory therapists, dieticians, lactation consultants, social workers, cardiologists, surgeons, pharmacists, and child-life specialists, depending on the circumstances

surrounding the patient (CCSO, 2021; Vergara & Bigsby, 2004). Given the significant assistance available in the NICU, transitioning from this environment, where mothers often receive extensive support, to their homes could pose challenges due to the absence of access to healthcare professionals (Spence et al., 2023).

While in the NICU, establishing a bond between mother and baby often involves physical interactions like skin-to-skin contact and breastfeeding, however such experiences may be constrained due to the complex health needs, diagnoses, and medical interventions administered by healthcare professionals (Palma et al., 2016; Klawetter et al., 2019; Pinar & Erbaba, 2020; Bigelow & Power, 2020). Such limitations can lead mothers to question their parenting abilities, fostering feelings of guilt that may adversely impact their psychological well-being (Palma et al., 2016; Anderson, 2017). Mothers in the NICU are particularly susceptible to post-traumatic stress, depression, and anxiety (Galbally et al., 2013; Palma et al., 2016; Anderson, 2017; Howard & Khalifeh, 2020). The ramifications of these mental health challenges extend beyond the mother, affecting neonatal physiological, psychological, and behavioral development into childhood (Ali et al., 2013; Caparros-Gonzalez et al., 2017; Anderson, 2017; Slomian et al., 2019). Considering the taxing and traumatic nature of NICU experiences for parents, it becomes imperative to delve deeper into the experiences of South Asian immigrant women, whose unique challenges, including acculturative stress, set their experiences apart and warrant investigation.

This qualitative descriptive research study seeks to describe and understand the experiences of South Asian immigrant women whose newborns have been hospitalized in a NICU within the last year. The presence of poor SDoH alongside institutional and systemic barriers at the health-system level, combined with individual and cultural values, underscores the need for further research in this area.

Review of the Literature

The literature review that follows intends to explore the existing evidence concerning crucial aspects of the current research study. Initially, the search strategy will be outlined, followed by an overview of the literature. Subsequently, a detailed examination will be conducted on the following topics: South Asian Immigrants, Preterm Birth in the NICU, Term Birth in the NICU, and Mothers' Perceptions in the NICU.

Search Strategy

To perform this comprehensive literature review, a systematic search was conducted across various databases, including Cumulative Index to Nursing Allied Health Literature (CINAHL), PubMed, Cochrane Library, JAMA Network, Google Scholar, Journal Storage (JSTOR), PsychInfo, and MEDLINE. Additionally, reference lists of identified articles were searched for relevant literature. The search terms encompassed a range of topics, such as Neonatal Intensive Care Unit experiences, mothering in a NICU, South Asian(s) mothers in the NICU, maternal and neonatal bond in a NICU, preterm birth in the NICU, common diagnoses in the NICU, and term neonates in the NICU. The term "AND" was employed to connect keywords in the search strategy, optimizing the retrieval of relevant literature. This search strategy was executed by the primary researcher.

Inclusion criteria for studies encompassed the following: a) peer-reviewed status, b) written in English, c) published between 2000-2024, d) exploration of various aspects of the NICU experience, including admission, transition for discharge, interactions with NICU personnel, and the overall NICU stay, and e) specific focus on the experiences of mothers in the NICU.

Overview of Literature Review

NICU experiences can prove overwhelming and stressful for mothers (Ionio et al., 2019; Lotterman et al., 2018; Nazari et al., 2020; Sanders & Hall, 2018; Vinall et al., 2018; Williams et al., 2021). Existing literature suggests that maternal engagement can serve as a coping strategy for NICU mothers (Ionio et al., 2019; Nazari et al., 2020). However, language barriers, which are common among immigrants in host nations, may introduce additional stressors when verbal communication is difficult with those who do not share the same language, further adding to the vulnerability of South Asian immigrant women. While some findings in existing literature may be applicable in other contexts, differences in healthcare systems among nations and contextual, cultural, and institutional disparities may limit their relevance. Therefore, given the significant influx of South Asian immigrants in Canada, along with their heightened risk of poor Social Determinants of Health (SDoH), cultural barriers, and general complications associated with newborns, further research is imperative to enhance neonatal and maternal outcomes within this demographic. Particularly noteworthy is the scarcity of research examining the experiences of South Asian immigrant women in the NICU. The study outlined in this thesis aims to address this gap by investigating the experiences of South Asian immigrant mothers in Canada within the NICU context.

South Asian Immigrants

South Asians in this study are defined as individuals born in India, Bangladesh, the Maldives, Nepal, Sri Lanka, Pakistan, or Bhutan (Statistics Canada, 2017b). In the late 19th century, several Sikhs from Punjab, India, arrived in British Columbia lured by economic opportunities in lumber, mining, railroad industries, and later agriculture (Tran et al., 2005; Government of Canada, 2022). This marked the beginning of South Asian immigration to

Canada (Government of Canada, 2022). A longitudinal survey of immigrants to Canada investigated the driving factors that influenced the South Asian community to migrate (Statistics Canada, 2003). The findings revealed that 55.4% of individuals decided to immigrate to Canada for a better quality of life (Statistics Canada, 2003). Nearly 40% of immigrants reported their motivation was to improve the future for their family, and 31% said their motivation was to be close to friends and family (Statistics Canada, 2003). The theme of familial significance is supported by Tran and colleagues (2005) in their findings from Statistics Canada's Ethnic Diversity Survey. Tran et al. (2005) claim that the South Asian community places a high value on adherence to cultural norms, social networks within cultural groups, and, most importantly, family interactions. Within South Asian communities, traditional gender roles dictate that men assume the role of household leaders, making final decisions and providing financial support, while women primarily fulfill the duties associated with motherhood and being a wife (Patel et al., 2012; Samuel, 2005). Despite taking pride in their roles as wives and mothers (Samuel, 2005), it remains uncertain whether this demographic is aware of the increased perinatal risks linked to their genetic predisposition (Talbani & Hasanali, 2002; Samuel, 2005). Research suggests that factors such as race and ethnicity, including those of South Asian women, have historically influenced maternal and neonatal outcomes, sometimes necessitating specialized care in neonatal intensive care units (NICUs) (Janevic, Zeitlan, & Auger, 2018; Kim et al., 2021; Zeng et al., 2021). For South Asian immigrant women, navigating a foreign healthcare system poses an additional challenge, particularly when confronted with the potential admission of their infant(s) to a NICU (Talbani & Hasanali, 2002; Samuel, 2005).

Preterm Birth in the NICU

Annually, 1 in every 10 babies worldwide is born premature (WHO; 2018; Liu et al., 2018; Barfield, 2018; Walani, 2020). This translates to approximately 15 million premature babies, 1 million of whom die as a result of preterm-birth-related complications (Barfield, 2018; Liu et al., 2018; Walani, 2020; WHO; 2018). From 2006 to 2007, the rates of preterm birth and small for gestational age (SGA) were approximately 8.1% and 8.3%, respectively, resulting in more than 54,000 live births with these diagnoses in Canada (Canadian Institute for Health Information [CIHI], 2009). Between 2000 and 2016, 19% of preterm neonates in Canada were of South Asian descent (Statistics Canada, 2022). South Asian immigrant women are more likely to experience preterm birth than Caucasians, which is the most prevalent diagnosis in the NICU and one of the main causes of infant death in Canada (Lee et al., 2020; Statistics Canada, 2022; Shepherd, 2012). Preterm birth is characterized as childbirth that occurs before 37 weeks of pregnancy (WHO, 2018; Center for Disease Control and Prevention [CDC], 2021). Across four studies, researchers underscore preterm birth predictors, encompassing: a) delivery indications (e.g., maternal or fetal distress, induced labour, cesarean section), b) spontaneous preterm labour with intact membranes (sPTB), and c) preterm premature rupture of membranes (PPROM), all of which are diagnoses warranting admission to the NICU (Barfield, 2018; Goldenberg et al., 2008; Frey & Klebanoff, 2016; Vogel et al., 2018;). The factors leading to preterm birth, as emphasized by the WHO (2024), may stem from a combination of various elements, such as chronic conditions, multiple pregnancies, insufficient prenatal care, or education, and, as previously mentioned, the impact of race and ethnicity. The WHO (2024) notes that the majority of preterm births take place in South Asia, underscoring the significance of examining the experiences of South Asian immigrant mothers in Canada.

Term Neonates in the NICU

Historically, the period between 37 and 42 weeks of pregnancy was considered a "term" pregnancy (The American College of Obstetricians and Gynecologists (ACOG), 2022). This classification assumed that the outcomes for newborns during this period were consistent and favourable (ACOG, 2022). However, to aid in discerning neonatal outcomes that varied depending on the precise timing of delivery within these 5 weeks of gestational age, the American College of Obstetricians and Gynecologists (ACOG) and the Society for Maternal-Fetal Medicine (SMFM) put forward additional classifications for the word "term". The classifications consist of the following: early term (37 weeks to 38 weeks and 6 days), full term (39 weeks to 40 weeks and 6 days), late-term (41 weeks to 41 weeks and 6 days), and finally, post-term (42 weeks and beyond; ACOG, 2022).

While NICUs are typically associated with the admission of preterm babies, it is important to acknowledge that term neonates also receive care in NICUs. Therefore, when conducting research in NICUs, it is crucial not to overlook this population, since there is a substantial amount of literature and statistics supporting their admission (Bassil et al., 2014; Govindaswamy et al., 2019; Mendoza & Lutz, 2023; Talisman et al., 2023).

In the 2021 Canadian Neonatal Network (CNN) annual report, 33 sites were evaluated across Canada and revealed that 15,760 neonates were born (CNN, 2021). Among these neonates, term (early term, full term, late-term, and post-term) newborns made up approximately 40% of the total number of neonates admitted to the NICU (CNN, 2021). Bassil et al. (2014) did a study to investigate the impact of preterm and term infants on Canadian NICUs. The researchers uncovered several significant discoveries, one of which centered on newborn mortality and short-term comorbidities based on the gestational age group (Bassil et al., 2014).

The variables that were investigated include mortality, pneumothorax, seizures, and hypoxic-ischemic encephalopathy (Bassil et al., 2014). The study conducted by Bassil et al. (2014) found that the mortality rate was highest among full-term infants, with 1.4% of infants affected. This was followed by early-term infants, with 1.1% of infants affected, and preterm infants, with 0.7% of infants affected. The study conducted by Bassil et al. (2014) revealed that pneumothorax was observed in 6.4% of full-term newborns, 5.3% of early-term infants, and 2.5% of preterm infants. The statistical analysis showed a significant association between pneumothorax and the infants' gestational age ($p < 0.001$). Seizures were observed in 7.4% of full-term newborns, 5.2% of early-term infants, and 1.7% of preterm infants. Hypoxic-ischemic encephalopathy was detected in 7% of full-term infants, 4.6% of early-term infants, and 1.6% of preterm infants. It is clear that while most NICU admissions are for preterm neonates, term neonates also face numerous neonatal problems that necessitate NICU hospitalization, and parents of NICU infants, regardless of gestational age, experience emotional and psychological repercussions (Govindaswamy et al., 2019).

Although NICUs are typically associated with preterm baby care, it is important to acknowledge that term neonates also receive care in NICUs. Consequently, the perceptions, needs, and NICU experiences of mothers of term neonates may vary or align with those of mothers of preterm babies.

Perceptions of Mothers in the NICU

The birthing process is typically a joyful and emotional experience for mothers (Lotterman et al., 2018). However, for mothers of infants who must be hospitalized in the NICU, this experience may be marred by uncertainty over their child's condition, the duration of their hospital stay, the likelihood that their child will survive, and other factors (Ionio et al., 2019;

Klawetter et al., 2019; Lotterman et al., 2018; Malakouti et al., 2013; Nazari et al., 2020; Sanders & Hall, 2018; Vinall et al., 2018; Williams et al., 2021). Nazari et al. (2020) conducted a qualitative descriptive study in which 35 women (18-40 years old) were interviewed to describe their NICU experiences; mothers described their NICU experience as *full of stress, anxiety, and worry* (Nazari et al., 2020). Themes also included *prayers for recovery, being hopeful, and awaiting discharge* (Nazari et al., 2020). These findings were echoed throughout many other studies investigating different factors relating to a mother's NICU experience (Ionio et al., 2019; Malakouti et al., 2013; Nazari et al., 2020; Sanders & Hall, 2018; Vinall et al., 20182020; Williams et al., 2021). Reports in the literature indicate that mothers of newborns requiring admission to the NICU navigate parenthood in a fear-provoking and intimidating environment (Fernández Medina et al., 2018; Wigert et al., 2006). In the NICU, mothers frequently encounter a myriad of challenges, such as feelings of distress and guilt, disruptions in the mother-baby bonding and attachment process, and a fear of losing their child (Fernández Medina et al., 2018). The effects of these challenges can negatively impact the mother-baby relationship and maternal and neonatal health (Anderson, 2017; Palma et al., 2016). In a phenomenological study by Malakouti et al. (2013), mothers of preterm infants in the NICU reported feelings of alienation from their newborns as there was a lack of interaction between mother and baby. These mothers also reported that nurses were beneficial in empowering maternal engagement (Malakouti et al., 2013). Similarly, Klawetter et al. (2019) discovered that mothers appreciated it when NICU providers utilized medical terminology to discuss diagnoses and procedures in their interactions with them. Mothers got the opportunity to learn more about their newborns' condition and, as a result, felt more involved in the care plan (Klawetter et al., 2019). Moreover, Vinall et al. (2018) emphasize the psychological consequences experienced by mothers of premature babies in the

NICU. Vinall et al. (2018) investigated the relationship between the frequency of invasive procedures, mothers' recollection of these treatments, and the occurrence of post-traumatic stress symptoms (PTSS) at the time of discharge. The study controlled for variables such as age, gender, illness severity, and NICU length of stay. The results revealed a positive correlation between PTSS and both the frequency of invasive procedures and the mothers' memory of these treatments at discharge (Vinall et al., 2018). In another study, Williams et al. (2021) studied acute stress disorder in mothers of NICU babies, which frequently results in post-traumatic stress disorder (PTSD). Their results indicated an increased prevalence of acute stress disorder in mothers; however, women from low-income households and different cultural backgrounds were reported at particularly high risk (Williams et al., 2021).

Reflexivity – A Positionality Statement

Reflexivity can be defined as a continuous collection of behaviours whereby researchers carefully examine, evaluate, and analyze the ways in which their subjectivity and surrounding circumstances influence the research processes (Olmos-Vega et al., 2023).

I, Rosie Deol, understand the significance of disclosing my positionality in order to openly discuss the possible influence of my personal history on the qualitative research process. The unique aspects of my experiences and identity inform how I approach, analyze, and engage with research participants and the data that is gathered.

It is important to acknowledge that the strengths and limitations of my understanding of the complexities within the context of research may have been shaped by factors such as my identity as a child of immigrants, my gender, career and education, and cultural background.

Child of Immigrant Parents

Growing up in a small Canadian suburb to hardworking, immigrant, blue-collar parents has instilled in me a deep understanding of the challenges faced by South-Asian immigrants. Witnessing my parents grapple with issues like economic instability, lack of post-secondary education, limited English proficiency, and limited social support, I emerged as an insider for this qualitative descriptive study. These early experiences cultivated in me a desire to listen, assist, and advocate for individuals, particularly immigrant mothers. Unbeknownst to my family and I, during our childhood, my mother received a misdiagnosis of ovarian cancer, turning to our primary care physician for guidance and support. This experience, coupled with my family's broader interaction with healthcare through our grandfather's leukemia, infused me with empathy, enabling me to comprehend the hesitation and anxiety immigrant patients may face in understanding medical information. Drawing on my history as a daughter of immigrants, I aimed to create a safe space for South Asian immigrant mothers who underwent a NICU experience, facilitating the sharing of their narratives and leveraging my personal experiences to foster trust and authenticity.

