

Understanding the Experience of South Asian Immigrant Women in the NICU: An Interpretive
Description

BY

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B.Sc., from University of British Columbia, 2001
B.N, from University of Manitoba, 2004

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ABSTRACT

This research study seeks to better understand the experience of South Asian immigrant women in the Neonatal Intensive Care Unit (NICU). The information gathered cannot be generalized to all South Asian and other immigrant populations nor is it the intent of this study. Instead, by examining the individual NICU experiences and challenges faced during this experience, themes emerge that can prompt neonatal nurses to examine their own practice with immigrant families. The main, overall theme identified in all participant responses was, Fear of the Unknown. Three subthemes that emerged from discussions regarding how participants experience nursing care were Trust, Teaching and Advocating. In terms of what participants identified as their most critical concerns while their infant was in the NICU, the three subthemes that arose were Language Barriers, Lack of Knowledge about the NICU and A More Comfortable NICU. On a broader scale, it is hoped that this research study will inspire all nurses to examine their interactions with all immigrant families in order to provide care that is holistic and individualized to the needs of their immigrant patient.

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A final thank you to my husband, Chris Wilson for pushing me into applying into the MN program in the first place and for always reminding me that I can achieve anything if I really want it. You have always believed in me and I am grateful to have you as my partner in life.

Dedication

To my mother

Reshma Garga

The bravest South Asian immigrant mother I know.

Thank you for inspiring me to undertake this research project with your own stories of struggle

and courage as you cared for my brother during the first years of his life at B.C. Children's

Hospital

Chapter One

UNDERSTANDING THE EXPERIENCES OF SOUTH ASIAN IMMIGRANT WOMEN IN THE NICU: AN INTERPRETIVE DESCRIPTION

Introduction & Background

According to Citizenship and Immigration Canada (2000), the number of immigrants that arrived in Canada between 1995 and 1999 was over one million. The 2001 census done by Statistics Canada also documents this diversity by reporting that approximately 5.4 million Canadians, or 18.4% of the total population were born outside of the country. Further enriching this demographic picture, the most common origins reported from recent arrivals were Asian, Caribbean, Arabian and African. In addition, it was found that most of these immigrants settled in large, urban centers (which house numerous Neonatal Intensive Care Units (NICUs) including tertiary care centers) such as Toronto, Canada, which has the highest magnitude of foreign-born citizens of all the cities in the world (Statistics Canada, 2003). Without question, Canada is a multicultural country home to immigrants, refugees and citizens who come from a multitude of ethnic backgrounds.

This phenomenon of ethnic diversity in Canada is reflected in hospital demographics and more specifically, NICUs. In a study done by Claydon, Mitton, Sankaran, and Lee, (2007) data related to ethnicity of premature babies born was collected from nine NICUs representing each of the five geographic regions of Canada (British Columbia, the Prairies, Ontario, Quebec and the Atlantic provinces). Of the total study population of known ethnicity, 63.5% were of Caucasian origin, 14.4% Aboriginal, 6.1% South Asian, 5.5% East Asian, 4.1% African, 1.7% Hispanic and the remaining 4.8% were labeled other. According to the 2010 British Columbia Women and Children's Health Centre (BCWH) NICU admission data, 11% of all 2010 admissions were of South Asian descent, which were the third highest ethnic group to be

admitted to the NICU. This data depicting the ethnic diversity of infants lead to questions about how to best care for these infants and their mothers, particularly in immigrant populations where disparities in health delivery or health outcomes may already exist.

Statement of the Problem

Many South Asian immigrant women have infants in the NICU at British Columbia Women's and Children's Health Centre (BCWH). Although there is considerable heterogeneity within South Asian groups, similarities of family values and structure, communication, religion and health beliefs may contribute to common obstacles faced by South Asian women. In addition, cultural factors and common issues related to the acculturation and assimilation processes also contribute to these challenges when faced with a new healthcare system (Ahmed & Lemkau, 2000).

Having a premature or critically ill newborn is a stressful and life changing experience for any parent. Delivery of a premature or critically ill infant triggers a cascade of psychosocial crises for the parents of these newborns (Bass, 1991). However, this experience can be compounded for South Asian immigrant women who must also deal with the stresses of being in a foreign country. These mothers may experience disadvantages many immigrant groups experience such as stress, underemployment, discrimination, poor housing, lack of access to services and inadequate social support. In addition, they may find the new healthcare system confusing and simply may not know where to go or who to ask for help. Language barriers and cultural differences further add to this level of confusion causing them to feel isolated and neglected (Simich, Beiser, Stewart & Mwakarimba, 2005). It is important that research be conducted that explores the experience of South Asian immigrant women in order to identify the unique challenges and obstacles they face. Exploring these challenges is essential for optimizing

the NICU experience and building health promotion strategies for these women during such a stressful and critical event.

Purpose of the Proposed Research Study

The purpose of this research study is to understand the experiences of South Asian immigrant women in the NICU. More specifically, the focus of this study will be how South Asian women experience nursing care in the NICU. The primary audience for this study will be neonatal nurses since they are the persons who provide care for both the infants and mothers in the NICU. It is my hope that this research will allow nurses to understand how South Asian immigrant women make sense of their NICU experience in order to provide care that is family centered and sensitive to the needs of all immigrant families. In addition, this research is also targeted at neonatal unit managers in hopes of creating change in NICU environments that allow for a more positive NICU experience for South Asian immigrant mothers and immigrant families overall.

Research Questions

The research questions addressed in this study are:

1. How do South Asian immigrant women experience nursing care in the NICU?
2. What do South Asian immigrant women identify as the most critical concerns or needs in terms of nursing care while their infant is in the NICU?
3. What do South Asian immigrant women identify as most and least supportive psychosocial neonatal nursing practices while their infant is in the NICU?

Significance of the Topic

This research is important to me for many reasons. As the daughter of a South Asian immigrant woman, I listened to the many challenges and barriers my mother faced with her first

encounters with the Canadian healthcare system. During her first three years in Canada, my mother, a young, naïve newcomer from India spent a great deal of time at British Columbia Children's Hospital with my brother who was born with bilateral club feet. Although my mother had the advantage that she spoke and understood English fluently, she still describes the experience as extremely isolating, stressful and full of difficulty. She was housed at Easter Seal House (funded housing nearby the hospital for out-of-town families) because my family was living in Penticton, B.C. at the time. The separation from my father, who had to work to provide for our family, and support from other relatives only added to her sense of loneliness and exacerbated her increasing stress levels.

Although my experiences as a first-generation South Asian woman and the impact of my mother's stories are not the focus of this research study, they influence my desire to delve deeper into the experience of South Asian immigrant women. Thus in accordance with an interpretive tradition, my own personal experiences, presuppositions and knowledge will act as valuable guides to inquiry and will make the research process a meaningful undertaking. Lopez & Willis (2004) state, "It is impossible to rid the mind of background of understandings that has led the researcher to consider a topic worthy of research in the first place" (p. 729). This view will be further explored in the methodology section of my proposal.

I have worked in the NICU at BCWH for the past six years and have encountered many South Asian women and their families. These women undergo the same struggles all families coping with having a sick infant in the NICU experience. However, they also encounter many of the same difficulties my mother experienced due to their immigrant status. For example, their inability to speak or understand English often leads to them being uninformed about the status of their infant until an interpreter can be brought in. They also lack a social support network

because although many of these women live in large families, these family members are often their in-laws or from their husband's side of the family. As a result, these women do not have someone who is "their own" to confide in.

In addition to these hardships, these women must also often endure stereotypes and judgments made by the nursing and medical team. For example, I have overheard many of my colleagues speak negatively of South Asian families who have wanted to continue care for their extremely premature son. Nurses have made comments such as, "Its only because it's a boy otherwise they would have let it die." As a result of listening to my mothers stories and experiences working as a neonatal nurse with South Asian families, I became interested in how South Asian immigrant women experience neonatal nursing care and the unique challenges they face. It is my hope that this research study exploring the experience of South Asian women in the NICU will allow me to better understand what my mother went through when she first immigrated to Canada. In addition, hopefully it will educate caregivers and provide insight into the unique journey of these immigrant women.

Chapter Two

Literature Review

Introduction

Currently there is neither scholarly nor non-academic literature addressing the exact phenomenon of understanding the experience of South Asian immigrant women in the NICU. There is however, literature that addresses areas related to this topic of inquiry such as South Asian immigrant women's health experience, immigrant health and the experience of families overall in the NICU.

South Asian Immigrant Women's Health Experience

In their 2002 study, Choudhry, Jandu, Mahal, Singh, Sohi-Pabla & Mutta conducted a qualitative study using interviews with South Asian immigrant women in order to identify their unique health needs and factors that affected their health status. They wrote, "Research indicates that many South Asian women lack knowledge of health risks, having differing ideas about self-care, experience language barriers, and are economically dependent" (2002, p. 75). The study concluded that maintaining culture and tradition, placing family needs before self and surviving by being strong were three dominant factors that were important to South Asian immigrant women and affected their health status and experience with the healthcare system.