While my background as a daughter of immigrants may provide benefits in establishing connections with participants, there exists a potential risk that they may presume I possess pre-existing knowledge (e.g., stereotypes, cultural expectations, and so on). To mitigate this, clear disclaimers emphasizing my identity as a second-generation Canadian, rather than an immigrant, were expressed to enhance participants' comfort in describing their experience.

Gender

Beyond my familial background, my gender is an additional factor that could influence my role as a researcher in this study. Reflecting on my interactions with both male and female

family physicians, I acknowledge the crucial role gender plays in addressing sensitive health topics. As a female researcher in a study centered on a female population, I aspired for my gender to contribute to fostering candid and authentic conversations, thereby diminishing judgment, discomfort, and hesitation.

Career and Education

My professional and educational trajectory, specifically my history as a NICU nurse at a large, urban hospital in the greater Toronto area, serves as a substantial foundation for this research endeavor. A pivotal juncture in my nursing journey—providing care for a South-Asian immigrant mother in the NICU—inspired my transition to a master's program focused on thesis research. This collective experience, combined with my familiarity with the hospital setting and NICU diagnoses, establishes me as an insider, enhancing my ability to connect with study participants.

Culture

Furthermore, cultural norms are prevalent in the South Asian community, including the taboo surrounding self-reflection and mental health which profoundly impact immigrant women in NICU environments. As a member of the South Asian community, I am aware of several cultural and gender expectations embedded within this community and thus, I hope this allowed participants to feel comforted and instilled comfort and reassurance among participants.

CHAPTER TWO: METHODOLOGY

Problem Statement

Existing literature indicates that the NICU poses significant stress, anxiety, and trauma for mothers (Lotterman et al., 2018; Sanders & Hall, 2018; Vinall, 2018; Ionio, 2019; Nazari, 2020; Williams, 2021). While some findings may have broader relevance, variations in national healthcare systems, environmental factors, cultural nuances, and institutional contexts may limit generalizability. With an increasing number of South Asian immigrants in Canada facing elevated risks related to social determinants of health, cultural barriers, and infant-related challenges, further investigation is crucial to enhance neonatal and maternal outcomes. While current research sheds light on mothers' NICU experiences in general, understanding the specific experiences of South Asian immigrant women remains limited. This study focuses on the experiences of South Asian immigrant mothers whose newborn has been admitted to a NICU within the past year.

Research Purpose and Question

Research Purpose

The purpose of this study is to describe and understand the experiences of South Asian immigrant mothers who have an infant admitted to a NICU in the past year for greater than 3 days.

Primary Research Question

How do South Asian women who have had a neonate admitted to the NICU describe their experience?

Secondary Research Questions

1) What are the challenges and barriers faced by South Asian immigrant mothers in the NICU?

2) What do South Asian immigrant mothers believe they require to meet their personal and cultural needs when mothering a baby in the NICU?

3) What are mothers' perceptions of the available supports and services for South Asian immigrant women in the NICU?

Theoretical Framework

This study is guided by the Theory of Cultural Marginality, which can be used to highlight the added dimension of acculturative stress experienced by South Asian immigrant women in the NICU. This challenge may manifest twofold, as this population grapples with acculturative stress both as immigrants in a new country and as mothers in an intensive care setting.

Theory of Cultural Marginality

Heesung Choi, a nurse researcher and theorist, developed the Theory of Cultural Marginality (Appendix I). This theory seeks to advance culturally sensitive care while raising awareness of the challenges marginalized communities encounter (Choi, 2008; Smith et al., 2010). There are three major concepts comprising this theory: 1) marginal living, 2) across-culture conflict recognition, and 3) easing cultural tension (Choi, 2008; Smith et al., 2010).

Firstly, marginal living is being in-between or in the transition between one or more cultures (Choi, 2008; Smith et al., 2010). For immigrant populations, marginal living entails a struggle between promise and conflict (Choi, 2008; Smith et al., 2010). Choi (2008) suggests that government promises to improve immigrant transitions, such as additional resources and opportunities, are not adequately reflected in the experiences of this population, leading to conflict (Choi, 2008; Smith et al., 2010).

Secondly, across-culture conflict recognition acknowledges the differences between one or more cultures, such as cultural expectations, values, and norms (Choi, 2008; Smith et al., 2010). An example is the immigration process, in which people move from one nation to another, such as from India to Canada, and must deal with the resulting conflicts between Canadian and Indian cultural value systems. Parenting expectations may also vary from country to country, further exacerbating across-culture conflicts.

The final core concept of the Theory of Cultural Marginality concerns the mitigation of cultural tensions. These tensions can lead to feelings of alienation, anxiety, and identity uncertainty (Choi, 2008; Smith et al., 2010). Four processes—assimilation, reconstruction return, poise, and integration—are identified as means to alleviate these tensions (Choi, 2008; Smith et al., 2010). Assimilation involves adopting the customs of a new culture; however, individuals might revert to their original cultural identity due to conflict or a desire to reconnect with their roots, a phenomenon referred to as reconstruction return (Choi, 2008; Smith et al., 2010). Poise is characterized by a temporary adaptation to a culture, while integration entails blending old and new cultural elements (Choi, 2008; Smith et al., 2010).

In summary, marginal living is experienced when an individual is between cultures or in a cultural shift. Then across-cultural challenges are acknowledged, and assimilation, reconstruction return, poise, and integration help relieve across-cultural tensions (Choi, 2008; Smith et al., 2010). This theory informed the development of the interview guide (Appendix E), guiding the inclusion of questions such as "How does identifying as a South Asian immigrant and the expectations of the culture affect your role and responsibility as a mother?" and "How would you describe your experience as an immigrant mother in the NICU?" These questions aimed to explore whether participants were experiencing marginal living.

Study Design

To explore the experiences of South Asian immigrant women who have undergone experiences in a Level III NICU, this study adopted a qualitative description (QD) approach formulated by Margaret Sandelowski. Qualitative description is used when a rich straightforward description of experiences of phenomena is desired (Sandelowski, 2000). Qualitative description conveys meaning and comprehension via detailed description using the participants' own words (Sandelowski, 2000). QD is less interpretative and more "data-near" compared to other qualitative methodologies like phenomenology or grounded theory (Sandelowski, 2010). The characteristics of QD align with and support the research question and purpose proposed in this study.

Study Setting

This research project took place at two NICUs located in two major metropolitan areas, catering to substantial ethno-racial populations, including immigrants and newcomers to Canada. These include Hamilton Health Sciences (HHS) and The Hospital for Sick Children (HSC), also referred to as SickKids. HHS is one of the largest neonatal care facilities in the province and a regional referral center, with approximately 70 beds serving over 1500 patients and families each year (Hamilton Health Sciences, 2019). Also, as per the 2016 census, the largest visible minority in Hamilton, Ontario, is South Asian, representing 22.1% of the visible minority population (Statistics Canada, 2016; Hamilton Immigration Partnership Council, 2019). In Hamilton, Ontario, two of the most common countries of origin among recent immigrants are India and Pakistan (City of Hamilton, 2018). Moreover, the neonatology program at SickKids specializes in providing advanced medical care and surgical interventions for critically ill newborns. The SickKids Neonatal Intensive Care Unit (NICU) has a capacity of approximately 38 beds and

admits more than 800 infants each year. The NICU specializes in treating neonatal illnesses including severe respiratory failure, encephalopathy, seizures, stroke, sepsis, and other surgical disorders (The Hospital for Sick Children, 2022). Just as in the city of Hamilton, South Asians constituted the largest visible minority group in Toronto, comprising 12% of the city's total population (Statistics Canada, 2022).

Sampling

Purposeful sampling was employed for this QD research study. Purposeful sampling entails selecting participants for research based on their ability to inform the phenomenon being researched (Cresswell, 2007). To exercise purposeful sampling, criterion sampling and maximum variation was used.

Criterion Sampling. As per Sandelowski (2000), researchers may select participants based on pre-determined variables in order to obtain information-rich descriptions to inform the research question. Sandelowski (1995) refers to this as phenomenal variation, otherwise known as criterion sampling. Therefore, participants were selected based on inclusion and exclusion criteria.

Maximum Variation. To increase data richness, maximum variation aims to recruit a varied sample of individuals who may share different types of experiences from multiple points of view (Creswell, 2013). Sandelowski (1995) defines demographic variation as a subtype of maximum variation. Demographic variation was used in this study as recruitment targeted participants with a range in age and who are from various South Asian countries with varying lengths of time in Canada.

Participant Inclusion and Exclusion Criteria. The eligibility criteria for the participants were as follows: a) South Asian immigrant women aged 18 to 40 years, as this falls

within the recommended childbearing age range (ACOG, 2024), b) identify as a mother who currently has, or has previously had an infant admitted to the NICU for more than 3 days in the past year, c) immigrated to South Western Ontario in the last 10 years from South Asian countries, and d) speaks English or one of the following South Asian languages: Hindi, Punjabi, Urdu and Tamil.

Exclusion criteria include a) identifying as a mother of an infant who succumbed to preterm birth-related consequence, b) refusal to participate in the study, c) infant is palliative, and d) critically ill preterm infants who is unstable. The select languages were chosen as Hindi is India's official language, Urdu is Pakistan's and Tamil is Sri Lanka's, and according to Statistics Canada (2011), Punjabi is one of the most common non-official languages spoken in Ontario. The primary researcher is fluent in English and Punjabi and served as her own translator.

The decision to select immigrants who have immigrated within the last 10 years was based on the healthy immigrant effect, which explains how, over time, various stressors at multiple levels such as individual (e.g., financial limitations, language barriers), societal (e.g., racism), and organizational (e.g., navigating healthcare systems) contribute to deteriorating health (Elsahat et al., 2021; Setia et al., 2011; Zoua et al., 2015). In a longitudinal study conducted by Kim et al. (2013), the health trajectory of immigrants to Canada revealed an increase in poor health within 4 years postmigration. Kim and colleagues (2013) also reported a particularly higher risk of poor health among South Asian and Chinese women. Furthermore, to reduce the challenges associated with the NICU admission procedure (e.g., shock), it was determined in consultation from NICU clinicians, that mothers of infants who had spent more than three days in the NICU would be invited to participate. Recruiting mothers beyond the initial first three days of admission to the NICU might reduce the burden of participation as

mothers might be more acclimated to the NICU setting. The eligibility criteria were expanded to include South Asian immigrant mothers of infants who had spent more than 3 days in the NICU within the past year. This adjustment aimed to streamline the recruitment process, enabling mothers to participate after having experienced their infant's NICU stay and allowing them time to reflect on their experiences.

Sample Size. Sandelowski (1995) advocates for researchers to aim for data saturation, where no new information emerges, even recommending the inclusion of two or three additional subjects as a precaution before concluding data collection. As such, approximately 10 participants were planned for recruitment in this study. However, determining the appropriate sample size remains challenging and is ultimately at the researchers' discretion, as Sandelowski (1995) highlights. Despite various factors considered in determining the sample size, unforeseen constraints in recruitment led to only 4 participants meeting the criteria and being selected for inclusion in the study.

Recruitment

The recruitment methods employed in this study encompassed face-to-face recruitment, displaying study posters at visible NICU areas (e.g., bedside, NICU bulletin boards, and so on), using social media platforms, engaging in community programs, and enlisting healthcare professionals as intermediaries to apprise prospective participants of the study. Building trust and rapport is crucial during the recruitment process. It is critical to remember that healthcare professionals' involvement is governed by their level of interest in the research. Thus, as the principal investigator, it was vital to thoroughly inform providers about this study's significant implications and potential contributions with a study information sheet. To do this, the researcher

conducted a presentation for each of the NICUs (HHS and HSC) detailing all aspects of the research project.

Moreover, to recruit South Asian immigrant women who have had a neonate admitted to the Level III or IV NICU for more than 3 days in the past year, social media avenues such as Instagram, Facebook, and Twitter were used to advertise the study (Appendix F). Collaboration with nurses and physicians to identify potential participants also supported recruitment (Cresswell & Poth, 2017). Gaining access to these participants was subject to approval from the NICUs. If participants were interested in the research study, they were to approach NICU staff (e.g., nurse or physician) to ask for further information or contact the principal researcher at the email or telephone listed on the study flyer (Appendix A).

Eligible participants received a copy of the Letter of Information and Consent Form (Appendix C), as well as a scheduled time and date for a screening phone call. During the screening phone call, the principal researcher provided a comprehensive explanation of the purpose of the research, methodology, and consent procedure (Appendix B). Subsequently, the participant and the researcher arranged a mutually agreed upon interview date via Zoom, phone call, or in person, provided that the participant had given verbal consent. Prior to the scheduled interview, the participant was asked to complete an informed consent form and a demographic questionnaire (Appendix D).

Data Collection

Data collection included semi-structured interviews, participant observation and a demographic questionnaire.

Semi-Structured Interviews

According to Sandelowski (1995), semi-structured interviews can be used to collect data. To collect participant primary data for this research study, semi-structured, 45–60-minute individual interviews were held. Depending on the participant's preference, the interviews were either over the phone using Zoom or in person at the Level III NICU. All participants opted for a phone interview for convenience. All interviews were audio-recorded, transcribed and audio records were destroyed when transcripts were verified.

Participant Observation

Sandelowski (2002) highlights the significance of employing several methods of data collecting, including observation, to enhance the depth and breadth of data. Due to the exclusive use of telephone interviews, participant observation was limited to the context of phone calls, significant occurrences were indicated by cues such as extended periods of silence. As the researcher, I would notify the participants during these moments that they had the option to take breaks or stop the interview if they desired.

Demographic Questionnaire

To learn more about the sample population, a demographic questionnaire was employed. The questionnaire was emailed to participants and once completed, was returned to the researcher. The questionnaire (Appendix D) recorded details such as: participant age, education, employment, birth country, first language, year of immigration to Canada, marital status, gestational age, number of children and number of children previously admitted to a NICU.

Data Analysis

Content Analysis

To remain consistent with the underpinnings of QD, a conventional, inductive content analysis was employed throughout this study (Sandelowski, 2000). Content analysis is data-derived, in which the researcher generates codes based on the text data (Hsieh & Shannon, 2005; Sandelowski, 2000). Content analysis is applicable when less is known about a phenomenon (Hsieh & Shannon, 2005; Sandelowski, 2000). This approach is the least interpretive among all qualitative analysis approaches and thus has allowed the primary researcher to remain loyal to participant voices and narratives (Sandelowski & Barroso, 2003).

The initial phase of conducting qualitative inductive content analysis involved a deep immersion into the data (Hsieh & Shannon, 2005; Tesch, 1990). This immersive process included multiple readings of participants' interview transcriptions to grasp the entirety of the interviews. Subsequently, meticulous line-by-line coding was undertaken, yielding meaningful units—discernible segments of text containing valuable information (Miles & Huberman, 1994). These meaning units were then sorted into codes, serving as labels or tags for the interview data (Miles & Huberman, 1994). Following this step, the codes were systematically organized into sub-themes based on their commonalities and differences (Hsieh & Shannon, 2005). Ultimately, these sub-themes were combined into three overarching themes.

Data Analysis Process

First, audio recordings were transcribed verbatim by the principal researcher. The accuracy of verbatim transcription was confirmed by comparing it to audio recordings (Braun & Clarke, 2006). The principal researcher then used NVivo, a trusted qualitative data analysis for inputting, searching, analyzing, managing, and coding data. The decision to use NVivo is based

on its ability to encrypt data in storage while only allowing the account user access and control over data. NVivo has also addressed and supported Canadian government requirements, ensuring that any data relating to Canada, or its residents is stored on Canadian servers. NVivo offers quick and easy access to information and a clear data trail (Bandara, 2006; Maher et al., 2018). The first two interviews were used to develop initial codes. First the researcher read the transcripts several times, then reviewed sections of data completing line-by-line coding. The initial codes were developed and compared with the study supervisor. Any changes needed were confirmed and amended in discussion with the study supervisor. Then, the developed codes were examined further and grouped into themes. Themes are more broader ideas that contain related or linked themes and concepts (Appendix H). This procedure is consistent with Sandelowski's (2000) description of QD as a data-derived methodology.