Similarly, Ahmed & Lemkau (2000) identified numerous cultural features that were relevant to health care and South Asian immigrant women. One such feature is family values and structure where women are expected to assume domestic responsibilities and bear children. Family needs are given higher priority than individual needs. Education is another such feature where South Asian women tend to be well educated but then upon immigration, subordinate their

own career aspirations to those of their husbands. Other features identified by Ahmed & Lemkau (2000) include, religion, cultural beliefs and practices and nonverbal communication.

Grewal, Bhagat & Balneaves (2008) conducted a qualitative study using focus groups with Punjabi women in order to describe the cultural traditions that surround Punjabi immigrant women's perinatal experiences and the ways traditional beliefs and practices are incorporated into the Canadian healthcare context. The participants also described their interactions with health care professionals during the pregnancy. The researchers found that the women believed the physician to be the most important health professional during the prenatal period and nurses during the labour and delivery period. The participants also experienced challenges in their interface with the Canadian health care system in areas such as accessing information, and understanding the role of technology and the role of hospital nurses in the postpartum period.

Immigrant Health

In the field of immigrant health, a great deal of literature exists exploring “the healthy immigrant effect,” which is the observed trend, “whereby the health status of immigrants at the time of arrival is high but subsequently declines and converges toward that of the native-born population” (Newbold, 2009, p. 545). The existing literature attempts to understand this “healthy immigrant effect” by determining if it can be explained primarily by socioeconomic, sociodemographic or lifestyle factors, which all may point to problems in the Canadian health care system.

An ongoing study related to immigrant health is currently being conducted by the Canadian Collaboration of Immigrant and Refugee Health (CCIRH) in hopes of establishing clinical guidelines for practice. More specifically, using a systematic, evidence-based approach, the CCIRH provides detailed methods and results related to the burden of illness for immigrants

and refugees compared to Canadian-born populations. They also include a summary of fifteen recommendations which they feel will provide a foundation for improving health care for immigrant populations. These recommendations are directed at a variety of areas related to immigrant health from infectious diseases such as tuberculosis and HIV, mental health issues such as depression, to women's health issues such as pregnancy and contraception use. For example, one recommendation is to develop interventions to prevent social isolation for pregnant immigrant women because they are at higher risk for maternal morbidity and having infants small for their gestational age (Pottie et al., 2010).

Other studies related to immigrant health explore the barriers to health services experienced by immigrants. Henry, Tator, Mattis & Rees (2000) wrote:

Some of the barriers to health and social services identified by minority-group clients were lack of information about the services provided, the unavailability of service, the service providers' lack of knowledge of the linguistic and cultural needs of different groups, and the inappropriateness of treatment modes and counselling (p. 210).

Many of these studies provide ways to combat these barriers in the form of culturally sensitive care, use of interpreters and linking with immigrant outreach programs in the community.

The connection between immigrant health status and the social determinants of health such as income status, education level and social support is another common theme in immigrant health literature. For example, immigrants are over-represented in lower-paying and lower-status jobs. According to the results from the National Population Health Survey, immigrants were significantly underrepresented in the upper middle-income quartile and non-European immigrants were significantly underrepresented in the highest income quartile (Dunn & Dyck, 1998). This phenomenon is significant because lower-paying and lower-status jobs result in

poverty and all three trends are social determinants of health. Aside from the obvious connection that low income levels do not allow individuals to financially practice healthy behaviours, there are also indirect ways low income affects health status. Wilkinson (1994) stated, “The stresses of economic insecurity or relative deprivation may impact directly on health, affecting both the endocrine and immune systems. Relatedly, psychosocial stress may cause people to start smoking or engage in behaviours which are detrimental to health” (p. 71).

Education, which is another social determinant of health, also affects this disparity in income levels and job status. Because the education and professional status of immigrants and refugees is often not recognized in Canada, it results in lower-paying and lower-status jobs (Dunn & Dyck, 1998). Social support also influences health status. Immigrants are less likely to have social support because of their arrival in a new country with a new language and numerous cultural barriers. In addition, they often have fewer family members and members of their own community in Canada to use as a support network. As a result, they experience social exclusion and loneliness, which can result in depression and lower health status. Dunn & Dyck (1998) stated:

Non-European, less well-established immigrants were overrepresented among those reporting that they did not; have someone to make them feel loved, have someone to advise them on personal decisions; have someone to confide in and talk about personal matters, and have someone to help if they needed it (p. 15).

Furthermore, this depression and loneliness caused by lower social support often goes undiagnosed and untreated because in many cultures they are not perceived as medical problems but as personal ones (Newbold, 2009). As a result, the compromised health status of immigrants declines even further.

The 2000/2001 Canadian Community Health Survey highlights many strengths of immigrant populations. For example, immigrants had significantly lower rates of alcohol dependence and depression than the Canadian-born population. In addition, immigrants were found to consume fruits and vegetables at a higher rate and had lower rates of overweight. Also, foreign-born teenagers were less likely to use illicit substances than their Canadian counterparts and adult immigrants had lower rates of smoking (Ali, McDermott & Gravel, 2004). Ahmed & Lemkau (2000) also highlight strengths of the South Asian culture such as strong family ties, encouraging educational or occupational success and maintaining family values.

There is also research that explores the vulnerable groups within the immigrant population. The Centres of Excellence for Women's Health (2001) stated, "The application of gender analysis to health has been effective in revealing gender gaps among immigrants and refugees, and the social processes that reinforce them" (p. 8). Thus, Canadian immigrant women have particular social, cultural and economic experiences that may require specialized nursing care and particular policy responses. For example, immigrant women may have to cope with distinct realities such as threats of violence, intergenerational tensions and changing familial roles and responsibilities (Bannerjee, 1985). Another vulnerable group within the population of interest are refugees who are sometimes viewed as involuntary migrants versus immigrants who are regarded as voluntary migrants. Although the two groups share many common characteristics and experiences, they also vary in age, economic, social and political status, education, national origin, culture and ethnic and racial identity.

The area of immigrant health is a field that is recently beginning to gain attention. As a result, many gaps exist in the literature and thus, further research is needed in order to address these gaps (Guruge & Khanlou, 2004). For example, mental health promotion among immigrant

youth and health issues of lesbian and bisexual immigrant women are examples of important topics that lack nursing research. As Canada's immigration rates continue to grow, the need for inquiry into this population is critical in order to deliver care that is based on evidence.

Experience of Families in the NICU

There is a great deal of literature exploring the family experience in the NICU with particular emphasis on parental stress and perceived parental role. In their phenomenological study, Schenk & Kelley (2010) interviewed nine women who had extremely low birth weight infants in the NICU. The major themes revealed in this study were "being the mama" and "making the connections." Within each of these major themes, minor themes existed such as being worried and scared, exhaustion, accepting help from family and community and relationships with doctors and nurses. Schenk & Kelley (2010) conclude this study by stating "Additional studies need to be conducted with samples of mothers, fathers, or families with a wider range of ethnic, geographic, and socioeconomic background" (p. 96).

Many studies also explore how various ethnic traditions and beliefs that are related to neonatology and perinatology influence family's experience in the NICU. For example, according to Bracht, Kandankery, Nodwell & Stade (2002), having a sick infant in the NICU is especially difficult for many Chinese families because they experience great shame for producing an infant with a disability. However, they will still love and accept their infant unconditionally but out of feelings of duty and obligation. Mothers of African background reported that the most difficult aspect of having a sick infant was that they were not with them at all times. These mothers experienced a great deal of separation anxiety and their prime focus was when their infant would be able to come home. In addition, they felt they were unable to fully love their infant in fear that their infant would die. Therefore, these mothers did not want to

fully attach themselves to their infant.

Grewal et al., (2008) found that women of Punjabi descent followed the cultural practice of *chilia* in which the new mother is encouraged to rest for forty days in the immediate postpartum period. This rest period is viewed as necessary for the new mothers healing process and it is believed that women who do not observe *chilia* may experience health problems later in life. As a result, new Punjabi mothers observing *chilia* may not visit their infant in the NICU frequently and may be viewed as neglectful or uninterested in the condition of their new infant. Other cultural practices Punjabi families may engage in are hanging neem (green leaves from a tree native to India) above the infant's crib or tying a black thread around the infant's ankle, wrist or waist. They may also wish to apply a dot of black kohl on the face of the infant. All of these practices are believed to ward off *najar* or evil spirits and keep the infant safe and promote healing. These practices are extremely important to some Punjabi families, however many do not follow them following the birth of a sick infant because they feel it is not allowed in a hospital setting.

Colon (2001) reported that in many Hispanic families, the role of major decision maker falls to the eldest member of the family, who may be a grandparent. Therefore, it is important for nurses to understand that any major decisions involving the care of the infant should be directed to this elder and the ultimate decision is left to them. Other Hispanic customs include dressing the infant in a hat and rubbing the infant with oil in order to protect his or her spirit. Hispanic families also believe it is acceptable to have a male infant's genitalia exposed as it is a sign of machismo. However, exposing a female infant's genitalia is viewed as dishonorable and disrespectful. Religion is usually an integral part of the Hispanic belief system and these families are usually quite close with their church leader.

Roberts (2003) has done extensive work with Islamic families and their cultural beliefs surrounding childbirth and infant care. In her studies, she encourages nurses to adopt a culturally sensitive stance and provides them with a framework to do so. She discusses how the Koran plays a very important role in the lives of many Islamic families and that time should be given to these families during important decisions because many may want to consult it for guidance. In addition, when using interpreters it is essential that the interpreter and the parent are of the same sex because in Islamic culture discussing health related issues between unrelated males and females is prohibited. Many times when an infant is admitted to the NICU, the mother's placenta will accompany the infant in order to determine whether the parents wish to consent to lab tests and studies related to placental blood and tissue. However, in Islamic culture the placenta is often buried as an act of symbolic return to the Creator.

Summary

A literature review of South Asian immigrant women's health experience, immigrant health and experience of families in the NICU can serve as a foundation for examination of South Asian immigrant women's experience in the NICU. Researchers have demonstrated that South Asian immigrant women face unique health challenges and have special health needs that must be acknowledged in order to deliver optimum medical and nursing care. These health challenges can often be intensified in a stressful environment such as the NICU. In addition, cultural factors, socioeconomic status and the social determinants of health all influence the health status of immigrant families and thus, all must be further explored and researched.

Chapter Three

Methodology

Introduction

This section describes the research design of this study: its sampling and recruitment method, data collection procedures, data analysis, means of ensuring rigor, and ethical considerations and procedures for protecting participant rights.

Research Design

This research study used interpretive description methodology to explore and understand the experiences of South Asian women in the NICU. The foundation of interpretive description is the investigation of a clinical phenomenon of interest to the discipline of nursing. The purpose of this qualitative methodology is to identify themes and patterns within subjective perceptions and offering interpretive descriptions, which can then inform clinical practice. More specifically, inductive analytical techniques are used in order to allow researchers to illuminate the characteristics, patterns, and structure of a clinical phenomenon such that they can be used in some manner to inform clinical nursing practice (Thorne, Kirkham & O'Flynn-Magee, 2004).

I chose interpretive description as the methodology for the study because it was a good fit for the structure and aims of the study. Its orientation toward clinical practice is appealing because the goal of this study is to influence how healthcare and nursing care is delivered to South Asian immigrant women in the NICU. Finally, this methodology has a detailed approach to research design and analysis, which is manageable for my level of knowledge.

Sampling & Recruitment

The sample size of this study was initially aimed at six to eight participants. However, only five participants were recruited and proved adequate to explore the phenomenon under

investigation. Many factors could explain the difficulty in recruiting more participants. Obtaining trust of the South Asian immigrant mothers was essential to the progress of this study. Like any other immigrant population, the South Asian community is reluctant to participate in research for fear of being investigated or other negative consequences (Grewal, 2003). In addition, a lack of awareness regarding the benefit and importance of research and language barriers were also contributing factors to low recruitment numbers.

Finally, although South Asian immigrant mothers who currently had infants admitted in the NICU were approached at a time when their infant was stable and not in critical danger, mothers were still understandably stressed and overwhelmed. Mothers may not wish to “add more to their plate” at time when they have enough on their mind and may want to focus on the health of their infant. As a result, they do not wish to participate in research, which also contributes to the low recruitment numbers. This theory could explain why the majority of participants enrolled in the study are mothers whose infants were discharged home and therefore they were no longer as stressed or worried about their infant.

The initial method of selecting participants for this study was purposeful sampling. According to Schatzman & Strauss, (1973) purposeful sampling allows the researcher to select people according to the aims of the research study. Categories such as age, gender, status, role, stated philosophy or ideology can serve as starting points from which the researcher chooses his or her sample. In this study, the criterion for sample selection reflects the intent of the research, which was to explore and understand the experience of South Asian immigrant women in the NICU. Thus, immigrant women of South Asian descent who had infants currently admitted in the NICU or had infants admitted to the NICU in the past five years were selected for this study. Immigrant women were defined as women who were born in a South Asian country (India,

Pakistan, Sri Lanka, Bangladesh, Afghanistan, Iran, Bhutan, Nepal and Maldives) and had immigrated to Canada anytime prior to the birth of their infant. Their length of stay in Canada was asked as part of the interview but it did not matter how long they had been in Canada to be part of the study. These women all now reside in British Columbia but did not necessarily need to have Canadian citizenship in order to participate in the study.

In addition, participants all had to speak and understand English at a conversational level in order to participate in the study. Purposeful sampling is also directed by a desire to include a range of variations of the phenomenon under study (Coyne, 1997). Therefore, although participants were selected in accordance to the inclusion criteria, both typical and atypical experiences were sought out in order to provide a well-rounded representation of the experience.

As the study progressed, it was hoped that theoretical sampling would be utilized to recruit participants. Glaser, (1978) states:

When the strategies of theoretical sampling are employed, the researcher can make shifts of plan and emphasis early in the research process so that the data gathered reflects what is occurring in the field rather than speculation about what cannot or should have been observed (p. 38).

Because interpretive description methodology dictates that data collection and analysis happen simultaneously, theoretical sampling must be employed in order to identify participants who can speak to particular issues that will be identified in the early analysis of the data (Hunt, 2009). In addition, theoretical sampling is key to the inductive data analysis process of interpretive description. Unfortunately, theoretical sampling was not utilized because of the difficulty in recruiting, which will be discussed in a later section.

I recruited participants in several ways and only recruited participants currently at BCWH NICU or who were in BCWH NICU in the past five years. I began the recruiting process by first presenting the study proposal to the NICU research team. This presentation was essential to obtain ethical approval from the University of British Columbia, which must be obtained before commencing any research studies taking place at BCWH. This presentation allowed the research team to learn the participant criterion, goals and overall nature of the study. The research team was then able to help recruit participants and also inform other NICU staff members about the study.

I then put up posters (Refer to Appendices A & B) that described the intent of the study and criteria for participation on various poster boards throughout the NICU, neonatal follow-up clinic and the rest of the hospital. Individuals who were interested in participating in the study could then contact me directly upon which, I would determine whether the individual was a good candidate for the study.

I also recruited through a third party by asking professional and personal contacts who were likely to know suitable participants to contact me if they knew of individuals who were interested in participating in the study. The third party contact distributed the recruitment poster (Refer to Appendices A & B) to interested participants and was someone who was supportive of the research study and in a position to know of potential participants (such as a NICU bedside nurse or the NICU program manager). Upon contact with potential participants, the third party or myself conveyed the nature and purpose of the study, expectations of participants, information about the researcher, and guarantees of confidentiality and anonymity. The third party provided the women with my contact information so that the women could contact me for more

information about the study and to volunteer. I then answered questions and explained the research study in more detail.

Finally, I recruited through word-of-mouth conversation (also known as snowball sampling) through nurse colleagues and participants themselves, who may know of other South Asian immigrant women in the NICU. There is also a parent support group and neonatal follow-up clinic where word-of-mouth conversation about the study could also occur. Through word-of-mouth, participants interested in the study were provided my contact details. Upon contact with interested participants, I provided a detailed account of the study, which included information related to; the consent process, supervision of the research project, resources for participants in the event that issues raised caused any emotional discomfort or stress for the participant, risks and benefits of the study, confidentiality, description of the interview and transcription process and the rights of the participant including option to terminate participation in the study.

Data Collection

According to Thorne et al., (2004) interpretive description is built upon a foundation of pre-existing knowledge and the researcher has preconceptions and existing experience, which guide the study. Thorne, Kirkham & MacDonald-Emes (1997) state, “Nursing’s interpretive description ought to be located within the existing knowledge so that findings can be constructed on the basis of thoughtful linkages to the work of others in the field (p. 173).” This existing knowledge can then continually be challenged as the inductive analysis of findings continues throughout the study. Thus, a critical review of the state of current knowledge should be conducted before conducting participant interviews. The literature review above reflects this review and will form the basis for the preliminary analytical framework.