Rigour

Rigour is a method of establishing trust and confidence in the results of a research study. Lincoln and Guba (1985) provide four methods for evaluating the rigour and trustworthiness of qualitative health research including credibility, transferability, dependability, and confirmability.

Credibility

Credibility is defined as the confidence or assurance in the accuracy of the findings (Lincoln & Guba, 1985). Prolonged engagement, data triangulation, peer debriefing, and member checking all contribute to credibility. Spending enough time in the field to understand the culture, phenomena of interest, and context is referred to as prolonged engagement (Lincoln & Guba, 1985). Prolonged engagement helped foster trust and rapport with participants and is important, generating a comprehensive discussion in interviews. In this study, establishing trust

and engagement involved the researcher initiating contact with potential participants, elucidating the study details, addressing questions, exchanging necessary documents for information, consent, and the demographic survey, and coordinating the interview timing and format in accordance with participant preferences. It also encompasses the researcher's positionality and personal attributes that facilitate participants' comfort and connection with the researcher. Moreover, previously established connections with important informants were maintained (e.g., emailing and staying in contact with the NICU managers and NICU team leaders) to increase access for recruiting participants.

Data triangulation involves the use of diverse data sources during an investigation to enhance comprehensive understanding (Lincoln & Guba, 1985). In this study, triangulation was accomplished comparing information from interview transcripts, participant observation and critical self-reflection. The term "member-checking" refers to returning to participants to confirm developing ideas (Lincoln & Guba, 1985). After the interviews in this study, participants were contacted to validate that their responses in the interview were accurately documented in order to ensure rigour and trustworthiness.

Transferability

Transferability requires a thick description of the results (Lincoln & Guba, 1985). A thick description is defined as obtaining enough information from interviews to provide transferrable results (Lincoln & Guba). Furthermore, the study's projected sample size of 10-15 participants and an hour-long length of interview aimed to generate a thick description by connecting with participants until data saturation occurs (Malterud et al., 2016). The findings from this research study may be transferable to other similar ethno-racial immigrant populations in Canada.

Dependability

A summary of the actions conducted throughout the interview research process is included in audit trails (Lincoln & Guba, 1985). Dependability was attained by providing an easy-to-follow audit trail that will make it possible for the research to be replicated (Lincoln & Guba, 1985). To maintain analytical consistency, an accurate data-collecting strategy and a consistent audit trail of analysis were developed, ensuring that the same data collection and analysis procedure was followed for each individual interview.

Confirmability

In accordance with Krefting (1991), coding and re-coding were done a month apart to check if the generated codes were consistent. Furthermore, coded transcripts, developing themes, and thematic maps were sent to supervisory committee members to ensure that interpretations appropriately reflected participant responses and were not unduly impacted by the primary researcher's subjective beliefs.

Ethical Considerations

The safety of participants and respect for their human rights are essential in all forms of human research (Orb et al., 2000). This study was approved by the Hamilton Integrated Research Ethics Board (HiREB) under project #15766 as well as the Research Ethics Board at HHS and HSC. Participants were provided with a $30 gift card for Presidents' Choice as a token of appreciation for their participation in the study. Moreover, this study was conducted in accordance with the Tri-Council Policy Statement: Ethical Conduct Involving Humans 2 (TCPS 2) (2018). The three central principles of TCPS 2 (2018)—respect for humans, concern for welfare, and justice—served as the study's ethical compass.

Respect for Humans

Respect for persons highlights the value of individuals and the regard and deference they merit (TCPS 2, 2018). This principle includes the researchers' moral need to uphold autonomy while safeguarding individuals whose autonomy is being undermined or diminished (TCPS 2, 2018). Participants were informed of the study's aim and objective, anticipated risks, and benefits, as well as what would likely occur, what may occur, and the implications of the research for practice (Orb et al., 2000; TCPS 2, 2018). Prior to and during the interview, consent was requested verbally and through consent forms. Participants' autonomy was emphasized as they were told to give only information that they were comfortable sharing and that were free to leave the research at any time without being penalized (Orb et al., 2000; TCPS 2, 2018). Participants in the research were given the chance to have their contributions to the study discarded if this happened. All information offered was understood by participants (Orb et al., 2000).

Concern for Welfare

A person's welfare is described as the standard of their life experience in all facets, including their physical, mental, and spiritual well-being (TCPS 2, 2018). Interviewing potentially vulnerable South Asian immigrant mothers to hear about their experiences in the NICU can be a sensitive topic. Though no participants asked, the researcher made mothers aware that a standard list of free and accessible supportive resources was available. The privacy and confidentiality of participants was protected throughout the study procedure and will continue to be post-publication (TCPS 2, 2018). Participants will be de-identified in all public materials.

Justice

Justice is the term used to describe the moral requirement to treat people equally (TCPS 2, 2018). To avoid the participants from being exploited, it is essential to understand their vulnerability (Orb et al., 2000). Participants were chosen based on study inclusion and exclusion criteria, not on prejudiced opinions unrelated to the research purpose, to ensure fair methodological decision-making (TCPS 2, 2018). To ensure that study findings truly represent the ideas the participant was seeking to express, any language hurdles were addressed in addition to enhancing participant comfort and comprehension (Orb et al., 2000; Premji et al., 2020).

CHAPTER THREE: FINDINGS

The findings of this research study were derived from a demographic questionnaire and semi-structured interviews conducted on four participants. The demographic questionnaire was used to obtain a thorough understanding of the specific demographic features of the study's participants. The participants completed both the consent form and the demographic questionnaire prior to the interview, and these documents were then sent to the researcher via email. Semi-structured interviews were conducted using a carefully crafted guide with questions aimed at exploring the participants' NICU experiences in depth. While the target duration for interviews was set at 45-60 minutes considering the busy schedules of these first-time moms, some participants were only able to allocate between 30-60 minutes. Despite the time constraints, these participants were still actively involved in the interviews. All participant interviews were conducted via telephone, as per their preference. The interviews were audio-recorded and subsequently transcribed with participants' permission. Moreover, participants were offered the option to review their transcripts if they wished to do so.

Demographic Overview

Information gathered from the survey included participants' ages, levels of education and occupation, places of birth, first language, marital status, number of children, gestational age, and history of NICU admissions. The results from the demographic questionnaire are presented in Table 1.

Table 1

Demographic Questionnaire Data

ID	Age	Education	Employment	Birth Country	First Language	Years Since Immigration	Marital Status	# of Children	Gestational Age	Previous NICU Experience
1	26-33	College Diploma/Degree	Part-time	India	Punjabi	4-6	Married	1	41	No
2	18-25	College Diploma/Degree	Full-time	India	Punjabi	4-6	Married	1	33	No
3	26-33	College Diploma/Degree	Full-time	India	Punjabi	4-6	Married	1	37	No
4	26-33	College Diploma/Degree	Part-time	India	Punjabi	1-3	Married	1	41	No

Three-quarters of the participants (n=3) were between the age range of 26-33 years, while one participant was between 18-25 years of age. All participants had completed a college diploma or degree. Participants disclosed their employment status before commencing their maternity leaves, with 50% (n=2) employed full-time and the remaining 50% (n=2) employed part-time. All participants were born in India and their first language is Punjabi. Participants were requested to indicate the timeframe of their immigration to Canada, selecting from the following options: 1-3 years ago, 4-6 years ago, and 7-10 years ago. 75% (n=3) of participants stated they had moved from India to Canada around 4-6 years ago, while the remaining participant reported arrival 1-3 years ago. Moreover, all participants indicated that they were married and that this was their first child, suggesting that they had no prior experience with the NICU before this admission. The gestational ages of the participants differed: Most (n=3) participants delivered full-term infants (37-42 weeks) gestational age, while the remaining participant delivered a preterm infant (28-36 weeks gestational age).

Findings from Semi-structured Interviews

Upon conducting a qualitative content analysis, 13 codes were generated. The identification of these codes revealed patterns that integrated into 8 distinct sub-themes. These

sub-themes were then synthesized into 4 overarching themes, encapsulating a comprehensive narrative (Appendix H). The themes are as follows: (1) Seeking to Understand, (2) The Impact of South Asian Culture on the NICU Experience, (3) Becoming a Mother One Step at a Time, and (4) Circle of Care. These themes summarize and represent the responses conveyed by the participants, providing a nuanced understanding of their experiences within the NICU.

Theme 1: Seeking to Understand

The *Seeking to Understand* theme delves into participants' reflections on their communication experiences with healthcare professionals during their time in the NICU. The phrase "seeking to understand" describes the process by which a person strives to understand a certain notion, idea, or situation. Participant responses were prompted by a series of inquiries, including: (1) How would you describe your experience as an immigrant mother in the NICU?, (2) Can you describe some of the challenges you experienced during your baby's hospitalization?, and (3) Can you describe your interactions with healthcare staff (e.g. nurses and physicians) throughout your hospitalization? The theme *Seeking to Understand* includes two sub-themes, *language barrier* and *health literacy*.

Language Barrier

A language barrier is a linguistic hurdle that hinders mutual comprehension between individuals, resulting in communication challenges and prompting individuals to seek understanding. Participants discussed the challenges they had while communicating with healthcare providers. A participant conveyed her perceptions about language stating: "I think it's important because sometimes even I think if the nurses and doctors all spoke Punjabi to me during the NICU I probably would have a better or faster understanding of what was happening" [Participant 1].

Participants shared the challenges and anxiety they experienced due to their limited English proficiency. This difficulty was not only experienced by the participants themselves but also extended to their husbands. One participant expressed:

> "If he went to see the baby on his own, he would feel anxiety because I'm not there to sort of help him, so he just doesn't ask questions, because he's afraid he won't even understand what they're saying, and he just goes to see the baby and comes back home". [Participant 3]

Likewise, another participant expressed a desire for a translator, particularly for individuals like her husband who, interested in understanding and inquiring about the baby, lacked proficiency in English:

> "Because we are Punjabi, I understand English a little bit but sometimes we don't understand it… So, for that, we need an Indian nurse or someone who can translate for us. If someone doesn't know English, then we should translate for them… I have a husband who knows English, but not very well. He can understand a little bit, but he can't speak it. It is very difficult". [Participant 2].

One participant expressed that if her husband visited the baby, she had to accompany him as he was less fluent in English than she was: "The main doctor was speaking in English. For that reason, I always attended the hospital with my husband because if the doctor came my husband couldn't understand... so sometimes I'd try to explain, or the nurse or translator would" [Participant 3]. Participants also reflected on when they did have a Punjabi or Hindi-speaking nurse. One participant expressed:

> "Yeah, like if we had an Indian nurse who spoke Punjabi, we would ask as many questions as we could and were able to and that we thought of because we weren't sure if

> we were going to get another Punjabi-speaking nurse the next day…For example, the Gujrati nurse, she spoke Hindi, but me and my husband understand Hindi, it's very similar to Punjabi so this made things easier." [Participant 3]

Health Literacy

As described by the Centers for Disease Control and Prevention (CDC, 2023), health literacy refers to an individual's capacity to seek out and understand information in order to make informed decisions and take appropriate actions related to their health or the health of others. Evidently, participants often resorted to looking for solutions for this communication barrier, relying on Google or family members for support. In one scenario, a participant illustrated the comfort she felt being offered interpretation services regarding her child's peripherally inserted central catheter (PICC) line:

> "I don't think there were many Punjabi-speaking nurses but my baby's pediatrician who came to see us every day was South Indian and spoke Hindi which is quite similar to Punjabi so I was able to understand him. One thing I really liked was for example when my baby had so many IVs the doctor recommended inserting a PICC line, and when he introduced this idea to me he asked if I wanted an interpreter so that I could fully understand what the benefits of PICC line would be for my baby and why he had suggested it." [Participant 2]

Cognizant of her limited English proficiency, one mother expressed:

> "I would always get nurses or doctors to write down medicine names or anything medical that I wasn't aware of. That way I would Google it myself or ask my family to help me understand, especially if I didn't feel comfortable asking the nurse or doctor myself." [Participant 1]

Additionally, within the theme of Seeking to Understand, there is an exploration of individuals' background knowledge in nursing science and healthcare. One participant emphasized that her experience and expertise as a nurse informed her understanding of certain aspects and facilitated her management of her NICU stay:

> "Another thing I think about is I'm lucky I can understand English and medical terminology but for mothers that don't know English or even do know English but still don't know medical terminology. That's what's hard. I knew whatever my doctor was describing, I was aware of what he was talking about because of my background... Well first of all I think it is extremely challenging to be in a NICU when you don't have medical knowledge. I was really lucky that I did but I don't know how mothers who don't, survive in the NICU." [Participant 2]

Her prior knowledge base also functioned as a pillar of support for her family, as she took on the dual responsibility of serving as both an English and medical terminology translator:

> "They planned doing a PICC line for my baby. So that was a big issue for my husband and my family. They had so many concerns and questions, they'd ask "How will they get it?" "She's so tiny, why are they going to do that?" and that's when I had to be their support as well and explain." [Participant 2]

Theme 2: The Impact of South Asian Culture on the NICU Experience

The Impact of South Asian Culture on the NICU Experience theme looks closely at the responses of participants and how their cultural background affected their NICU stay. Two sub-themes were identified: 1) Concerns about societal perceptions and 2) Comparison to India.

Concerns about Societal Perceptions

Mothers in this study share the influence of their South Asian cultural heritage on their NICU experience, particularly how it heightened concerns about societal perceptions. One mother expressed that having her baby in the NICU made her worry about what other members of the South Asian community would think. She expressed: "Yes, well I was worried about what other people would think or say" [Participant 3]. Another participant reflected on one of the biggest challenges she faced during her NICU stay, which involved not knowing the gender of her baby:

> "My baby was born quite early, in fact, her main part, the part that tells us if it's a boy or girl, that wasn't developed yet."… "The doctor wasn't able to confidently tell us whether we had a boy or a girl."… "This was very difficult for us. It took them three weeks to tell us that we had a baby boy. We used to ask almost every day, what the gender of my baby was."… "For those three weeks, I didn't tell anyone I delivered a baby. Only me and my husband knew. You know how it is in our culture, the first question they ask is if it's a boy or a girl and I didn't have the answer to that question so I just didn't bother telling anyone. I kept thinking what are people going to think or say? We finally had a baby and we don't even know if it's a boy or girl? I just would rather not tell anyone." [Participant 3]

Not wanting to tell family members or relatives was a common finding among participants. One participant conveyed that she didn't want support from anyone because she was worried about what they would think or if they would judge:

> "I would try my best to take care of myself and you know as a first-time mother I was scared but I didn't even want any help from any one if I'm being honest. You know how

it is, if you ask for support or help from someone, they'll never let you forget it. So, I just was happy to prepare for my baby to come home on my own. When we become mothers you know, these capabilities come on their own. God only puts people through challenges, who he knows can endure them. I hope that what I've experienced brings good karma later down my life or my baby's life." [Participant 2]

Another participant pondered the repercussions of a NICU stay on South Asian mothers, highlighting that certain behaviours and attitudes within South Asian communities are deeply ingrained and may remain resistant to change:

"No one cares for the mother. The poor mother is the one who suffers because she stresses for her baby, what people think, and then her own condition. I found it hard to survive too you know, I worried for my physical health, my mental health and I had my emotions too you know…but I'd say I had an easier time coping because I was a [healthcare professional]. I knew what was happening to my kids and to me. But I think Indian families… they don't really know how to support each other. They don't know what to do or say or how to act. They worry about older Indian traditions like giving "gudti" to the newborn. These are things they worry about and I don't think that's something we can change." [Participant 2]

A mother emphasized the significance of gender within South Asian communities and addressed the challenges faced by South Asian mothers:

"On top of that, being Indian, you know how it is…if it's a girl, there's already so much tension and stress because boys are preferred over girls. Then on top of that, if the baby's not healthy, and has to stay in the hospital, that's another issue Indian mothers have to face." [Participant 4]

Comparison to India

During the interviews, several participants discussed how their South Asian culture prompted introspection about their birth country, India. Participants expressed doubt over the likelihood of their infant flourishing if a similar situation were to happen in India. A mother shared, "I believe that if I were still in India, my baby might not receive this level of care" [Participant 1]. Likewise, another participant remarked, "I consider myself fortunate; we've heard about deliveries in India, and, you know, they lack proper checkups there, the care is not as extensive as it is here" [Participant 2]. Another participant expressed skepticism about the care she would receive if a similar situation occurred in India: "At times, I think that if this happened in India, I doubt we would have received the care that we did" [Participant 4].