Multiple data sources are often used in interpretive description because it avoids overemphasis of interview data and neglect of pre-existing knowledge that has led the researcher to explore the phenomenon of interest in the first place (Thorne et al., 2004). According to Thorne et al., (1997) the use of data sources such as nursing case reports, media reports and personal narratives add considerable strength to the usual data sources and can help generate practice knowledge for nursing. In this study, primary sources of data include audio-recorded interviews with participants, transcripts of interviews and notes that I kept. Secondary sources included literature relevant to establishing a current state of knowledge about the experience of South Asian immigrant women in the NICU. These secondary data sources allowed me to evaluate the products of inductive analysis and provisional findings (Hunt, 2009).

A third party such as a NICU bedside nurse or social worker identified all the participants in the study. The third party would approach a mother and first identified if she met the study criterion (i.e. were a South Asian immigrant mother, spoke conversational English etc.). Once the mother met all the criteria, the third party would provide a brief background about the study and then asked if I could contact them. If the mother agreed, the third party would relay this information to me and then I would contact the potential participant. I would then provide the necessary information and ethical considerations pertaining to the study and then secure a time to meet to conduct an interview.

The interviews either took place on site at BCWH in a private room or at the participant's home. I began the interview process by asking the participant questions pertaining to her background (e.g. Demographic Data, Refer to Appendix E). The gathering of this background information allowed me to develop a rapport with the participant in addition to gathering valuable demographic information about the participant. I then used sample interview questions

(Refer to Appendix F) to guide the interviews. Interviews were audio recorded and supplementary memo and summary notes were written after each interview. A hired transcriber was used to transcribe the taped interviews verbatim. Thorne et al. (2004) state, “As with all interpretive research processes, data collection and analysis inform one another iteratively, and thus the shape and direction of the inquiry evolve as new possibilities arise and are considered (p. 11).” Thus, because data gathering and analysis happened simultaneously, interview questions were altered or new questions were added in order to explore new concepts and themes that arose as data was analyzed.

All the interviews were conducted in English, however if needed, the women spoke Punjabi or Hindi at intermittent times during the interview to better express themselves because I am able to understand Punjabi and Hindi and can speak at a functional level. Most of the interviews took place with only the mother, however; some of them also included either another family member or the husband. The questions were directed solely at the mother but at times, either the husband or another family member would interject. These mothers all asked for another individual to be present at the interview, which I allowed. The interviews ranged from 15 -30 minutes in length and were informal in nature.

Once I felt the interview was complete, the audio recorder would be switched off and more conversation about the questions asked would follow. This conversation was also informal and the participants spoke more freely and gave both positive and negative feedback about their NICU experience. These conversations were reflected in the supplementary notes and memos I made following each interview. The combination of the transcribed interviews, supplementary notes and memos, personal experience and relevant literature sources were used to guide data analysis.

Data Analysis

Data analysis occurred simultaneously with data collection and flowed from the content of the interview, the framework derived from secondary sources and through reflexive memos and summary notes. Thorne et al. (1997) wrote, “Many researchers find a reflective journal a valuable asset to guiding as well as documenting the reactive processes of interpreting or countering bias within the research process” (p. 175). Thus, memos were made at each stage of the data collection and analysis process. I wrote memos relaying any assumptions regarding the topic before beginning the interview process. Further memos were created that chronicled my reflections and perspectives on each individual interview. In addition, these memos allowed me to interpret and understand data and refine categories and codes.

Summary notes were also written describing key points from each interview. These notes were revisited at each stage of the research process in order to remind me of each participant’s narrative. Thorne et al. (2004) stated, “Coding too meticulously, too early, or in too much minute detail can derail even the most enthusiastic analyst in exhaustion (p. 11).” Thus, in order to achieve an effective inductive analytical technique, repeated immersion in the summary notes and memos occurred prior to coding, classifying or creating linkages in the data (Thorne et al., 1997).

In order to allow for a responsive interaction between data analysis and data collection, analyzed data and new insights developed from early interviews were incorporated into later interviews. Coding aimed to identify categories and linkages in the data, explore relationships and patterns between data sources (Hunt, 2009). According to Thorne et al., (2004) “For some investigators, creative coding (using symbols, colors or conceptual codes, and visual tools such as concept mapping) may help with inductive imagining (p. 14).” Therefore, a concept map was

used to link relationships between codes and concepts. Provisional findings were compared with secondary data sources in order to challenge my analysis and interpretation of the data.

Rigor

According to Lincoln & Guba (1985), four factors can be used to establish trustworthiness of data in the qualitative paradigm of inquiry such as interpretive description. These factors are credibility, transferability, dependability and confirmability. Credibility refers to the confidence the researcher has that the data is truthful to the findings and will be addressed in many ways. Firstly, interpretations are supported with direct quotes from participants. Secondly, data is drawn from discussions with participants, health care professionals, secondary literature sources and experts in the field to verify interpretations. Finally, interpretations were also made by drawing on my personal experiences as the daughter of a South Asian immigrant and on my extensive clinical experience in providing neonatal nursing care to women and families of South Asian background.

Transferability is enhanced when results are not context bound (Sandelowski, 1986). Thus, having a diverse sample in terms of religion, age, level of education and employment status supported transferability. However, it is acknowledged that the findings are not transferable to all South Asian immigrant women with an infant in the NICU. Dependability and confirmability are supported using audit trails and by ensuring all possible explanations of data are thoroughly explored and through reflexivity, which involved me being aware of how my own experiences and background shaped the study.

A key tenet to the data analysis process of interpretive description is that although the method is participatory and collaborative, it is the researcher who is the driving force behind the analysis. Thorne et al. (2004) stated, “Thus, an explicit awareness of the investigator as

interpreter becomes an essential element in generating “findings” that have the potential for credibility or “interpretive authority” (Thorne et al., 1997) beyond the artistic license of the individual author.” Thus, particular attention must be paid to rigor in order to eliminate researcher biases and preconceptions from infiltrating research findings. I accounted for findings in an auditable manner via the supplementary memos and field notes used in this study. These memos and field notes served as a means by which one can retrace the development of abstractions and ensured that my interpretation and analytical directions are defensible (Thorne et al., 1997). Furthermore, I provided sufficient information to allow one to follow the analytical reasoning process and judge whether the analysis is grounded within the data.

Another means of ensuring scientific rigor and validity is the “thoughtful clinician test” (Thorne et al., 2004), which involves the researcher presenting provisional findings to those who have expert knowledge of the phenomenon. The goal of this “test” is to determine whether the findings are plausible and confirm “clinical hunches” and to illuminate new relationships and understandings (Thorne et al., 2004). Thus, I used secondary data sources such as relevant published and non-published literature as sources of expertise. For example, past theses related to South Asian immigrant women’s health were consulted. In addition, input from other South Asian neonatal nurses, physicians and respiratory therapists were also used as a source of expertise.

Finally, emerging understandings from past interviews were shared with subsequent participants (while still maintaining confidentiality) in order to allow me to receive feedback and determine how consistent emerging understandings were with participant experiences. For example, in one interview a mother suggested the need for more “Punjabi-speaking nurses in the unit.” Thus, this idea was proposed to a subsequent participant in order to gain input regarding

this suggestion. The feedback obtained was used to refine the analytical process and allowed the participants to have ownership over the findings of the study.

Ethical Considerations

This research study gained approval from both the University of Victoria's Human Research Ethics Committee (HREC) and the University of British Columbia / Children's and Women's Health Centre of British Columbia Research Ethics Board (UBC C&W REB). An application for Ethical Review of Human Research was submitted using guidelines for application provided by both universities. Once both the HREC and UBC C&W REB granted approval, participants were recruited using a recruitment poster (Refer to Appendices A & B), through a third party and word-of-mouth conversation. Recruited participants then underwent a consent process, which relayed information about the nature and purpose of the research study according to the protocols of ethical research (Refer to Appendix C).

Participants were informed of the risks, benefits and inconveniences as a result of involvement in the study. The only known inconvenience was the time associated with participation in an interview. Although the potential for emotional or physical responses was minimal, it is possible when discussing personal experiences. Potential risks were related to the possibility of becoming upset, feeling fatigued, and/or experiencing emotional distress when engaged in the interview. To prevent or deal with these risks, the consent form explained to the participant that if they experienced any fatigue, distress, or unease during the interview, they could end the interview and reschedule at their convenience. In addition, participants were given the NICU social worker's telephone number if they wished to discuss concerns that lingered after the interview. If requested or thought to be appropriate by me, participants were also provided with names and phone numbers of support services available for additional counseling. None of

the interviewed participants became emotionally distressed to the extent that contact information for additional counseling services was required.

The consent process also ensured participants that participation in the study was entirely voluntary. Individuals approached for consent were guaranteed that participating or declining the study would not influence the current care of their infant in the NICU or any subsequent follow-up care. Confidentiality was guaranteed and participants were given the option to choose not to answer questions on any sensitive topic, and could stop the interview at any time. In addition, participants were able to withdraw at any time before, during or after the study.