Theme 3: Becoming a Mother One Step at a Time

The third theme identified in this research study is *Becoming a Mother One Step at a Time*. This theme encompasses three sub-themes: 1) Maternal Self-Doubt and Uncertainty, 2) Navigating Motherhood in the NICU, and 3) Motherhood Beyond the NICU.

Maternal Self-Doubt and Uncertainty

Each participant in the study was a new mother, and their first encounter with motherhood coincided with their baby's admission to the NICU. Participants shared how their NICU experience triggered self-doubt and uncertainty about their parenting skills. One participant articulated:

> "Yeah sure I've taken care of babies before I have little cousins and I helped them and raised them but this was my first ever baby. Even though I had experience helping my little cousins, when it came to breastfeeding or changing diapers, I used to hand the baby

over to the mother. But in this case, the baby was mine. I didn't know what to do." [Participant 1]

Similarly, another participant conveyed that the duration of her baby's stay in the NICU prolonged her self-doubt: "During my time in the NICU, I kept thinking, 'How will I care for this baby? Will I be capable of it? Can I provide proper care for him?'" [Participant 3]. Another participant, unfamiliar with breastfeeding, expressed, "Being a mother for the first time, I know nothing about latching. I want to try and learn." [Participant 2]. Reflecting on her own health, one participant conveyed: “I would try my best to take care of myself and you know as a first-time mother I was scared” [Participant 2]. Being a first-time mom, one participant expressed: “It is also our first baby, I feel like first babies have a different level of attachment, it was really hard having him there and not home right away” [Participant 3].

Navigating Motherhood in a NICU

Participants in this study shared their struggles in navigating motherhood throughout their NICU journey. One significant challenge they encountered was the separation from their babies not only immediately after delivery but also when the mother would go home to rest and recover. One participant shared her experience of being apart from her baby following her caesarean section (c-section):

> “For the day and a half that I never got to see him I was really upset I kept telling the doctors “I want to go see him, I want to go see him” and then finally the doctor who helped me during my delivery allowed me to sit in a wheelchair and one of the nurses took me into the NICU. That was really hard for me, having to wait, but I felt way better after seeing my baby.” [Participant 1]

Another participant experienced similar feelings after her delivery as well:

> "Yes, there was a separation with the child. Right after delivery, my baby went to the NICU and you know, I gave birth on the 16th, and it wasn't until the 22nd that I got to hold my child for the first time... Even after I delivered, I asked if I could breastfeed my baby and they said no. They told me to pump and then they'd give it to my baby for me and I didn't like that. I feel like that shouldn't have happened" [Participant 2]

Mother-baby separation was also noted when mothers went home to recover from their C-sections. Participant 2 shared:

> "I did feel separation anxiety... like I didn't live close to [name of town], but I did feel like even though my child was far away, there was proper care being provided." …
> "Yeah, because when the child is there for that long of a time, the separation, the bond... it's not there. They don't know about their mother or father. They don't know about their own house. They just know the hospital."

Another participant articulated, "I really felt detached. Like my baby was staying at the hospital, meanwhile, I was staying at home. That was difficult." [Participant 3] This sentiment was echoed by Participant 4 who expressed:

> "My biggest challenge was coming home, not with the baby, but just myself. They discharged me but moved my baby in the NICU. I came home and I felt guilty about that. I cried the whole night. Even the next day, when I went to go see her, I kept thinking how did I leave her for this long overnight on her own. I felt really bad. I kept thinking, was she in safe hands or not? Will they treat her well? Will they feed her? If I'm being honest, I can't explain that type of fear I felt."

Furthermore, many participants noted that maneuvering through motherhood in the NICU became notably challenging due to their experiences of undergoing a cesarean section. These

participants had expected to have a typical delivery, as defined by the Society of Obstetricians and Gynecologists of Canada (SOGC; SOGC, 2024), involving the spontaneous onset of labour between 37 and 42 weeks of pregnancy, resulting in a vaginal birth. In a typical childbirth scenario, the baby is delivered headfirst, with immediate skin-to-skin contact and breastfeeding initiated within the first hour (SOGC, 2024). Unfortunately for some of the participants in this study, their experiences deviated from this expectation. A participant reflected on their childbirth experiences, which, despite anticipating a typical delivery, ultimately involved a c-section:

> "I thought I was going to have a normal delivery. Then, I had developed a fever, which wasn't going down and at that time the doctor told me that the baby's heart rate and so on so forth was healthy, so they wanted to wait another hour or so to see if my fever would come down. But then all of a sudden, the baby's heart rate was getting really high, my fever was still really bad and then that's when the doctor asked for my consent for a c-section. I ended up going through an emergency c-section and that's when I was terrified I just kept telling the doctor "Please do anything to keep my baby safe. Do whatever you have to do. I want the baby to come into my hands safely"..."I mean, thank God we even did do a c-section and delivered and that was a good decision on my doctor's part because maybe my baby wouldn't have survived" [Participant 1].

Another participant shared her experience as she also underwent an emergency C-section:

> "I had an induced labour, it was intended to be a normal delivery, but I was diagnosed with gestational diabetes at the 26th-week mark and at the end of the last week around 36 weeks, I also had hypertension and wasn't able to keep pushing so the doctor had to do an emergency cesarean section for me" [Participant 2].

Participants conveyed how undergoing a cesarean section added complexity to their journey of navigating motherhood in the NICU. One participant conveyed:

> "For one and a half days, my husband stayed in the NICU with our baby because I started experiencing dizziness and I had a lot of bleeding and because there was a lot of blood loss the doctors had to take care of me in a separate area" [Participant 1].

Another participant discussed the difficulties she faced after her c-section and described the physical challenges she encountered during the recovery process:

> "I couldn't handle sitting and praying for long periods of time because I had a c-section and I was still in some discomfort."… "It was difficult to go up the stairs or get into a car. My stitches actually ended up opening, I was really bothered and uncomfortable" [Participant 2].

One participant reflected on her birthing experience, emphasizing that though she had a normal delivery, her baby was still sent to the NICU, which she was not anticipating:

> "I had a normal birth, but nothing after that was normal. When they told me they were going to shift my baby to the NICU side, I didn't know what they meant or why. I have always known the NICU babies to care for premature babies, so I didn't know why they were shifting her there because I gave birth at 42 weeks. I was scared. I was scared when they moved her, I thought she must have been really sick for her to go there. I was scared when they gave her injections but then I kept telling myself, that this was for the benefit of her health. I was happy afterwards they shifted her there because she got the help she needed to get better." [Participant 4]

Motherhood Beyond the NICU

The sub-theme *Motherhood Beyond the NICU* underscores the importance of participants' sentiments regarding their strong eagerness to be discharged from the NICU as well as their feelings upon leaving the NICU and returning home.

Participants described their experience during the NICU and the hope of being discharged as soon as possible:

> "I kept thinking when will we get out of the NICU? When will we go home? At first they told us that we would be in the hospital for only seven days for antibiotics. But then after the 5th day, they told us that the antibiotic treatment will actually be for 14 days not 7. This made me even more scared and made me wonder if there was something else going on with the baby because they told us he only had a fever, which he didn't even have anymore, so why do we need to stay for another week? This is why I was so scared." [Participant 1]

Another participant noted how she comforted her husband by assuring him that they would be returning home soon:

> "I used to explain to my husband too, there are several other babies there too. Not just ours. Don't worry, everything will be okay. If we don't get discharged one day, I used to tell him, don't worry, we'll get discharged another day. I knew we were going to go home." [Participant 2]

One participant shared her encounter when they were informed that they were cleared for discharge and ready to head home:

> "When I reflect, I feel like I spent very little time with my baby while she was in the NICU and when my baby came home she didn't latch. When they discharge you, they

> don't clear those things and make you feel comfortable about it. They mention your future appointments, they give you a list of things to do, but I don't think they really value how you'll do when you get home. That's the thing." [Participant 2].

Participants also reflected on their experiences after leaving the NICU. One participant conveyed the fear she experienced during her time in the NICU and how her perception of pregnant women has since evolved:

> "Yeah, that was one of the scariest things I've gone through, but I just wanted my baby safe. When I left the NICU, I kept thinking to myself, I hope no one ever has to go to the NICU. When my husband and I see pregnant women in public like in the grocery store for example, we both always pray that they have a normal delivery and don't have to experience a difficult time like us and never have to visit a NICU." [Participant 1]

Another participant emphasized her inability to forget anything that occurred during the NICU: "To this day, I remember every date and time everything occurred. I'll never forget. But that's okay, right now, my baby is okay, the weight is okay, and now know the baby is healthy and happy and everything is normal" [Participant 2]. Moreover, a participant detailed the well-being of her baby following their time in the NICU: "Yeah you know, he's thriving. He's playing, he's a little naughty. He smiles. He does so many activities and plays with so many toys. I'm so grateful we made it out of the NICU." [Participant 1].

Theme 4: Circle of Care

The fourth overarching theme, *Circle of Care*, encompasses participants' reflections on their interactions with healthcare staff and family members. This theme comprises two sub-themes: *perceptions of care*, and *support and coping*.

Perceptions of Care

When asked about the experiences and interactions participants had with healthcare staff such as nurses and physicians, participants talked about times they wished they could have had another nurse due to lack of communication during nursing care. One participant discussed her experience with a nurse as they were being discharged from the NICU:

> "To be honest, we only had one incident with a nurse and that was when we were being discharged. To start, we had to wait for her for maybe 1.5 hours and our baby was fussy and crying, we kept saying we had to go, our baby needed to be fed, etc. etc. Then she came, she checked my baby's diaper, then on top of that, they were giving her iron, checking her vitals…it was just so much at once. Then I got really upset. I said I will feed my baby myself, I will change my baby myself. Please just stop. I got frustrated and finally admitted that I too, am [a healthcare professional] and I know this isn't how you're supposed to do things. The nurse wasn't even telling me why she was giving her iron or how much and that really bothered me. Tell me, I am the parent. I want to know. So yeah, with that specific nurse, I was really upset. Then she apologized. But because she knew I was [a healthcare professional], she kept informing me of every little thing after and that's what I didn't like. Because you should do this with every mother." [Participant 2]

Another participant expressed her concerns about her interaction with a nurse whom she felt should have provided more attentive care for her baby, who had a peripherally inserted central catheter (PICC) line:

> "There was this one nurse, she was also Indian, and she was the day nurse. During shift change, they gave report at the bedside and she was showing the oncoming night nurse

my baby's PICC line. When she showed the night nurse my baby's arm, she moved my baby's arm really rough and I kept saying "please handle him gently", but because she was so aggressive, my poor baby didn't stop crying. When I told that nurse to be gentle, I could tell from her demeanor she was upset. She said "no don't worry I know, I handle babies every day, this is my daily job". I could tell she had an ego. But yeah I don't know what she did, for so many days, my baby was doing so well with the PICC line but after she yanked his arm the way she did, he didn't sleep the whole night. He was so irritated. And every time he'd cry, his arm would move, and that would make the IV pump go off. It went off so many times that even I learned how to use it and silence it. The sound of the IV pump alarm was so loud and it was hard to keep waiting for a nurse to come every single time to come silence it. I didn't want to wake my baby and other babies so luckily I was able to learn what to press to silence it. The next day, the previous day nurse came again and she was our nurse again. I didn't want to say anything, and my husband asked me not to say anything to that nurse, but I ended up saying something because I really felt so upset that she handled my baby in that way. I kept telling her even the night before like "he's already so little, so fragile, he's gone through so much since he was born, he didn't sleep all night, I didn't sleep all night". I didn't want to say something, but I had to. I was too upset. You know, since he was born he's had so many IV's, he had IV's in his hands, his feet, and even his head. It wasn't until towards the end of the treatment when they decided to put a PICC line in. I kept thinking like my baby has already suffered so many times, so I told the nurse like "how would you feel if you had a PICC line in you and someone handled your arm so roughly? Wouldn't you feel so frustrated too? He's so vulnerable, he can't even speak and tell us how he feels". After that, she

> treated him well throughout the day. She was very gentle and thoughtful but I still wished I could have had another nurse." [Participant 1]

Another participant described her interaction with a nurse as her infant was also provided with a PICC line. The participant conveyed:

> "Her IV was changing daily. I couldn't see her getting pricked daily. My question to the nurses was why did you wait 3 days to put in a PICC line? I was not asking them why are they getting the PICC line in. If you were getting the PICC line, you should have got it on the first day so my baby didn't need to go through all that." [Participant 2]

Participants discussed the attitudes and behaviours of some of the nurses that they interacted with during the NICU. One participant expressed: "Maybe one or two of them, when we go, wouldn't even say hello or hi or would ask us if we'd like to hold our baby. None of that" [Participant 3]. Participant 2 conveyed a similar sentiment, expressing: "For example, last night I went to go see my baby and that nurse was very rude and aggressive, meaning like her behaviour was unkind. If we asked her questions, she'd answer in a different way than sometimes with other parents". Participant 3, feeling similarly, stated: "Sometimes me and my husband would think maybe it's because we have an accent or because were Indian, is that why she's treating us like this? This made us not want to ask questions anymore".

One participant reflected on how she felt in the NICU when receiving information or updates regarding her baby from a nurse or doctor:

> "I think nurses and doctors should try to be clear with their statements. As parents, we rely a lot on what our nurses and doctors say to us. You know, it is common for a doctor to say "at this moment, your baby is fine" or "right now, your baby is okay". I think for that present moment, we feel relief but then anxiety builds up again." [Participant 2]

Furthermore, participants also reflected on moments in which they received *good* care. One participant described her experience being brought over from the maternal unit to the NICU to see her baby:

> "So on the second day they put me in a wheelchair and brought me over to see my baby in the NICU. One thing I really liked was that they decorated his incubator. My husband also kept saying that the nurses really like the baby, they keep calling him cute and have been very helpful throughout the past day and half."… "In terms of his care all the nurses and doctors were very friendly. They cared a lot for him especially when I was unable to care for him, they all cared for him fed him, changed him, and did everything for me while I was recovering." [Participant 1]

Participant 3 discussed how some nurses made her feel included and involved in the care, even though English was their second language:

> We had Indian and Gujrati nurses and they were all really kind. Even if we had language issues, the nurses took their time to clearly answer our questions. For example, the Gujrati nurse, she spoke Hindi, but I and my husband understand Hindi, it's very similar to Punjabi so this made things easier. So whenever, we had her, every time we'd enter the NICU, she would greet us very nicely, say hello and give us an update that we understood. She was really kind, she would always ask if we wanted to be part of the care, if we wanted to hold our baby, etc."

Similarly, another participant expressed gratitude toward the nursing staff for delivering excellent care to her baby: "I had good experiences with the nurses in the NICU. They asked a lot of questions about how I felt, they came very frequently and they provided my baby with really good care" [Participant 4]. In summary, participants in this study defined *good* care as

healthcare professionals who demonstrated kindness, provided frequent updates, and involved families in the circle of care.

Support and Coping

The sub-theme *Support and Coping*, within the overarching theme of *Circle of Care*, explores the role of individuals within this circle in helping participants provide support and cope during their NICU stay. During this challenging period, the participants shared their reflections on the support they received from their husbands. Participant 1 conveyed:

> "Well, while I was in the NICU, the only visitors allowed to see my baby were myself and my husband. So it was hard to rely on other members of my family. The biggest support I had was my husband. He was there for us all the time. For me and my baby. I also rarely saw other parents in the unit and if I did, I didn't want to bother them."

Likewise, Participant 3 conveyed that she relied on her husband for support, stating: "I talk to my husband because he is very supportive. He supports me in everything."… "My husband takes care of me. Before, during and after delivery. He took care of me. He always does." Similarly, participant 4 conveyed: "My husband and my mom were my biggest supporters."

According to the participants, the support from husbands and extended family members played a vital role during the NICU stay, proving to be invaluable and significantly enhancing the manageability of the experience. One participant expressed that without her husband's and extended family's support, she wouldn't know where she'd be:

> "My husband always reassured me that our baby will be okay. He reminded me that I can ask any questions as well. He and I would exhaust Google, we would google search so many things, so many times a day. My family is full of doctors as well, so my cousin and

> aunt and sister-in-law, they're all doctors. So I used to ask them questions all the time. I spoke to them almost daily and I would feel better after talking to them and to my husband. and I'm glad I believed them and trusted them, especially my husband, because now my baby is so good, so healthy, meeting all his milestones and if it weren't for my husband's support, I don't know where I'd be." [Participant 1]

When asked about how they coped during their NICU experience, many participants identified relying on prayer and faith as their coping mechanisms. Participant 2 articulated, "I would pray. I would also just call the nurses or I would go see my baby. I couldn't handle sitting and praying for long periods of time because I had a c-section and I was still in some discomfort." Similarly, Participant 1 sought comfort in prayer, stating, "I would also say to pray as much as you can; praying helped me feel better." She added, "My brother and my parents are in India, and they did a special prayer for our baby there too."

Despite participants recognizing various forms of support and coping mechanisms they developed during their stay, they also acknowledged additional support they wished they had received, given the challenging nature of a NICU hospitalization. Participant 2 expressed:

> "Something as simple as a pamphlet for common NICU diagnoses. This is the diagnosis, this is an estimated length of stay, this is common side effects, common medications, and no I'm not saying I'm asking for assurance, I don't expect every situation to be the same, but just something so parents know what to expect."

Participant 2 also voiced that she wished for more communication, more compassion, and for healthcare staff to ensure parents they're not alone:

> "I think it's important for nurses and physicians to emphasize and reassure to parents that this has happened to other babies. You're not alone. Your baby is not the only one who's

> endured this. I think these are important things to say to the family. To remind them that just because they're at the NICU, it doesn't mean our baby is not normal, they are just going through a tough time, but everything will be okay. All a parent wants to hear is everything will be okay. These are things I wish were communicated. Just some more compassion."

Another participant reflected on the language barrier and hoped for translation services: "I wish we had a translator who could tell us in Punjabi what the nurse or doctor is saying." [Participant 1]

Furthermore, as the interviews drew to a close, participants were encouraged to share any advice or supportive messages they wished to offer to future South Asian mothers in the NICU. Participant 1 responded:

> "Just ask direct questions to the doctors and nurses, don't be afraid. It's scary, but ask questions, it will make you feel better. Also, stay as much as you can, I know it's not an ideal space to sit and if you're recovering yourself from the c-section, then it can be hard to sit for so long, but try your best to stay as long as you can for your baby. I would also say to pray as much as you can, praying helped me feel better. But yes, just ask questions as much as you can. Don't have any doubts."

Participant 2 pondered and emphasized the significance of actively participating in the care of the baby:

> "My advice is that if your baby goes to the NICU, try to spend as much time with your baby as possible. Make sure you ask nurses to hold your baby. As moms, we can't see our baby crying, we can't see them in dirty diapers. I want mothers to know that if you're in the NICU, you can still take care of your baby. Don't be scared. I was away from my

> baby for 14 days and that was hard. I could only come see my baby for an hour or two and that too, was difficult for me. So I would tell future mothers, to do more, if you can feed them, feed them. If you can change them, change them. Spend time with them. Because without these opportunities, and sometimes you have to make the opportunities yourself, the baby suffers and the mother suffers, both of us suffer."

Participant 3 reiterated the sentiments expressed by earlier participants but underscored the significance of placing trust in NICU staff:

> "I would also say to trust the NICU staff, I think they know best and especially when we need their help for our baby's health, it is okay to rely on them for support. I also think ask a parent, ask to be part of the care. Ask to bathe your baby, to hold your baby, to do diaper changes, etc. Don't be afraid to do that."

Participant 4 communicated similar comments, advising: "I would tell future moms to be strong, and trust what the nurses and doctors are doing. I know it can get scary, but it will be over soon."

CHAPTER FOUR: DISCUSSION

Discussion Overview

In this research study, four South Asian mothers participated in interviews to share their experiences of their newborn being cared for in a NICU. Their responses help answer the study question, "How do South Asian women who have had a neonate admitted to the NICU describe their experience?". This chapter interprets, and discusses the four themes—1) Seeking to Understand, 2) The Impact of South Asian Culture on the NICU Experience**,** 3) Becoming a Mother One Step at a Time, and 4) Circle of Care —derived from the study data, drawing connections with existing literature. Study strengths and limitations are presented and the chapter concludes with potential implications for future research focusing on nursing practice and the South Asian community.

Seeking to Understand

The first major theme of this study is *Seeking to Understand.* A significant observation from participant interviews was their ongoing endeavour to seek an understanding of various aspects of their NICU experience, including their baby's diagnosis, prognosis, medications, and the necessary education for a successful transition home. Participants explored the factors that impacted their capacity to gain understanding and unveiled the influence of language barriers and background knowledge on navigating the experience of having a baby in the NICU.

The term "language barrier" is defined by the Merriam-Webster dictionary (2024) as "a difficulty for people communicating because they speak different languages". In the healthcare setting, language barriers are recognized for affecting patient safety, the delivery of high-quality care, access to healthcare services, and, ultimately, impacting the overall patient experience (Al Shamsi et al., 2021; Ellahham, 2021; Pandey et al., 2021; Yeheskel, 2020). In the NICU, the

patient experience revolves around individual families, aligning with the principles of family-centered care (FCC, Neu et al., 2020; Reid et al., 2021). Introduced in 1992, the FCC approach aims to foster a considerate response to the unique needs of each family and encourage parental involvement in the care and decision-making processes for their infants (Neu et al., 2020; Reid et al., 2021). Unfortunately, the participants in the present study conveyed that a language barrier hindered their capacity to quickly and fully understand the occurrences that took place during their stay in the NICU. In addressing challenges with health literacy, participants mentioned turning to Google as a method for acquiring information about medications or other health-related terms discussed during conversations with healthcare providers. Consequently, family involvement in the decision-making and care of their infant was restricted. These findings are consistent with the existing literature. In a study conducted by Palau et al. (2018) English-speaking and Spanish-speaking parents were evaluated in a NICU to explore the extent of their understanding of their infants' diagnoses. The findings of the study demonstrated that Spanish-speaking parents were not only four times more likely to inaccurately describe their infants' diagnoses but also self-reported having limited knowledge of the NICU interventions administered to their babies (Palau et al., 2018). In a recent Canadian study conducted by Bajgain et al. (2020) researchers define a good patient experience as one encompassing "respect, effective communication, shared decision-making, physical comfort, emotional support, and continuity/timely access to care" (p. 1). It can be argued that when effective communication is hindered by a language barrier, there is a heightened difficulty in addressing the remaining components essential for a good patient experience. Bajgain et al. (2020) also reported that individuals from diverse immigrant communities express apprehensions regarding language barriers, noting heightened anxiety and emotional distress stemming from concerns about

miscommunication with healthcare providers and the potential for misinterpretation. The results of the present study align with the notion presented by Bajgain et al. (2020). Participants noted that the challenges and anxiety emanating from their limited proficiency in English affected not only themselves but also their husbands. They expressed a joint effort to be present at their baby's bedside, anticipating nurse or physician interactions where questions might be asked, or information conveyed. Being together increased the likelihood of comprehending the information. Some mothers shared that if their husbands, also immigrants with limited English proficiency, were alone at the bedside, they experienced anxiety due to difficulties in understanding. Thus, participants who had better English proficiency compared to their spouses would sometimes serve as translators, relaying information to their husbands if confident in their understanding.

Moreover, participants not only conveyed challenges related to the language of communication between English and Punjabi but also highlighted difficulties arising from the inclusion of medical terminology in the communication. One participant emphasized feeling fortunate to possess a substantial background in health sciences. As a result, the utilization of medical terminology during her NICU stay did not overwhelm her. Instead, she expressed concern for mothers in the NICU who were unfamiliar with medical terminology, recognizing that it could significantly complicate their NICU experience. Moreover, in a study by Ahmed et al. (2017), immigrant patients shared their perspectives on facing communication barriers with physicians. These patients voiced difficulties in grasping medical terminology when presented in languages other than their native ones (Ahmed et al., 2017). In the current study, difficulty with medical terminology was noted, with one participant mentioning resorting to Google to learn medical terms. This finding aligns with research by Todd & Hoffman-Goetz (2011), a Canadian

qualitative study focused on the cancer information-seeking experiences of Chinese immigrants. Todd & Hoffman-Goetz (2011) identified strategies employed during information seeking, and akin to the current study involving South Asian immigrant women, participants expressed the need to grasp complex and unfamiliar medical terminology to effectively communicate with their physicians (Todd & Hoffman-Goetz, 2011). Ultimately, Todd & Hoffman-Goetz (2011) found that this led to a decreased likelihood of seeking further clarification on certain issues. Notably, Zhao (2023) illustrates that even patients familiar with the host culture and language encounter challenges with medical language, underscoring the significance of the difficulties faced by patients and families who do not share the same native language. While one participant, drawing on her healthcare background, reported no difficulty understanding medical terminology, the remaining participants stressed their preference for healthcare providers who spoke the same or a similar language to enhance communication and comprehension.

The Impact of South Asian Culture on the NICU Experience

The second major theme identified within this study was *The Impact of South Asian Culture on the NICU Experience.* All participants shared a common identity as South Asian immigrant mothers. Each participant delved into the repercussions of South Asian culture and its impact on their NICU experience. Participants engaged in discussions regarding concerns about societal perceptions of their newborn being in the NICU. Participants were also concerned about their abilities to protect the baby's well-being, as well as the stigma associated with acknowledging illness or mental health difficulties encountered in the NICU, which they saw as a taboo topic within their cultural context. Consequently, participants hesitated to discuss these matters with many family members or relatives beyond their husbands. They refrained from sharing news about the baby and avoided seeking assistance even when it was needed.

Studies have shown that although mental health illnesses are common in South Asian communities, they are less likely to be reported and therefore treated (CAMH, 2019a; Karasz et al., 2019; Gadalla, 2010). This behaviour might be a result of the stigma surrounding mental health in South Asian communities, which is influenced by several cultural elements (such as the importance of disguising weaknesses for the sake of familial reputation) that are commonly overlooked (Chaudhry & Chen, 2016). Intriguingly, several researchers have discovered and reported that South Asians are unwilling to seek help if they feel stigmatized for having a mental illness and feelings of shame (Wynaden et al., 2005; Arora et al., 2016; Chaudhry & Chen, 2016; Karasz et al., 2019). More than ten years following the study by Wynaden et al. (2005), subsequent researchers such as Arora et al. (2016), Chaudhry & Chen (2016), and Karasz et al. (2019) have documented similar findings, underscoring the significance and consistent prevalence of shame in South Asian cultures and the apprehension of being judged. Chaudhry and Chen (2016) illustrate this theme with the term *"izzat"*, which is understood by Punjabi, Hindi, and Urdu-speaking South Asians. In English, this term is defined as reputation or honour. Researchers found that South Asian individuals preferred to have their *izzat* than to admit to having mental health conditions to avoid being referred to as "mentally ill" (Chaudhry & Chen, 2016). Confirming earlier reports, Anand & Cochrane (2005) discuss that *izzat* while underlining the difficulty in seeking professional assistance, particularly if it comes from someone of the same ethnic origin, due to the fear of exposure and judgment from South Asian groups.

Findings in the present study suggest that the stressors of the NICU, parents may require additional mental health support. As an immigrant, various negative SDoH may make it challenging to seek mental health services (Karasz et al., 2019; Statistics Canada, 2021). Compared to Caucasian communities, South Asian populations perceive the most significant

barriers to receiving mental health services (e.g., counselling and examinations) and thus, are 85% less likely to seek help (CAMH, 2019b; Gadalla, 2010; Karasz et al., 2019). The impact of stressors and poor SDoH on seeking help is particularly important to remember in acute-care settings such as NICUs.

Becoming a Mother One Step at a Time

The third significant theme identified in this study revolves around the concept of *Becoming a Mother One Step at a Time*. This overarching theme demonstrates the intricate journey participants embarked upon as they embraced motherhood in the NICU one step at a time. These steps mirror the three discernible sub-themes identified within the study: 1) maternal self-doubt and uncertainty, 2) navigating motherhood in the NICU, and 3) mothering beyond the NICU.

The first step as conveyed by each participant centers on the reactions of mothers undergoing their first childbirth experience. As a result, it is anticipated that their descriptions involve a significant degree of apprehension. Despite discussing past experiences with newborns (such as caring for cousins, nephews, or nieces), participants voiced uncertainties about their ability to parent effectively. This uncertainty led to feelings of self-doubt and fear, emotions that have been previously examined and documented in the existing literature concerning first-time motherhood and the experiences of mothers with infants in the NICU (Palma et al., 2016; Anderson, 2017).

The second step in the journey of becoming a mother for participants in this study involved navigating motherhood in the NICU. Participants began by describing their initial hopes of a vaginal or "normal" birth but ended up having c-sections, which increased their sentiments of worry and uncertainty. Participants reported their physical limitations in sitting for

extended periods, climbing stairs, and entering and driving a car. Some also stated they experienced bleeding and dizziness. Participants explained that these difficulties and the discomfort they felt were a barrier to effectively tending to their infants and being physically present in the NICU. Their responses align with existing literature. For example, Wang et al. (2021), found that maternal complications such as a c-section disrupted the mother-baby bonding experience and presented difficulties for the mother in simultaneously tending to her own recovery and engaging with her baby. A prevalent finding among participants in the current study was their expectation of a typical childbirth (i.e., vaginal delivery). However, due to unforeseen circumstances (e.g. hypertension, gestational diabetes) participants had unanticipated c-sections. Mothers expressed their profound fear, concern for their health and the well-being of their baby, and the overwhelming anxiety associated with the entire experience of being in the NICU. This finding is supported by a recent study by Orovou et al. (2023), which underscores the significance of recognizing maternal depression and anxiety. The study also illuminates how unexpected events, like a c-section, can impact a mother's mental preparedness, potentially intensifying distress levels (Orovou et al., 2023). Karlström (2017) further supported that women who underwent an unplanned c-section were twice as likely to express fear regarding the childbirth experience compared to those who had a spontaneous birth.

Another facet of navigating through motherhood in the NICU involved experiencing instances of separation between mother and baby. During this research, participants reported experiencing separation from their baby on two occasions. Initially, it occurred immediately after childbirth when the mother was in the labour and delivery room, and the baby was transferred to the NICU. Subsequently, they encountered anxiety related to their separation when mothers took time to return home for rest and recovery, while their baby remained in the NICU. These

findings are consistent with what is reported in the current literature. Garg et al. (2023) conducted a study investigating stress, postpartum depression, and anxiety among mothers with newborns admitted to the NICU. Their findings suggested a direct link between a parent's psychological well-being and the quality of the parent-baby attachment and relationship. The study highlighted those mothers initiating motherhood in the challenging NICU environment experienced difficulties in mother-baby attachment (Garg et al., 2023). Additionally, the research conveyed that both physical and emotional separation from the child contributed to increased stress and complicated the adaptability to the environment (Garg et al., 2023). Spence (2023) emphasizes that compared to parents of healthy infants, parents of babies in the NICU face heightened levels of stress, and negative emotions, and perceive inadequate social support. The findings of Spence's study consistently align with those of other research studies (Ionio et al., 2019; Klawetter et al., 2019; Lotterman et al., 2018; Malakouti et al., 2013; Nazari et al., 2020; Sanders & Hall, 2018; Vinall et al., 2018; Williams et al., 2021). These studies, along with the responses gathered from participants in the current research, collectively reveal reports of stress and anxiety related to the NICU experience and parenting in the NICU.