All data included in this research study is confidential. Participants are referred to only in pseudonyms and although interviews were audio recorded and transcribed, identifying information was kept separate from the audio recording and transcription notes. Data was stored in a locked and secure password protected computer and the researcher handled the audio recorded interviews. A paid transcriptionist transcribed the audio recordings and also upheld ethics of confidentiality and signed a contract (Refer to Appendix C). Transcripts were coded, used in analysis, and were available only to my supervisor and myself while the study was in progress. Transcribed data will be kept for the possibility of secondary analysis because this research is potentially the first of a series of studies with the phenomenon of understanding the experience of South Asian immigrant women in the NICU. For purposes of communication with participants, I kept one list of participants' names, addresses, phone numbers, e-mail address (if applicable), and codes. This list was kept in a separate location from the transcribed data. Audio recordings will be erased upon completion of analysis and thesis requirements and the file containing the list of participants will be destroyed at the end of the study.

Summary

The qualitative research method of interpretive description was chosen for this study because it was appropriate for the level of skill of the researcher and fit the aims of the study. Sampling and recruitment, data collection procedures and data analysis were all performed in accordance with the chosen methodology in order to further examine the experience of South Asian immigrant women in the NICU.

Chapter Four

Findings

Introduction

This chapter begins with a description of the sample characteristics or demographic data of the five participants. Following the sample characteristics is a description of the main theme and subthemes I identified through interpretive description methodology. The theme and subthemes are described by using direct quotes from participant interviews in order to illustrate and substantiate my interpretations.

Sample Characteristics

Six mothers were formally recruited for the study. However, I withdrew one participant after several unsuccessful attempts to contact her and secure an interview time. Thus, the sample for the study included five women who identified themselves as South Asian immigrant mothers. They were representative of various sub-groups and religions, including 3 Sikhs, 1 Muslim and 1 Hindu. The women's ages ranged from 30 to 53 years and they were all married. All of the women except one were born in India and the other was born in Pakistan. The number of years they had been in Canada ranged from 6 to 30 years and all except one resided in an urban area of the Lower Mainland. The other resided in a small town in British Columbia. The women all had various reasons for immigrating to Canada, some immigrated after their parents obtained Canadian citizenship, others came after their husbands sponsored them and others came together with their husbands because they either had other family residing in Canada or simply wanted to forge a new life for themselves in Canada.

All the women except one had attended college in their native country and most had some form of education upon their arrival in Canada. All of them were currently either on

maternity leave or had decided not to go back to work after the birth of their infant. However, all used to work in jobs that ranged in employment status from professional to working class. All the mothers except one had some extended family (siblings, in-laws, aunts and uncles) living in Canada. The other did not have any other family except her husband living in Canada. For all the mothers, the infant(s) (one mother had a multiple birth) admitted in the NICU were their first biological children. However, one mother had stepchildren living at home as well. The women all could speak English at a conversational level but only one identified it as her first language. The others identified Punjabi, Hindi or Marathi as their first language.

The women all identified doctors and nurses as their support people at the time of NICU admission. In addition, some women identified both close family friends and family members such as in-laws and their husband as sources of support. This support ranged from driving the women to and from the hospital, bringing cooked meals or performing other daily tasks for the women. Most of the women (n=2) reported their health status as good after admission to the NICU. However, several of the women (n=2) were recovering from cesarean sections and thus had a great deal of pain and others (n=1) had complications such as pneumonia.

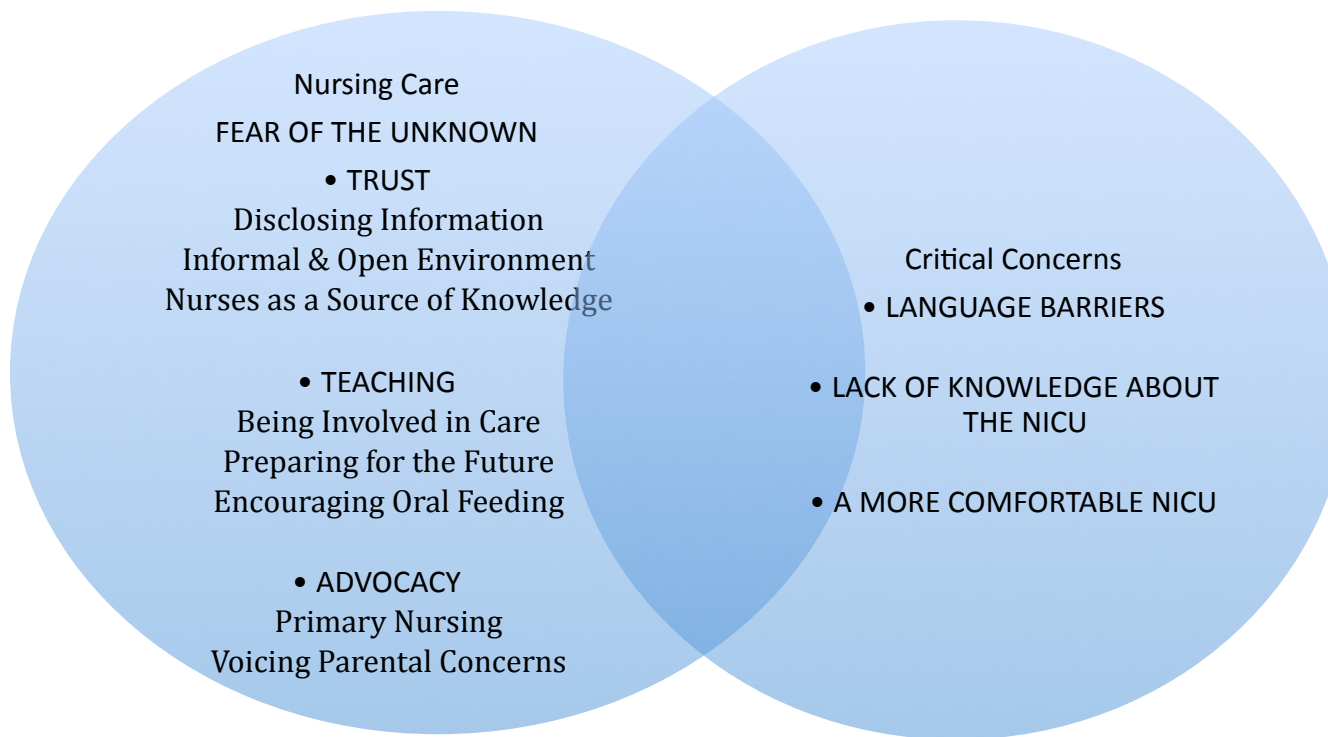
This was the first time all the mothers had infants admitted to the NICU however, several of the mother's infants were admitted to another NICU but then transferred to BCWH NICU after some time due to complications in their infants condition. For most of the women, having a sick infant was their first real encounter with the Canadian healthcare system. However, some of the women (n=2) had previous minor surgeries or past miscarriages while others had complications with their pregnancy and had to be admitted for bed rest or other pregnancy related procedures (n=2). The infants of the women all had a variety of diagnoses ranging from extreme prematurity, congenital deformities, asphyxia to unknown. In addition, at the time of

birth, the infants all ranged in age from 25 weeks to full-term.

Emergent Themes

The main, overall theme identified in all participant responses was, Fear of the Unknown. Three subthemes that emerged from discussions regarding how participants experience nursing care were Trust, Teaching and Advocating. Three factors that led to building Trust were, disclosing information, an informal and open environment and nurses who were viewed as a source of knowledge. Teaching was demonstrated when participants were involved in care, prepared for the future and oral feeding of their infant was encouraged. Advocacy was demonstrated through primary nursing and voicing parental concerns.

In terms of what participants identified as their most critical concerns while their infant was in the NICU, three subthemes were identified; Language Barriers, Lack of Knowledge about the NICU and A More Comfortable NICU. How participants experience nursing care and their critical concerns are connected because nursing care should aim to meet these critical concerns (Refer to Figure 1).

Figure 1: Themes & Subthemes

Fear of the Unknown

During conversations with participants, the theme that was most apparent was, Fear of the Unknown. Participants described their NICU experience, as one of the most stressful and worrisome events of their lives and at the core of these emotions was the inability to know what would happen next. Only one participant felt somewhat prepared for the NICU environment because she had been told she would most likely deliver a preterm infant. She had also been given a tour of the NICU prior to giving birth. However, she expressed that despite this knowledge, she still felt fearful of what would happen during her NICU stay. She recalled:

That [NICU Tour] made me more stressful since [Participant's Infant] was inside me and I would panic more like what is going to happen.