Furthermore, navigating motherhood in the NICU also entails transitioning home from the NICU. Given the challenging nature of the NICU, it is not unexpected that participants in this study expressed a strong longing to return home as soon as possible during their NICU stay. During interviews, participants conveyed their consistent inquiries during their stay in the NICU such as "When will we go home?". Mothers discussed the continuous changes in the discharge date, resulting in delays that heightened their concerns. This situation of delays in discharge home led them to believe that their babies were more unwell than they were being informed. As a result, participants began to doubt the transparency of information provided by nurses and

physicians, questioning whether they were withholding details. This finding is similar to a report from the Canadian Pediatric Society (Anderson & Narvey 2022), which identified one of the most common questions asked by parents in the NICU is “When will my baby come home?”. While this question is frequently posed, Anderson and Narvey (2022) underscore the significance of preparing families for life at home. Participants in the current study expressed their lack of confidence in being sufficiently prepared for the transition home. One participant shared the difficulties she encountered when her baby struggled to latch for successful breast feeding after discharge. She expressed a desire for better support before leaving the hospital to avoid such challenges post-discharge. Smith et al. (2022) stress the significance of delivering comprehensive discharge education to every family. Preparation for discharge should include assessing the extent of each family's understanding of infant care and determining if additional assistance or support is needed to improve their skills for home-based baby care (Smith et al., 2022). Such support may involve demonstrating skills or sharing resources and materials outlining key steps and milestones for the baby, advising on breastfeeding positions, and offering tips for successful latching (Smith et al., 2022). Offering tailored emotional and educational assistance enables families to undergo a smooth transition home with their newborn (Purdy et al., 2015; Smith et al., 2022).

Despite a wealth of literature highlighting the negative effects of a NICU stay, it is crucial, during the discharge process, to carefully consider each family's support system, cultural practices, and readiness for the journey into parenthood at home. The findings of the current study coincide with the evidence presented in the existing literature however, the unique aspect of this study and what it adds to the current research body is the inclusion of detailed

descriptions of a distinctive sample population, exclusively comprising adult women of South Asian descent.

Circle of Care

The fourth and final overarching theme identified in this study is the *Circle of Care.* The term "circle of care" refers to the concept wherein a healthcare professional can infer that they have implied consent from a patient or client to access or share personal information (Information and Privacy Commissioner of Ontario, 2015). Beyond healthcare professionals, the circle of care can include a patient's family and friends (College of Nurses of Ontario, 2016). During the interviews, participants shared their thoughts on their engagements with their circle of care, encompassing nurses, physicians, and family members. Participants recounted both favourable and unfavourable encounters with nursing staff. Favourable experiences centered on nurses who were encouraging active involvement in caring for their baby, addressing language barriers, and offering supportive non-essential care for the baby, such as decorating the incubator. Unfavourable experiences were associated with the attitudes and behaviours of nurses, insufficient explanations during care, and a lack of clarification regarding the baby's prognosis. Their experiences were consistent with what is noted in the current literature (Kim, 2023; Lomotey et al., 2019; Negarandeh et al., 2021; Rihan et al., 2021; Wang et al., 2021).

Participants also recounted their positive and negative interactions with their family members. All participants expressed gratitude for the support of their husbands and emphasized how crucial their presence and involvement were in caring for both them and the baby. The significance of companionship was highlighted, with participants acknowledging uncertainty about overcoming the challenging experience without their spouses. The literature on NICU experiences has previously discussed the support provided by husbands or fathers. Research

indicates that during NICU stays, husbands prioritize the needs of mothers and infants, learning to collaborate and increasing their engagement to demonstrate support (Rihan et al., 2021; Stefana et al., 2022). These findings parallel the descriptions shared by participants in the current study, as each participant emphasized the significant role their husbands played as one of their primary support systems during their NICU stay.

Discussion Summary

Overall, the experiences of participants in the current study align with many findings in recent and older reports in the literature. What distinguishes the present study and sets it apart from the current body of literature is its focus on South Asian immigrant mothers. Despite being one of the largest and fastest-growing populations in Canada this population is underrepresented in existing literature (Statistics Canada, 2023). Consequently, this study begins to address and bridge that gap.

Study Strengths

Qualitative description research is renowned for its capacity to attain a profound comprehension of a poorly elucidated phenomenon (Sandelowski, 2000). Pioneered by Margaret Sandelowski, qualitative description (QD) enables researchers to remain closely connected to the data and the essence of participants' expressions and experiences (Sandelowski, 2000). This study aligns with that philosophy by concentrating on the verbatim expressions, sentences, and experiences of the participants. The findings and discussion adhere to the interview data, thereby enhancing the research study's depth and facilitating a comprehensive exploration of a phenomenon previously unexplored within the context of South Asian immigrant women. Methodologically, the current study also attained a comprehensive understanding of the findings through a "thick description" approach, where participants extensively explored their thoughts

and emotions to provide detailed descriptions of their experiences. Furthermore, despite not reaching the intended sample size, the inclusion of four participants still resulted in data saturation, indicating information redundancy, as supported by Sandelowski (2000).

This research study benefits from the homogeneity of the participant group of mothers, consisting exclusively of South Asian immigrant women. All participants share common characteristics, such as being born in India, having Punjabi as their first language, and being first-time mothers. This homogeneity offers several advantages, including a more focused understanding of a particular phenomenon, the potential for richer and more nuanced findings, and increased trustworthiness due to the shared commonalities observed in participant responses.

Furthermore, an additional strength of this study lies in the composition of the sample, comprising individuals who have all had recent experiences in the NICU within the past year, rather than including women currently situated in the NICU. This study maintains its strength as it affords participants the chance to reflect on and process their experiences before engaging in the interview discussions.

Study Limitations

As mentioned earlier, the homogeneity of the sample served as a strength, but it also served as a limitation in this study. While homogeneous samples offer certain advantages, such as a focused analysis, they also pose limitations in terms of transferability. Studies with homogenous samples are recognized for their restricted applicability, as the findings are often specific to that particular group and may not be extrapolated to a more diverse population (Bornstein et al., 2015; Jager et al., 2017). However, the methods and outcomes of this study might apply to other ethno-racial communities that have similarly been under-researched.

Another limitation of this research study is the recruitment process. One of the original recruitment strategies was to conduct face-to-face recruitment within the NICU setting. However, this proved unfeasible, leading to the adoption of indirect methods, which ultimately yielded no success over several months. Therefore, adjustments were made to the research question, expanding the inclusion criteria to South Asian mothers with NICU experiences within the past year. The recruitment process also influenced the sample size, posing a limitation in this study. Initially aiming to enroll 10 participants, only 4 were ultimately deemed eligible and included by the end of recruitment.

Implications

This study begins to fill a critical gap in research on the NICU experiences of South Asian immigrant women, providing a foundational platform for future nursing research, South Asian studies, and advancements in nursing practices. The findings offer insights with several implications for clinical nursing. For example, delays in discharge led to heightened doubts about transparency, emphasizing the importance of clear communication and preparation for potential delays to alleviate parental concerns. Participants expressed a need for reassurance that their babies' diagnoses were not unique, suggesting the potential value of creating informative materials or engaging in discussions with healthcare providers to address these concerns.

Furthermore, the study sheds light on nursing and physician interactions, aiming to foster culturally sensitive care practices and equip healthcare providers with the skills needed to cater to South Asian immigrant mothers' needs during their NICU stay, discharge, and beyond. Additionally, it is hoped that this research will spur further exploration into the influence of South Asian culture on hospital experiences, including taboo topics like mental health, and general health practices.

Future research avenues could include studying the experiences of South Asian mothers with previous parenting experience or those lacking support from spouses or family members. Moreover, investigations into the impact of demographic factors, such as years since immigration or specific infant criteria, on the NICU experiences of South Asian mothers could provide valuable insights. In addition to exploring the NICU experience, future research could delve into understanding how South Asian culture shapes the health and wellness of mothers.

While this research study contributes valuable insights to the literature on NICU experiences, the distinct participant group offers the potential to illuminate the specific needs expressed by this demographic, raising the possibility of its relevance to other first-time and/or ethno-racial immigrant groups as well.

The next steps for actions for healthcare professionals entail gaining insight into the unique needs of individual patients and their families and devising tailored care plans to ensure the provision of necessary support for a positive patient experience. Nurses and physicians are urged to actively inquire whether mothers and families fully comprehend all the information provided during their NICU stay. If not, they should promptly inform them of the availability of translation services and ensure their accessibility for every interaction. Furthermore, some participants in this research study underscored their dissatisfaction with their interactions with healthcare professionals, naming concerns about the perceived "roughness" in the care provided to their babies. It is strongly recommended that nurses and physicians consistently prioritize gentle, compassionate, and safe care practices for infants under their supervision.

Conclusion

The objective of this qualitative descriptive research was to describe and understand the experiences of South Asian immigrant mothers in the NICU. The principal findings of this

investigation are categorized into four overarching themes: 1) Seeking to Understand, 2) The Impact of South Asian Culture on the NICU Experience, 3) Becoming a Mother One Step at a Time, and 4) Circle of Care. The themes illuminated various aspects of the NICU journey, encompassing challenges such as language barriers, worries about societal perceptions, maternal self-doubt and uncertainty, navigating motherhood within and beyond the NICU, perceptions of care and support, and coping mechanisms during the NICU stay. These findings serve as a foundation, offering insights into future nursing practices, research endeavours, and studies focusing on the South Asian community.

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Appendix A: NICU Study Flyer

Version 1 - 12/21/22

Page 1 of 1

SOUTH-ASIAN IMMIGRANT MOTHERS' NICU HOSPITAL EXPERIENCES

Are you a South-Asian immigrant mother? Do you want to share your NICU experience? If so, you are invited to participate in this **research study!**

REQUIREMENTS:

- South Asian immigrant adult women between 18 and 40 years of age
- Identify as a mother of a preterm infant admitted to the NICU for > 3 days
- Immigrated to South Western Ontario in the last 10 years from South Asian countries
- Speak English or 1 of the following languages: Hindi, Punjabi, Urdu and Tamil

WHAT DOES IT INVOLVE?

- 45–60 minute interview
  - one-on-one
  - via Zoom, telephone, in person

GET A $30 PRESIDENT'S CHOICE GIFT CARD FOR PARTICIPATING!

If you are interested in sharing your experience, please email the student researcher, **Rosie Deol.**

deolg7@mcmaster.ca

Thank you for choosing to contribute.
Your experience matters.

The Hamilton Integrated Research Ethics Board has reviewed this study under project #15766.

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Appendix B: Email/Telephone/In-person Script

Hello! My name is Rosie Deol, and I am a graduate student researcher at McMaster University's School of Nursing. I was provided with your name and contact information by staff at Sick Kids Hospital after you expressed you were interested in this research project that I'm conducting focusing on the experiences of South Asian immigrant mothers with an infant in the NICU. This study is being done as part of my master's degree program and is being supervised by Dr. Mary Woodward from The Hospital for Sick Children and Dr. Olive Wahoush from McMaster University.

To participate in this study you need to be: a) a South-Asian immigrant woman between the ages of 18 and 40; b) identify as a mother of a preterm infant admitted to the NICU for > 3 days; c) have immigrated to Canada in the last 10 years from South Asian countries and d) speak English or 1 of the following languages: Hindi, Punjabi, Urdu and Tamil.

Your participation in this study is entirely optional, are you comfortable hearing more about this study at this time?

You are not required to participate in this study. I can provide you with the study information sheet so you can decide if you would like to be interviewed. If you have any questions, please email me or call me at any time.

If you agree, I will review the information letter and consent form with you now.

Thank you for contacting me. Do you have any questions, comments or concerns?

Appendix C: Letter of Consent/Information

LETTER OF CONSENT/INFORMATION

A Qualitative Description of South-Asian Immigrant Mothers' NICU Hospital Experiences

Investigators:

Local Principal Investigator:
Dr. Olive Wahoush
School of Nursing
McMaster University
Hamilton, ON, Canada
(905) 525-9140 ext. 22802
E-mail: wahousho@mcmaster.ca

Student Investigator:
Name Gurvir Deol
School of Nursing
McMaster University
Hamilton, ON, Canada
Phone 647-920-6700
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Study Purpose

Gurvir (Rosie) Deol is conducting this research project as part of her Master of Nursing degree requirements. The purpose of this study is to (a) describe and understand the experiences of South Asian immigrant mothers who currently have or previously had a preterm or term infant admitted to a Level III NICU for greater than 3 days in the past year and (b) identify the perceived challenges and needs of South Asian immigrant women during NICU hospitalization.

What will happen in the study?

Data for this study will be gathered using semi-structured interviews, participant observation, and a demographic questionnaire. You will first be asked to complete a demographic questionnaire, which will consist of ten questions (a combination of multiple choice and short answer questions) concerning your demographic data, such as age, birthplace, and educational level. This should be completed before to the interview. This will be emailed to you, and you can either email the completed questionnaire back or submit a hard copy if your interview is in person.

The following phase is a confidential semi-structured one-on-one interview. You will be asked to participate in person, via telephone or through Zoom. Zoom is an externally hosted cloud-based service. A link to their privacy policy is available here: https://explore.zoom.us/en/privacy/.

While the Hamilton Integrated Research Ethics Board has approved using Zoom to collect data for this study, there is a small risk of a privacy breach for data collected on external servers. If you are concerned about this, we would be happy to make alternative arrangements for you to participate, perhaps via telephone or in person. Please talk to the researcher if you have any concerns.

The aim of this interview is to collect in-depth data about your experience as a South-Asian immigrant mother with an infant in the NICU. The interview will last approximately 45-60 minutes long. In order for the research team, including myself, to examine the data at a later stage, the interview will be audio-recorded with your consent. You will be contacted to set up an appropriate time and place for the interview if you agree to take part in the study. To make sure the description of your personal experience is accurate, you may be asked to verify a summary of your interview. You should be aware that any personal information you provide to the researcher will be coded, preventing any possibility of your being identified.

Potential Harms, Risks or Discomforts:

It is unlikely that this study will cause any harm, risks, or discomfort. If answering a question makes you feel uncomfortable or you don't want to, you are not compelled to. We can skip a question, end the interview, or take a break if necessary if you feel uncomfortable.

Potential Benefits

This study may not benefit you directly however, this study will 1) assist in establishing new avenues of research for studies with comparable research subjects in the future; 2) contribute to the understanding of the experiences of South Asian immigrant mothers in the NICU; 3) help identify or inform new resources and supports available for South Asian immigrant mothers in the NICU and 4) inform nursing practice. Each participant may benefit from taking part in this research project since it may provide a platform for them to talk about their experiences, which may be beneficial.

Incentive

If you choose to participate in this research study you will be awarded a $30 President's Choice gift card.

Confidentiality

Privacy and confidentiality are critical components of this study. You are participating in this study confidentially. I will not use your name or any information that would allow you to be identified. No one but me (or other members of the research team such as the supervisory committee) will know whether you participated unless you choose to tell them. To maintain privacy and confidentiality, participants will be de-identified (e.g. names) in all aspects of data collection, including audio recordings, field notes, transcriptions, and publications of data. All sources of data collection will be kept in an online encrypted secure file on a password-protected laptop stored in a secure location. Only those directly involved in overseeing the research process will be given access to study data. Every recorded interview will be transcribed and stored in an encrypted secure location. The research team (such as the supervisory committee) will have access to your de-identified information in order to evaluate and analyze data.
All data retrieved will be solely used for the research study and will be stored and discarded in compliance with McMaster University policies. The recordings will be deleted after transcription and the remaining identifiable data by August 2026.

Participation and Withdrawal

Your participation in this study is voluntary. It is your choice to be part of the study or not. If you decide to be part of the study, you can decide to stop (withdraw), at any time, even after signing the consent form or part-way through the study. If you decide to withdraw, there will be no consequences to you. If you decide to withdraw from the study, the information you gave up to the moment of withdrawal will be securely stored in the same manner that the information of other participants is stored. Alternatively, you can remove any personal information or data acquired through the study. I will, however, urge that you notify me of your desire to withdraw your data by phone or email no later than two weeks following your interview. This is due to the fact that once the interview is concluded and data is obtained, your data will

be anonymized, evaluated, and joined with data from other interviews for a more thorough analysis. As a result, it will be hard to identify and delete your data.