Participants all relayed that waiting was the most difficult part when they first learned their infant had been taken to the NICU and they had to wait to visit them. One participant expressed:

I think it was morning by the time I got to see her- I can't really remember. The waiting was hard. I didn't know what was going on with her.

Upon arrival in the NICU, participants were bombarded by the noise, busyness, equipment and myriad of tubes and infusions connected to their infant. From this point onward, participants felt they were never able to relax or not worry about what would happen next. Participants felt they never fully understood the diagnosis of their infant or what the course of action would be. One participant said:

They told us because maybe he had not oxygen when they put that tube inside, so maybe it can be damage of his brain. That is why it was scary. I wanted to ask them- how is he? I want to see him. I was very excited to see him.

Participants would also overhear other medical information being relayed to other parents and would start comparing it to their own infant and then worry whether this would also happen to their own infant. One participant stated:

We have so many questions and I was always comparing if I would hear something else, I would always compare it to him.

Trust

Unanimously, trust was perceived as the single most important factor regarding the care participants received from all health care professionals but especially nurses who participants felt they interacted most with during their NICU experience. All of the participants interviewed described experiences in the NICU where trust was either built or broken. For example, one participant relayed how she did not trust a nurse who would not provide accurate information about her infant because the information was seen as bad news. Participants expressed appreciation and gratitude towards the nurses who cared for their infant and relayed that the nurses were competent, compassionate and had a high level of skill and professionalism. However, participants also relayed stores of mistrust, resentment and anger at what they perceived as neglect towards their infant, lack of knowledge about nursing and medical issues and simply “not caring”.

Disclosing of Information

All the parents interviewed expressed the importance of nurses disclosing information truthfully and accurately. It was important to participants that they were kept informed about their infants' health status and progress. They could not understand the reasoning behind why some nurses would not disclose information or update them on the status of their infant. One participant stated:

And second, maybe it's all personal but for us, we needed answers. Some of the nurses wouldn't talk – what they thought was not important, but sometimes they would not disclose things and they would not tell us what is to be done. We didn't get answers from a couple of nurses.

Participants felt trust was built with nurses by this disclosing of information. In addition, parents felt less stressed and worried when they were provided accurate and honest information. When parents were informed, they felt a sense of control and involved in their infant's care. One participant emphasized:

I used to try get as much as possible from them [The Nurses] and then I would maybe ask the doctor. If I had some questions that was dangling, I would ask. There was no point coming home, thinking about the situation, and then he [Participant's Husband] would sort of talk to me, and I would [talk] to them. So we would made sure of what needed to be said.

The option of asking questions about their infant helped build trust with both the nursing and medical staff. One participant expressed:

That was very helpful to me because at that time I was thinking I don't know about the medical of what is going there because everything was new for me. I cannot remember what is going on then. That I can call them. How I can ask, because now I have not much knowledge of this one, about the medical. So that was comforting for me.

Informal & Open Environment

An informal and open environment also helped facilitate trust between health care professionals and participants. For example, having complete access to their infant's chart was important to participants. By being able to freely look through every component of their infant's

chart, participants' felt like they were part of the decision-making team and that information was not being hidden from them. One participant recalled:

They would say like, but some of the nurses were like you can read anything. There is a file over there in the drawer; you can read anything you have. Any questions, just ask, and if we don't know, we'll call the doctor.

Being able to participate in morning rounds with the healthcare team was also perceived as beneficial to participants. One participant stated:

The rounds. That was the best part. Joining the rounds. That was very good. Because there, there was open discussion between the doctors and the nurses and we knew everything about it and they themselves when they went for the rounds, they had the group of other doctors, young doctors, come, I suppose-and they had so many questions, and we would also know about it. So that was really good. Even the doctors used to ask, do you have any questions at that time, so that was good.

This informal and open environment alleviated participant's feelings of anxiety and fear about voicing their concerns or asking questions especially to the physician, who traditionally in South Asian cultures is seen as a figure of power and authority. In most South Asian countries, questioning a physician can be perceived as disrespectful and insulting. One participant recalled:

I was telling my mother, she was coming here to visit us for six months- I was telling her, I said one day-we went to see her [Participant's Infant]-we were sitting like we were on the doctor's chair, right. The doctor was sitting down.

Nurses as a Source of Knowledge

Participants relayed that they most trusted nurses whom they identified as knowledgeable, competent and skillful. Participants trusted nurses who were confident and

knowledgeable about the procedures and equipment associated with their infant's care. Many participants were able to pinpoint specific occasions where a nurse did not demonstrate adequate nursing care. Most of these occasions were focused on a particular nursing care task. For example, one participant stated:

And one thing I find a little hard, I was worrying when the nurses suction them, suction him, and they put the tube suction catheter back in the suction catheter, not in the bag. Because all the time, a long time somebody not change that, a long time, it is because they have so much secretion, it was stuck in the tube in the hospital. At home, it okay, when we suction, we put in and clean every time, not much dirt. In the hospital, in 1 hour, half-hour, stuck everything in the tube. I don't like that one.

Another participant felt that if she did not trust her nurse's ability to look after her infant or her/his level of skill then she would stay at her infant's bedside in order to monitor the nurse. The participant stated:

And then we had seen the same nurse was doing with the other baby and that baby's oxygen had gone to thirty. And we were like oh my God, she's doing the same thing again. And same with the makeup like. She was doing her lipstick. Yeah, and at one time, I had told him, you were saying that we should go and complain because she shouldn't do it again to some other child but I said forget it, her job might be in trouble or something so just leave it like don't. I didn't leave that place whenever she was on duty- I didn't leave that place. I used to be always there with him.

Participants also expressed appreciation for nurses who would admit they did not know the answer to their question but then find another resource such as the physician or another member of the healthcare team in order to answer it. They felt this ability to direct participants

to the physician or another source demonstrated that the nurse cared, valued their question and was knowledgeable. One participant expressed:

All the nurses. I mean if I had any questions, they were always ready with the answer. If they didn't know the answer, they always paged the doctor and said we will get an answer over here. But most of the nurses-yeah, they were quite a few nurses who wouldn't care like –but most of the nurses, I could say like 90% of them, were all were helpful.

Teaching

Being Involved in Care

Participants all viewed nurses as a source of knowledge and thus, felt that those who took the time to teach them new skills or procedures related to the care of their infant facilitated trust between them and the nurse. One participant stated:

The nurses over there had told me everything. When I came to the NICU, they told me everything like you would have to go and pump there, and the storage of the milk, since he wasn't drinking milk at that time. I had to freeze it. So they had told me where the freezer is and everything. They were quite helpful.

Learning was an integral part of participant's NICU experience and participants felt it was part of the nurse's role to provide teaching and encourage them to participate in their infant's care. Unanimously, participants appreciated being involved in their infant's care in any way they could and did not feel supported by nurses who would not allow or encourage them to participate. One participant stated:

Like put the diaper on, give a bottle. At [Another NICU Facility], you are not allowed to give a bottle to the child everyday. No, it's every other day. No, not ever other day- it's

every 2 days or something like that. Since we had come from Children's and we were so used to all this, it was very difficult for me in [Another NICU Facility] to like get used to this kind of. Since he was growing better and better, I wanted to be more with him.

Thus, it was important for participants to be allowed to participate in the daily care of their infant especially as their infant became more stable and healthier. Participants felt like “normal parents” when they could participate in feeding, diaper changes and taking temperatures because it prepared them to fully care for their infant upon discharge home.

Preparing for the Future

Participants all felt more at ease when nurses demonstrated procedures and prepared them for the future by teaching them about potential procedures. One participant stated:

They [The Nurses] support me. They gave me encourage too when I was sick too. They prepare me for everything for her [Participant's Infant] to use this one. They showed me everything. The nurses told me everything for how to care my baby when I move to my home.

Many participants relayed their anxiety regarding their infant receiving a gastrointestinal feeding tube, which requires a minor surgery. Most participants whose infant received this tube were extremely against it and felt it was not necessary. However, after teaching and information from the nurse, they would consent to the procedure and understood why it was needed.

Participants understood that their infant would be unable to go home without a gastrointestinal feeding tube and it was required to feed their infant. One participant described:

She [The Nurse] got me ready for [Participant's Infant] G-tube way before anybody even talked about it and she was just saying this could be the possibility. I know its still hard because I was really against the G-tube, getting it.

Encouraging Oral Feeding

For most participants, getting their infant to fully orally feed was a huge challenge and usually the final hurdle before discharge home. Therefore, nurses who taught participants how to breastfeed were perceived as extremely supportive. One participant stated:

She [The Nurse] said to me, you come to everyday in the NICU for your daughter. Because I have the C-section, I didn't feel well, that's why I never go to everywhere, everyday. I went to there some days, after couple days, after three days. Because my husband, he went to everyday for brought breastmilk. Then she [Participant's Infant] knows day by day. She [The Nurse] increase the hands for me and I gave her [Participant's Infant] the breastfeed too. Then after she [Participant's Infant] used me for the breast milk.