Please note that as a participant, you are asked not to make any unauthorized recordings of the session. If you choose to do your interview on Zoom, a video file is automatically recorded and will be deleted immediately after by the researcher.

For the purposes of ensuring proper monitoring of the research study, it is possible that representatives of the Hamilton Integrated REB (HiREB), this institution, and affiliated sites or regulatory authorities may consult your original (identifiable) research data to check that the information collected for the study is correct and follows proper laws and guidelines. By participating in this study, you authorize such access. By participating in this study you do not waive any rights to which you may be entitled under the law.

Information about the Study Results

I expect to have this study completed by approximately by April 2024. If you would like a brief summary of the results, please let me know how you would like it sent to you.

Questions about the Study

If you have questions or need more information about the study itself, please contact me at: Deolg7@mcmaster.ca. If you wish to speak to my supervisor, Dr. Olive Wahoush you may contact her at McMaster University, School of Nursing at the phone number (905) 525-9140 ext. 22802 or through email at wahousho@mcmaster.ca.

This study has been reviewed by the Hamilton Integrated Research Ethics Board (HiREB). The HiREB is responsible for ensuring that participants are informed of the risks associated with the research, and that participants are free to decide if participation is right for them. If you have any questions about your rights as a research participant, please call the Office of the Chair, HiREB, at 905.521.2100 x 42013.

CONSENT

Study Title: A Qualitative Description of South-Asian Immigrant Mothers' NICU Hospital Experiences

Declaration: This study and this consent form has been explained to me. I have read or had read to me the information in this letter regarding the study being conducted by student researcher, Gurvir Deol.

I have read the information presented in the information letter about a study being conducted by Gurvir Deol of McMaster University.

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

I understand that if I agree to participate in this study, I may withdraw from the study at any time. I will be given a signed copy of this form. I agree to participate in the study.

_____	_____	_____
Name of Participant (Printed)	Signature	Date

Consent form explained in person by:

_____	_____	_____
Name and Role (Printed)	Signature	Date

Appendix D: Demographic Questionnaire

Date:

Participant ID #:

Thank you for consenting to participate in this research. Please read each question carefully and choose the most appropriate answer. This questionnaire has 10 questions designed to learn more about you as a South Asian immigrant mother. Please note everything will be kept strictly confidential.

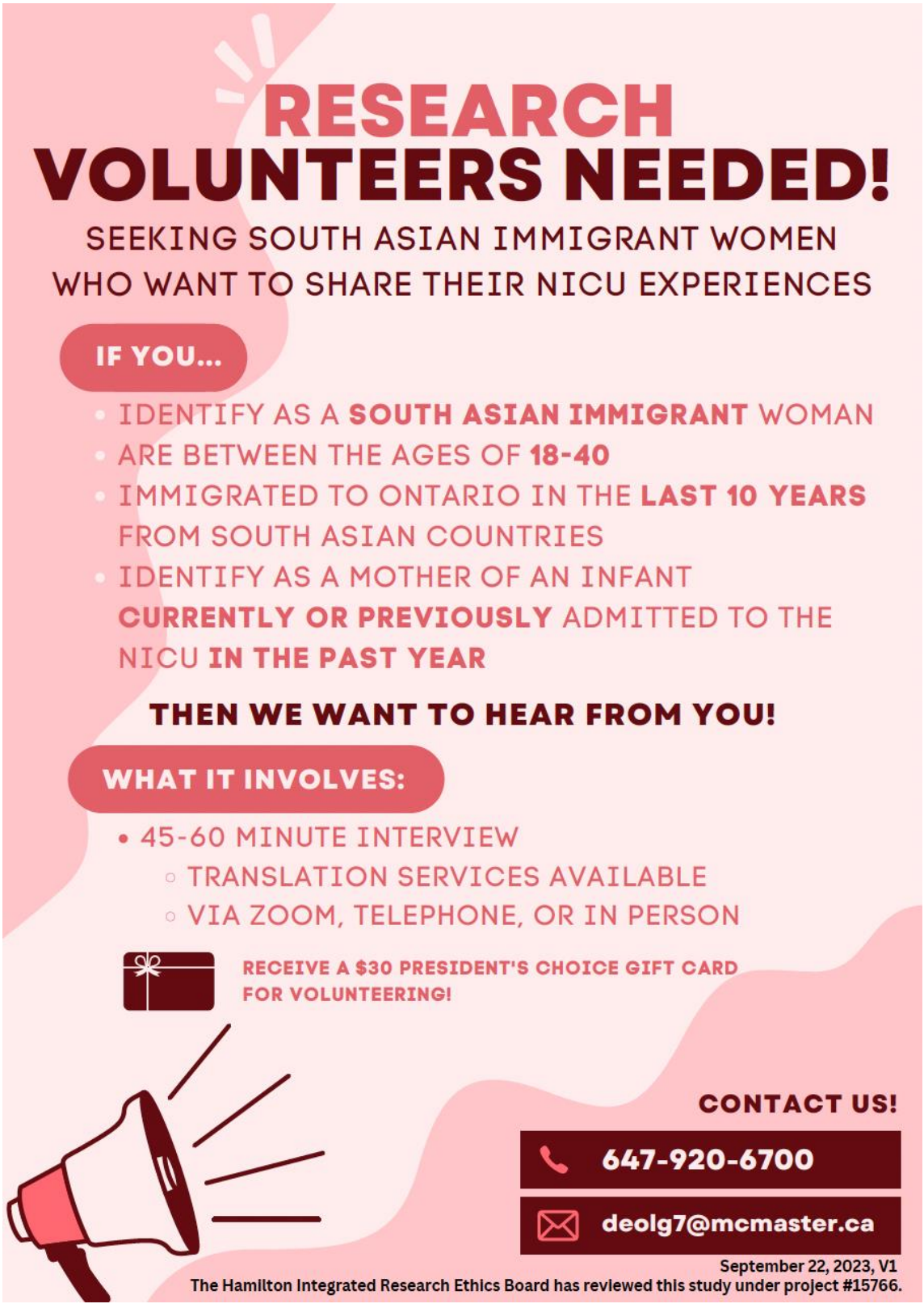
1. Age
   - ☐ 18-25 years old
   - ☐ 26-33 years old
   - ☐ 34-40 years old
2. Education Level
   - ☐ Highschool Diploma
   - ☐ College Diploma/Degree
   - ☐ University Degree
   - ☐ Master's Degree
   - ☐ Other:_____
3. Employment Status
   - ☐ Full-time
   - ☐ Part-time
   - ☐ Unemployed
   - ☐ Other:_____
4. Country of Birth
   - ☐ India
   - ☐ Pakistan
   - ☐ Bangladesh
   - ☐ Sri Lanka
   - ☐ Maldives
   - ☐ Bhutan
   - ☐ Nepal
   - ☐ Other:_____
5. What is your first language?
   - ☐ Punjabi
   - ☐ Urdu
   - ☐ Tamil
   - ☐ Hindi
   - ☐ Other:_____
6. How many years ago did you immigrate to Canada?
   - ☐ 1-3 years
   - ☐ **4**-6 years
   - ☐ 7-10 years
7. What is your marital status?
   - ☐ Single
   - ☐ Married
   - ☐ Divorced
   - ☐ Widowed
   - ☐ Other:_____
8. Number of Children (including the current child in the NICU):
9. At what gestational age did you give birth? (e.g. 33 weeks):
10. Have you had a child admitted to the NICU before this experience?
    - ☐ Yes
    - ☐ No

Appendix E: Interview Guide

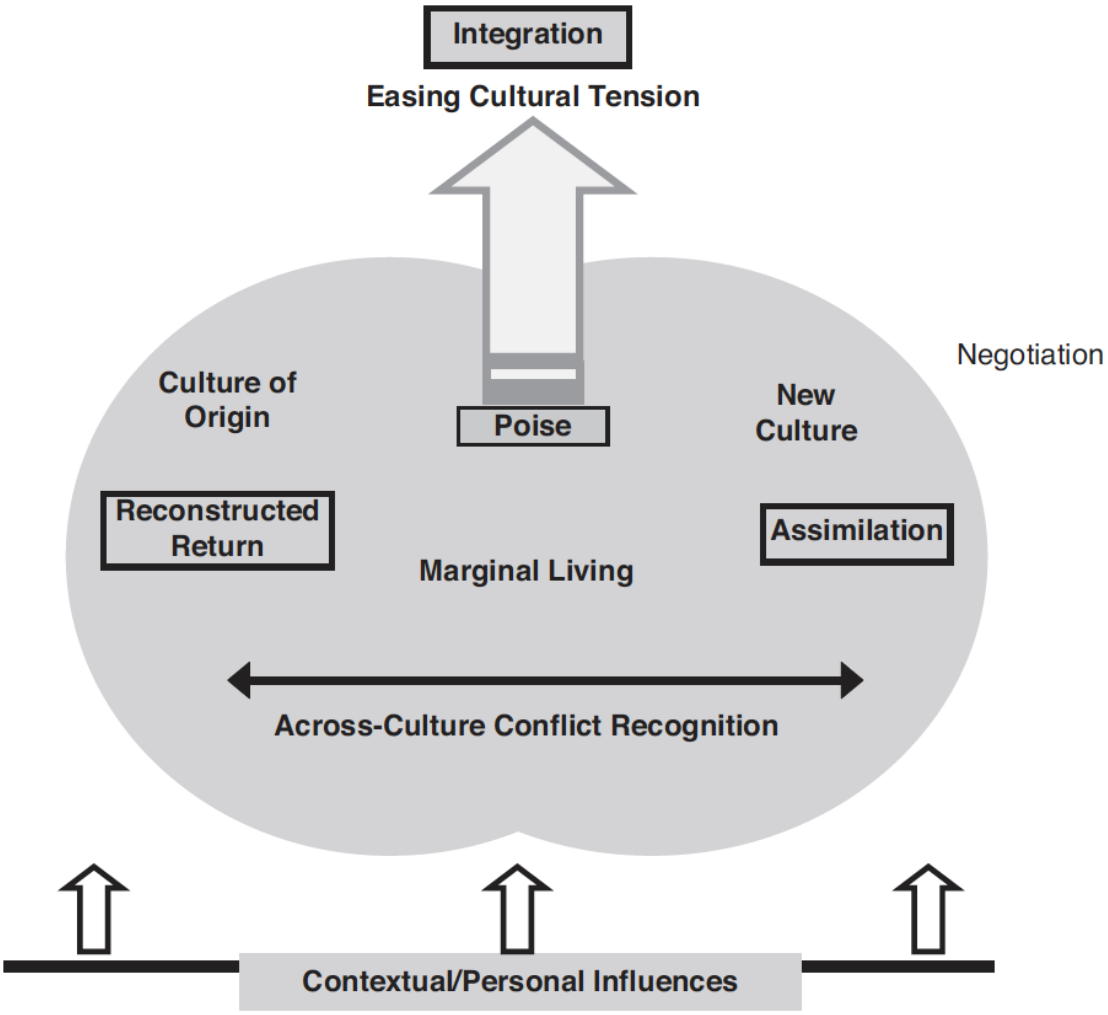
Study Background:
Thank you for taking the time to speak with me today. I would first like to ensure you that anything that is discussed today will remain confidential unless there are any safety concerns. This study is being conducted to describe and understand the experiences of South Asian immigrant mothers who have a preterm infant admitted to a Level III NICU for greater than 3 days and (b) identify the perceived challenges and needs of South Asian immigrant women during NICU hospitalization.

1. Can you tell me about your experience as a mother in the NICU thus far?
   Probe:
   - Did you know before the birth of your child that they would be admitted to the NICU?
   - How did you feel?
   - How did you cope with being in the NICU with your baby?
2. How would you describe your experience as an *immigrant* mother in the NICU?
   Probe:
   - How does your status as an immigrant affect your experience in the NICU?
   - How did you cope with being in the NICU with your baby?
3. Can you describe some of the challenges you experienced during your baby's hospitalization?
   Probe:
   - Did you know of supports that were available to you during your stay?
   - If so, what were they? Did they help you with your challenges?
   - If not, what type of support/resources do you wish were available to you?
4. How does identifying as a South Asian immigrant and the expectations of the culture affect your role and responsibility as a mother?
   Probe:
   - What are the cultural expectations of a South Asian mother?
   - What was culturally important to you during your baby's NICU hospitalization?
5. How has your mental, emotional, and physical health been during your baby's NICU hospitalization?
   Probe:
   - How did you feel?
   - What support did you have?
   - Did you share your challenges with anyone?
6. Can you describe your interactions with healthcare staff (e.g. nurses and physicians) throughout your hospitalization?
7. If you could give advice to another South Asian mom prior to their NICU hospitalization stay, what would you say and why?
8. Is there anything else you would like to share with me about your experience?

Appendix F: Social Media Flyer



Appendix G: Theory of Cultural Marginality



Appendix H: Themes, Sub-Themes, Meaning Units

Theme	Sub-theme	Meaning Units
Seeking to Understand	Language Barrier	I think it's important because sometimes even I think if the nurses and doctors all spoke Punjabi to me during the NICU I probably would have a better or faster understanding of what was happening. So when my baby was in the hospital I don't think there were many Punjabi speaking nurses but my baby's pediatrician who came to see us every day was South Indian and spoke Hindi which is quite similar to Punjabi so I was able to understand him. One thing I really liked was for example when my baby had so many IV's the doctor recommended inserting a PICC line, and when he introduced this idea to me he asked if I wanted an interpreter so that I could fully understand what the benefits about PICC line would be for my baby and why he had suggested it. But I declined anyway because I was able to understand what he was saying. Because we are Punjabi, I understand English a little bit but sometimes we don't understand it. Yeah. So for that, we need an Indian nurse or someone who can translate for us. If someone doesn't know English, then we should translate for them. Like, this is what this means. I have a husband who knows English, but not very well. He can understand a little bit but he can't speak it. It is very difficult. Especially, if he went to see the baby on his own, he would feel anxiety because I'm not there to sort of help him, so he just doesn't ask questions, because he's afraid he won't even understand what they're saying and he just goes to see the baby and comes back home. Yeah, like if we had an Indian nurse who spoke Punjabi, we would ask as many questions as we could and were able to and that we thought of because we weren't sure if we were going to get another Punjabi-speaking nurse the next day. For example, the Gujrati nurse, she spoke Hindi, but I and my husband understand Hindi, it's very similar to Punjabi so this made things easier. The main doctor was speaking in English. For that reason, I always attended the hospital with my husband because if the doctor came my husband couldn't understand. But I could understand most of what he was saying, but if I didn't, he brought a nurse or a translator that spoke my language to help me

		understand. My husband couldn't really understand, so sometimes I'd try to explain or the nurse or translator would.
	Health Literacy	No, I think the hardest part was language, but I would always get nurses or doctors to write down medicine names or anything medical that I wasn't aware of. That way I would google it myself or ask my family to help me understand, especially if I didn't feel comfortable asking the nurse or doctor myself. Another thing I think about is I'm lucky I can understand English and medical terminology but for mothers that don't know English or even do know English but still don't know medical terminology. That's what's hard. I knew whatever my doctor was describing, I was aware of what he was talking about because of my background. Well first of all I think it is extremely challenging to be in a NICU when you don't have medical knowledge. I was really lucky that I did but I don't know how mothers who don't survive in the NICU. Like for example, they planned doing a PICC line for my baby. So that was a big issue for my husband and my family. They had so many concerns and questions, they'd ask "How will they get it?" "she's so tiny, why are they going to do that?" and that's when I had to be their support as well and explain.
The Impact of South Asian Culture on the NICU Experience	Concerns about Societal Perceptions	On top of that, being Indian, you know how it is…if it's a girl, there's already so much tension and stress because boys are preferred over girls. Then on top of that, if the baby's not healthy, and has to stay in the hospital, that's another issue Indian mothers have to face. Then the third concern is the mothers' health. No one cares for the mother. The poor mother is the one who suffers because she stresses for her baby, what people think, and then her own condition. I found it hard to survive too you know, I worried for my physical health, my mental health and I had my emotions too you know…but I'd say I had an easier time coping because I was a nurse. I knew what was happening to my kids and to me. But I think Indian families… they don't really know how to support each other. They don't know what to do or say or how to act. They worry about older Indian traditions like giving "gudti" to the newborn. These are things they worry about and I don't think that's something we can change. I would try my best to take care of myself and you know as a first-time mother I was scared but I didn't even want any help from any one if I'm being honest. You know how it is, if you ask for support or help from someone, they'll never let you forget it. So, I just was happy to prepare for my baby to come home

		on my own. When we become mothers you know, these capabilities come on their own. God only puts people through challenges, who he knows can endure them. I hope that what I've experienced brings good karma later down my life or my baby's life. Yes, well I was worried about what other people would think or say. My baby was born quite early, in fact, her main part, the part that tells us if it's a boy or girl, that wasn't developed yet. The doctor had told us they did genetic testing and those reports took a really long time to come. The doctor wasn't able to confidently tell us whether we had a boy or a girl. The doctor had also done an ultrasound and even that report showed that it was not clear whether it was a baby boy or a baby girl. This was very difficult for us. It took them three weeks to tell us that we had a baby boy. We used to ask almost every day, what the gender of my baby was. This was really, really hard. For those three weeks, I didn't tell anyone I delivered a baby. Only me and my husband knew. You know how it is in our culture, the first question they ask is if it's a boy or a girl and I didn't have the answer to that question so I just didn't bother telling anyone. I kept what are people going to think or say? We finally had a baby and we don't even know if it's a boy or girl? I just would rather not tell anyone.
	Comparison to India	Sometimes I think that if this happened in India, I doubt we would have received the care that we did. I'm just lucky, we've heard of deliveries in India and you know, they don't have proper checkups there, they don't care as much as they care here. I think perhaps if I was still in India if my baby would still receive this type of care.
Becoming a Mother One Step at a Time	Maternal Self-Doubt and Uncertainty	Yeah sure I've taken care of babies before I have little cousins and I helped them and raised them but this was my first ever baby. Even when I did help my little cousins obviously when it was time for the baby to be breast fed or for a diaper to be changed I knew to hand over the baby to the mother but in this case the baby was mine. I didn't know what to do. When I was in the NICU, I thought "How will I take care of this baby? Will I even be able to? Will I be able to provide good care for him?" As a mother, for the first time, I don't know anything about latching. I want to try and learn. I would try my best to take care of myself and you know as a first-time mother I was scared.

		It is also our first baby, I feel like first babies have a different level of attachment, it was really hard having him there and not home right away.
	Navigating Motherhood in the NICU	Yeah sure I've taken care of babies before I have little cousins and I helped them and raised them but this was my first ever baby. Even when I did help my little cousins obviously when it was time for the baby to be breast fed or for a diaper to be changed I knew to hand over the baby to the mother but in this case the baby was mine. I didn't know what to do. When I was in the NICU, I thought "How will I take care of this baby? Will I even be able to? Will I be able to provide good care for him?" As a mother, for the first time, I don't know anything about latching. I want to try and learn. I would try my best to take care of myself and you know as a first-time mother I was scared. It is also our first baby, I feel like first babies have a different level of attachment, it was really hard having him there and not home right away. Although that was nice to see and hear for the day and 1/2 that I never got to see him I was really upset I kept telling the doctors "I want to go see him, I want to go see him" and then finally the Doctor who helped me during my delivery allowed me to sit in a wheelchair and one of the nurses took me into the NICU. That was really hard for me, having to wait. But I felt way better after seeing my baby. I did feel separation anxiety…like I didn't live close to Brampton, but I did feel like even though my child was far away, there was proper care being provided. Yes, there was a separation with the child. Right after delivery, my baby went to the NICU and you know, I gave birth on the 16th and it wasn't until the 22nd that I got to hold my child for the first time. Even after I delivered, I asked if I could breastfeed my baby and they said no. They told me to pump and then they'd give it to my baby for me and I didn't like that. I feel like that shouldn't have happened. Yeah because when the child is there for that long of a time, the separation, the bond…it's not there.

		They don't know about their mother or father. They don't know about their own house. They just know the hospital. I really felt detached. Like my baby was staying at the hospital, meanwhile, I was staying at home. That was difficult. My biggest challenge was coming home, not with the baby, but just myself. They discharged me but moved my baby in the NICU. I came home and I felt guilty about that. I cried the whole night. Even the next day, when I went to go see her, I kept thinking how did I leave her for this long overnight on her own. I felt really bad. I kept thinking, was she in safe hands or not? Will they treat her well? Will they feed her? If I'm being honest, I can't explain that type of fear I felt. For one and a half days, my husband stayed in the NICU with our baby because I started experiencing dizziness and I had a lot of bleeding and because there was a lot of blood loss the doctors had to take care of me in a separate area I had an induced labour, it was intended to be a normal delivery, but I wasn't able to keep pushing so the doctor had to do an emergency cesarean section for me. Then the third concern is the mothers' health. No one cares for the mother. The poor mother is the one who suffers because she stresses for her baby, what people think, and then her own condition. I found it hard to survive too you know, I worried for my physical health, my mental health and I had my emotions too you know…but I'd say I had an easier time coping because I was a nurse. It wasn't a planned c-section. I was induced because I had hypertension, but then my blood pressure was dropping, my blood sugar was dropping and then my doctor said we couldn't wait and did a c-section. I had an induced labour, it was intended to be a normal delivery, but I wasn't able to keep pushing so the doctor had to do an emergency cesarean section for me. I was diagnosed with gestational diabetes at the 26th-week mark. And at the end of the last week around 36 weeks, I also had hypertension. Then the doctor didn't want to wait, so he did a c-section.

		I couldn't handle sitting and praying for long periods of time because I had a c-section and I was still in some discomfort. It was difficult to go up the stairs or get into a car. My stitches actually ended up opening, I was really bothered and uncomfortable. I mean, thank god we even did do a c-section and delivered and that was a good decision on my doctor's part because maybe my baby wouldn't have survived. One thing I want to add is when I first went to the hospital, I went because I was having contractions and I thought I was going to deliver. I thought I was going to have a normal delivery. Then, I had developed a fever, which wasn't going down and at that time the doctor told me that the baby's heart rate and so on so forth was healthy, so they wanted to wait another hour or so to see if my fever would come down. But then all of a sudden, the baby's heart rate was getting really high, my fever was still really bad and then that's when the doctor asked for my consent for a c-section. I ended up going through an emergency c-section and that's when I was terrified I just kept telling the doctor "Please do anything to keep my baby safe. Do whatever you have to do. I want the baby to come into my hands safely". I had a normal birth. So when they told me they were going to shift my baby to the NICU side, I didn't know what they meant or why. I have always known the NICU babies to care for premature babies, so I didn't know why they were shifting her there because I gave birth at 42 weeks. I was scared. I was scared when they moved her, I thought she must have been really sick for her to go there. I was scared when they gave her injections but then I kept telling myself, that this was for the benefit of her health. I was happy afterwards they shifted her there because she got the help she needed to get better.
	Mothering Beyond the NICU	I kept thinking when will we get out of the NICU? When will we go home? At first they told us that we would be in the hospital for only seven days for antibiotics. But then after the 5th day, they told us that the antibiotic treatment will actually be for 14 days not 7. This made me even more scared and made me wonder if there was something else going on with the baby because they told us he only had a fever, which he didn't even have anymore, so why do we need to stay for another week? This is why I was so scared.

		I used to explain to my husband too, there are several other babies there too. Not just ours. Don't worry, everything will be okay. If we don't get discharged one day, I used to tell him, don't worry, we'll get discharged another day. I knew we were going to go home. When I reflect, I feel like I spent very little time with my baby while she was in the NICU and when my baby came home she didn't latch. When they discharge you, they don't clear those things and make you feel comfortable about it. They mention your future appointments, they give you a list of things to do, but I don't think they really value how you'll do when you get home. That's the thing. To this day, I remember every date and time everything occurred. I'll never forget. But that's okay, right now, my baby is okay, the weight is okay, and now know the baby is healthy and happy and everything is normal. Yeah, that was one of the scariest thing I've gone through, but I just wanted my baby safe. When I left the NICU, I kept thinking to myself, I hope no one ever has to go to the NICU. When my husband and I see pregnant women in the public like in the grocery store for example, we both always pray that they have a normal delivery and don't have to experience a difficult time like us and never have to visit a NICU. Yeah you know, he's thriving. He's playing, he's a little naughty. He smiles. He does so many activities, plays with so many toys. I'm so grateful we made it out of the NICU.
Circle of Care	Perceptions of Care	To be honest, we only had one incident with a nurse and that was when we were being discharged. To start, we had to wait for her for maybe 1.5 hours and our baby was fussy and crying, we kept saying we had to go, our baby needed to be fed, etc. etc. Then she came, she checked my baby's diaper, then on top of that, they were giving her iron, checking her vitals…it was just so much at once. Then I got really upset. I said I will feel my baby myself, I will change my baby myself. Please just stop. I got frustrated and finally admitted that I too, am a RN and I know this isn't how you're supposed to do things. The nurse wasn't even telling me why she was giving her iron or how much and that really bothered me. Tell me, I am the parent. I want to know. So yeah, with that specific nurse, I was really upset. Then she apologized. But because she knew I was an RN, she kept informing me of every little thing after and that's what I didn't like. Because you should do this with every mother. Her IV was changing daily. I couldn't see her getting pricked daily. My question to the nurses was why are you getting the PICC line in for 3 days? I was not asking them why are they getting the PICC line in.

		If you were getting the PICC line, you should have got it on the first day so my baby didn't need to go through all that. I think nurses and doctors should try to be clear with their statements. As parents, we rely a lot on what our nurses and doctors say to us. You know, its common for a doctor to say "at this moment, your baby is fine" or "right now, your baby is okay". I think for that present moment, we feel relief but then anxiety builds up again. There were some nurses, and I won't say that nurses name, but like for example, last night I went to go see my baby and that nurse was very rude and aggressive, meaning like her behaviour was unkind. If we asked her questions, she'd answer in a different way than sometimes with other parents. Sometimes me and my husband would think maybe it's because we have an accent or because were Indian, is that why she's treating us like this? This made us not want to ask questions anymore. Meanwhile, some other nurses, maybe one or two of them, when we go, wouldn't even say hello or hi or would ask us if we'd like to hold our baby. None of that. There was this one nurse, she was also Indian, and she was the day nurse. During shift change, they gave report at the bedside and she was showing the oncoming night nurse my baby's PICC line. When she showed the night nurse my baby's arm, she moved my baby's arm really rough and I kept saying "please handle him gently", but because she was so aggressive, my poor baby didn't stop crying. When I told that nurse to be gentle, I could tell from her demeanor she was upset…she said "no don't worry I know, I handle babies every day, this is my daily job". I could tell she had an ego. But yeah I don't know what she did, for so many days, my baby was doing so well with the PICC line but after she yanked his arm the way she did, he didn't sleep the whole night. He was so irritated. And every time he'd cry, his arm would move, and that would make the IV pump go off. It went off so many times that even I learned how to use it and silence it. The sound of the IV pump alarm was so loud and it was hard to keep waiting for a nurse to come every single time to come silence it. I didn't want to wake my baby and other babies so luckily I was able to learn what to press to silence it. The next day, the previous day nurse came again and she was our nurse again. I didn't want to say anything, and my husband asked me not to say anything to that nurse, but I ended up saying something because I really felt so upset that she handled my baby in that way. I kept telling her even the night before like "he's already so little, so fragile, he's gone through

		so much since he was born, he didn't sleep all night, I didn't sleep all night". I didn't want to say something, but I had to. I was too upset. You know, since he was born he's had so many IV's, he had IV's in his hands, his feet, and even his end. It wasn't until towards the end of the treatment when they decided to put a PICC line in. I kept thinking like my baby has already suffered so many times, so I told the nurse like "how would you feel if you had a PICC line in you and someone handled your arm so roughly? Wouldn't you feel so frustrated too? He's so vulnerable, he can't even speak and tell us how he feels". So yeah, I said something, I didn't want to but I said quite a bit of stuff, because that really upset me. After that, she treated him well throughout the day. She was very gentle and thoughtful but I still wished I could have had another nurse. I was even thinking of complaining to the doctor, but then my husband stopped me and said its okay, you're just upset, we don't want to have any impact on her job. So I didn't say anything, I didn't want her to get in trouble. But I felt strongly about voicing my concern and I'm glad I said something to her so she can think twice before handling my baby and other babies.
	Support and Coping	Well, while I was in the NICU, the only visitors allowed to see my baby were myself and my husband. So it was hard to rely on other members of my family. The biggest support I had was my husband. He was there for us all the time. For me and my baby. I also rarely saw other parents in the unit and if I did, I didn't want to bother them. My husband always reassured me that our baby will be okay. He reminded me that I can ask any questions as well. He and I would exhaust google, we would google search so many things, so many times a day. My family is full of doctors as well, so my cousin and aunt and sister-in-law, they're all doctors. So I used to ask them questions all the time. I spoke to them almost daily and I would feel better after talking to them and to my husband. and I'm glad I believed them and trusted them especially my husband, because now my baby is so good, so healthy, meeting all his milestones and if it weren't for my husband's support, I don't know where I'd be. I talk to my husband because he is very supportive. He supports me in everything. My husband takes care of me. Before, during and after delivery. He took care of me. He always does. My husband and my mom were my biggest supporters I would pray. I would also just call the nurses or I would go see my baby. I couldn't handle sitting and praying for long periods of time because I had a c-section and I was still in some discomfort. I knew that our baby was going to be there for a few days. So I came to terms with that. I used to explain to my

		husband too, there are several other babies there too. Not just ours. Don't worry, everything will be okay. If we don't get discharged one day, I used to tell him, don't worry, we'll get discharged another day. I knew we were going to go home. My brother, and my parents are in India, and they did a special prayer for our baby there too. I would also say to pray as much as you can, praying helped me feel better. Something as simple as a pamphlet for common NICU diagnoses. This is the diagnosis, this is an estimated length of stay, this is common side effects, common medications, and no I'm not saying I'm asking for assurance, I don't expect every situation to be the same, but just something so parents know what to expect. But anyway, so, for that, I wish we had a translator who could tell us in Punjabi what the nurse or doctor is saying. I think its important for nurses and physicians to emphasize and reassure to parents that this has happened to other babies. You're not alone. Your baby is not the only one who's endured this. I think these are important things to say to the family. To remind them that just because they're at the NICU, it doesn't mean our baby is not normal, they are just going through a tough time, but everything will be okay. All a parent wants to hear is everything will be okay. These are things I wish were communicated. Just some more compassion. Just ask direct questions to the doctors and nurses, don't be afraid. It's scary, but ask questions, it will make you feel better. Also, stay as much as you can, I know it's not an ideal space to sit and if you're recovering yourself from the c-section, then it can be hard to sit for so long, but try your best to stay as long as you can for your baby. I would also say to pray as much as you can, praying helped me feel better. But yes, just ask questions as much as you can. Don't have any doubts. My advice is that if your baby goes to the NICU, try to spend as much time with your baby as possible. Make sure you ask nurses to hold your baby. As moms, we can't see our baby crying, we can't see them in dirty diapers. I want mothers to know that if you're in the NICU, you can still take care of your baby. Don't be scared. I was away from my baby for 14 days and that was hard. I could only come see my baby for an hour or two and that too, was difficult for me.

		So I would tell future mothers, to do more, if you can feed them, feed them. If you can change them, change them. Spend time with them. Because without these opportunities, and sometimes you have to make the opportunities yourself, the baby suffers and the mother suffers, both of us suffer. I would also say to trust the NICU staff, I think they know best and especially when we need their help for our baby's health, it is okay to rely on them for support. I also think ask a parent, ask to be part of the care. Ask to bathe your baby, to hold your baby, to do diaper changes, etc. Don't be afraid to do that. That's all I can really think about. I would tell future moms to be strong, and trust what the nurses and doctors are doing. I know it can get scary, but it will be over soon.