Participants also said that nurses who encouraged them to visit frequently to either breastfeed or bottle-feed were helpful and an integral factor to discharge home. Nurses who informed participants that by visiting frequently and providing oral feedings would result in the cessation of nasogastric feeds and discharge home.

Advocating

Primary Nursing

Participants who had primary nurses all voiced their appreciation and praise for them. Primary nurses are nurses who volunteer to care for the same family throughout their NICU stay. As a result, primary nurses develop a strong bond with the family and become experts in the needs and care of the infant. As a result, the healthcare team takes the opinion of primary nurses as especially important and will even plan to do particular milestone procedures only when a primary nurse is working. Although all nurses advocate for families, primary nurses are in a

special position to do so because of their particular knowledge of the family and their infant.

One participant became teary as she described how her primary nurse advocated for her and was integral to the care of her infant. She expressed:

[Primary Nurse] is the best nurse and yeah, other nurses too. I have learned a lot. Each nurse brought difference experiences. [Primary Nurse] is a strong woman! That's what I like about her. She speaks her mind and that's what I like about her. Yeah, she's a strong woman.

Participants reported feeling comfortable disclosing personal fears and opinions to their infants' primary nurses instead of the entire healthcare team because they felt the team was not listening to them or because participants were not healthcare professionals, they did not have the knowledge base to have opinions. As a result, primary nurses would advocate for them by bringing these concerns and opinions forward to the team.

Participants who had primary nurses described how it was helpful to have the same nurse work with them in a unit that is staffed by almost 200 nurses. Primary nurses came to have comprehensive knowledge about both the family's and infant's specialized needs and prevented situations where "the nurse did not know the baby" and information was not passed on during handover and thus, adequate care was not delivered. Participants felt their primary nurses fully understood the complex needs of their infant and was then able to deliver the best care. One participant stated:

It's only for the primary nurses might be knowing about it. The doctors knew about it.

Primary nurses also developed special bonds with the family and some kept in touch after the family was discharged home. Another participant who became emotional when expressing her gratitude for her primary nurses stated:

They were like second moms to him. I have seen the nurses over there in the night. Because he was a premature baby and he was always crying and all that, they were holding him all the time, like nothing like why should I keep carrying him. They were very good, the nurses.

Voicing Parental Concerns

Participants expressed their appreciation for nurses who would take the time to listen to their concerns and then voice them to the rest of the healthcare team. One participant stated:

The nurses were okay. It was good to talk about whatever we ask and they tried to answer us.

Voicing parental concerns was especially important to participants who felt less confident in their English speaking skills or depended on someone to drive them to the hospital and thus, were not always part of morning rounds or could not visit daily. Participants felt more comfortable and at ease talking one on one to their nurse instead of voicing their concerns to the whole healthcare team. One participant stated:

No because I can speak English right. I can understand. Sometimes there is a more confident word for the medications and stuff, and it's really hard to understand but normally I can talk to the nurses.

Language Barriers

Unanimously, all participants expressed that more interpreters or Punjabi/Hindi speaking staff were a critical need during their NICU stay. One participant expressed:

Interpreters would be good but if there are Punjabi nurses there, we don't need to hire interpreters. It will cost too right.

Even participants who were completely fluent in English felt lack of English speaking skills would make the NICU experience especially difficult. One participant expressed:

When a person speaks English, the person opposite you takes you in a positive way. If you can't, then oh, what is she asking me? Why does she need to know? Automatically.

Participants who struggled with speaking English felt they were not taken seriously or were unable to fully express their questions, concerns and ideas. When they would encounter a nurse who could speak Punjabi or Hindi, they felt more at ease and relieved. One participant expressed:

She [The Nurse] come to me then she told me I can speak Hindi so whatever you need to ask you can ask anytime. So I was comfortable, so I was more comfortable with what I need to ask I can ask.

Participants felt especially frustrated when nurses would speak quickly to them knowing that English was not their first language. In addition, nurses who used large gestures, slang terms and a great deal of medical terminology were perceived as not helpful. Participants also felt further confused by nurses who had strong accents. They felt it was already difficult understanding a Canadian born English speaking nurse and then having to understand the English of a foreign born nurse with a unique accent was even more difficult. One participant stated:

I was not comfortable. I was not understand her English. Otherwise, I understand what they asking for, but I was not understanding. Her accent, she [Accented Nurse] was trying to understand me by gestures, then sometimes I understand then sometimes not. I was thinking it was very hard to talk to her. After that, I told the one nurse, the Punjabi nurse over there, that she [Accented Nurse] was back right? I told Punjabi nurse that

she [Accented Nurse] was coming so I won't understand her-its very hard for me. Also she [Accented Nurse] was coming to me and she was laughing either. The Punjabi nurse was telling me that she talked with her. She told her [Participant's Infant]'s mom not understanding and she said yeah, yeah, yeah.

Although participants said it was uncommon to have nurses who were insensitive to their fluency level in English, they did on occasion have nurses who became frustrated or impatient with them because participants could not understand them or communicate effectively. On these occasions, participants did not wish to engage with the nurse and thus, would not learn anything from the nurse or obtain information about their infant's status.

Participants who used interpreters found it very helpful especially to explain surgical procedures and during care conferences with the entire healthcare team. One participant stated:

Yeah we use interpreter. When we have meeting and sometimes when they had surgery, I was asking them.

Participants also found it helpful to have staff that spoke Punjabi or Hindi and would rely on them for updates and information about their infant. One participant expressed:

If somebody if somebody is speaking Punjabi – I want to ask something to the doctor. Then some nurses over there, they bring the nurses. Sometimes the one working the front desk, she help us. She speaking Punjabi. She is young.

Another participant shared:

Yes, I more confident in Punjabi. [Punjabi-speaking Doctor] was a doctor and was pretty nice too. He just told us the situation and MRI for her brain. He said we have to do an MRI and if MRI is normal, then it is easy to fix her legs. We were so worried about that when he told us, but we went to the Gurdwara and prayed to the God right. MRI

was normal and everything is fine now.

Lack of Knowledge about the NICU

All participants compared the Canadian healthcare system to their native healthcare system and felt that their lack of knowledge about how the NICU environment worked affected their NICU stay. For example, participants described how the healthcare system in India does not encourage visiting sick patients or parents staying for too long especially in an NICU environment. One participant stated:

They [Indian NICU] may not let you stay in the NICU. Maybe one person. They don't like that. It's very challenging there, knowledge and they don't know why you're asking those things. So those things are there.

Some of the participants were unaware that they were allowed to read their infants charts because they were not allowed to do so in their native countries. In addition, they were unaware of certain resources such as social workers and interpreters either because their NICU experience was their first encounter with the Canadian healthcare system or such resources were unavailable in their native country. One participant stated:

Because in Canada, I never go in the hospital. First time I go to the hospital for my delivery. Because I have no experience for anything. I had some problem in talking to the doctor about my delivery and my daughter too, because I was so sick.

Another participant stated:

For a person to come from India and then I probably know much better what is happening. But for people who doesn't know, will get frustrated initially.

Participants were also initially unaware they could voice concerns to the medical team and even question care. However, as their NICU stay lengthened they were encouraged to ask

questions, be part of rounds and ask for any information regarding resources and support services. One participant recalled a situation where the NICU healthcare team repeatedly removed the PICC line of her infant immediately after the team felt he no longer required it. However, on both occasions the infant required the PICC line and thus, it needed to be re-inserted. Only after the participant voiced her concerns did the healthcare team decide to keep the PICC line longer to ensure it was no longer needed.

A More Comfortable NICU

All participants voiced their opinion that the NICU could be made more comfortable to parents while their infant was in the NICU. Unanimously, they expressed that the NICU could be made more comfortable if the unit was designed as individual rooms for each infant and family instead of many large rooms with small bedside spots. The BCWH NICU has a small area with six private rooms. Each of the participants had stayed in one these private rooms for some time during their NICU stay. However, because infants are constantly shuffled to accommodate nursing staffing or the needs of other infants in the unit, participants were eventually moved back to the larger rooms. Thus, participants were able to compare being in a single private room to a larger, public room. Participants felt a private room allowed them to interact with their infant in a more normal way, ensured privacy and still allowed for adequate nursing care.

Participants also felt individual rooms would allow them to be more healthy and take care of themselves because they would be able to take naps and have some alone time to de-stress and think. One participant stated:

I think they need to make it a little more comfortable, like you know, a napping place for moms.

Participants also felt that a single room would allow them to focus only on their infant and not be distracted by what was going on with another infant in the same room. They felt by being able to see what was happening with other infants added to their feelings of stress and made them feel depressed and discouraged. One participant expressed:

It [Single Rooms] would be better. Sometimes it's disheartening. It's depressing kind of like looking around. Babies are crying and there are doctors crying. It was sort of distressing overall.

In addition, following the admission of their infant into the NICU, many of the participants were admitted in the postpartum units where they could see and hear other mothers interacting and sleeping in the same room as their healthy, term infant. This was especially difficult for participants and led to feelings of depression and sadness. Therefore, a single room would allow NICU mothers to spend quality alone time with their infant much like postpartum mothers. One participant tearfully expressed:

When I was leaving [Participant's Infant] for the first day to go to the hotel, I just...it shouldn't happen. It's hard. So you think maybe there should be like a place where each parent has their own room and just be with their baby. When I was [Postpartum Unit] upstairs, I could hear the babies and moms and I got jealous.

Participants also felt the NICU did not provide any resources for them while they tried to visit their infant with a sibling. Although the sibling is allowed to visit the infant with the family, participants felt they could not fully focus on their infant because of the needs of the sibling. As a result, they would end up with one parent caring for the sibling in the parent lounge and the other visiting the infant. For participants who visited alone, they would have to find a

family member or friend to care for the sibling so they could visit their infant. One participant stated:

I have many families with many moms saying like I have my child and I have kept her at my mom's place or something. I had to take my child to friend's place and all that; otherwise they had to keep the child at the waiting room outside.

Many of the participants were from out of town and thus expressed the desire for access to facilities for everyday living. For example, participants who lived out of town and were staying at family friend's places expressed that washing and cooking facilities should be made accessible in the NICU. The cooking facilities would be used to cook food for parents so they would be able to eat homemade food some days and the washing facilities would be used to wash the infant's clothes. One participant felt her family was already inconveniencing the family friend by staying with them for so long and she didn't want to further burden them by asking to use their kitchen and washing machines everyday. She stated:

I find hard. I was bringing some clothes for them. It was everyday small. We cannot put in the machine, because somebody living with somebody else. We have not one. It was very hard. So many we cannot buy. The small one we came over there and then wash. It was okay, but everyday we use the washing. I was thinking they spend so much money for them, it's only if they make some clothes then everybody can use them.

This lack of essential amenities made the NICU environment uncomfortable and inconvenient for participants. This inconvenient NICU exacerbated participant stress levels because they had to think about personal tasks such as where they would wash their clothes or make food while dealing with their sick infant.

Summary

This chapter described and illustrated South Asian immigrant women's experience in the NICU. Overall, participants all described the nursing care they received in the NICU as positive. They felt that trust, teaching and advocacy were components of optimum nursing care and made their NICU experience less stressful and more manageable. These components are not unique to South Asian immigrant families and will be discussed further in the final chapter. Similarly, the critical need of having a more comfortable NICU is also not specific to South Asian immigrant women. From my personal experience as a neonatal nurse, many of the ideas outlined to make the NICU more comfortable are echoed by all families regardless of ethnicity.

The critical concerns of language barriers and lack of knowledge of the NICU are somewhat unique to immigrant families and will be discussed in the final chapter. New immigrant families may not be aware of particular intricacies, resources or their own rights in relation to the Canadian healthcare system when compared to their Canadian-born counterparts. It is clear that South Asian immigrant women do have some unique needs in terms of language and further education about the Canadian healthcare system and BCWH NICU in order to make both a more navigable and positive experience.

Chapter Five

Discussion of Findings, Implications & Conclusions

Introduction

In this chapter, the findings will be discussed in light of relevant literature and research. Interpretive description was developed for nursing research and is built upon a foundation of pre-existing knowledge and the researcher has preconceptions and existing experience, which will guide the study. As a result, references to literature include my own clinical experience as both a practicing BCWH NICU neonatal nurse and cultural knowledge as the daughter of a South Asian immigrant woman. References to literature will also include both published works and unpublished dissertations.

To date, there is no research conducted examining the experience of South Asian immigrant women in the NICU. The purpose of this study was to examine how South Asian immigrant women experience nursing care in the NICU, what they identify as their most critical concerns and what they identify as supportive nursing behaviors during their NICU stay. This study's findings provide important information on the South Asian immigrant women's NICU experience, which can allow neonatal nurses to make this experience more positive.

Although most of the findings would be echoed by any parent with an infant in the NICU, they are still important to discuss because they can prompt neonatal nurses to examine their own nursing practice. A knowledge of which nursing behaviors are perceived as helpful, positive and holistic can allow neonatal nurses to alter the care they deliver in order to incorporate such behaviors. Likewise, the critical concerns identified by participants can be applicable to any immigrant group and thus, nurses can work to overcome these concerns in order to make the NICU experience less stressful.

The findings of this study cannot be generalized to all South Asian immigrant women or any other immigrant group nor is it the intent of this study. However, the findings can raise questions for further research on South Asian immigrant women's health. This chapter will discuss the implications of the findings for clinical nursing practice and nursing research. Subsequently, the chapter ends with a discussion of the limitations of the study and final conclusions.

Discussion of Findings

Fear of the unknown was the overarching theme interpreted from the findings of this study. Like most parents who have a sick infant admitted in the NICU, the participants in this study all relayed experiencing a fear of the unknown. McGrath (2001) stated:

The sequence of events these infants and families experience in the NICU are often equated to a roller coaster ride, with many unexpected ups, downs, and turns of events. Parents seldom feel safe from the fear and uncertainty of recurring problems for their infants until long after discharge (p. 75).

Fear of the unknown can originate from not knowing what the outcome of care will be and what will happen day to day resulted in feelings of anxiety, stress and worry (Brunssen & Miles, 1996). In a study looking at parental stressors in a critical care environment, Farrell & Frost (1992) found that parents, "need to know what is happening to the child, why it is happening and what the likely course of events are to be during the time of the child's admission (p. 137)." Although the information received could be traumatic or potentially bad news, parents felt a sense of control and less fearful when they were given honest and accurate information. Conversely, even improvements in the infant's condition brought on parental feelings of fear and stress. For example, "graduating" from the critical rooms to the more stable rooms in the unit

can cause mixed feelings of excitement and relief but also worry and stress regarding how this new environment would function and if the NICU staff would deliver appropriate care (Gavey, 2007).

The technological and chaotic environment of the NICU can also contribute to feelings of fear and anxiety (McGrath, 2001). Parents reported feeling overwhelmed and generally scared of the NICU as they observed the critical care equipment in a loud and impersonal environment. Johnson (2007) states, “Because of the complexity of illness, parents of critically ill infants are anxious and fear the worst with every visit to the NICU (p. 257).” Likewise, parents are fearful to become involved in the care of their infant because of the foreign, intimidating nature of the NICU. In addition, parents are fearful to touch or hold their infant because of the technology, wires and tubes attached to their infant (McGrath, 2001).

Trust was one of the subthemes identified in this study. The disclosing of information is an essential component of establishing trust between parents and healthcare staff. In their study about parents’ experiences of sharing information and decisions with neonatal staff, Alderson, Hawthorne, & Killen (2006) found that parents trusted healthcare professionals who provided information about their infant as a means of genuinely involving parents in both protecting their infant and planning with healthcare staff about providing the best care possible. Baker & McGrath (2009) found that nursing behaviors that fostered a trusting relationship with mothers included communication of accurate information about the infants’ condition, inclusion in care and decision making no matter how insignificant the care seemed to the healthcare team.

An open and informal environment is also a key component in fostering trust between nurses and parents. In their work on “chatting” and “social talk,” Fenwick, Barclay and Schmied (2001) discussed how this informal form of conversation is an important tool for building rapport

and a trusting relationship with mothers. They stated, (2001) “‘Trust’ was developed which enhanced women’s sense of safety and further facilitated her ability to express herself openly and honestly (p. 587).” The ability to visit their infant freely and come and go from the unit without restrictions was also important to parents and facilitated trust. Lupton & Fenwick (2001) found that mothers reacted negatively when told, “the nursery is closed” and were not allowed to visit their infant. Instead, a welcoming environment and supportive unit policies such as allowing parents to visit freely foster trust between parents and the NICU healthcare team. Encouraging parents to be part of rounds is also essential to building trust with the healthcare team and provides an opportunity for them to ask questions and be updated about their infant’s progress (Little, 2001). Griffin (2003) stated, “Including parents on rounds for their child encourages information sharing between staff and parents, and it recognizes family members as key decision makers and acknowledges the important role parents play in the recovery of their child” (p. 136).

Trust is also built when parents view nurses as competent, skillful and a source of knowledge. Cescutti-Butler & Galvin (2003) stated, “Parents whose babies are in the care of the NICU need to have confidence that the health care professionals looking after their baby are competent and abide by high ethical and clinical standards” (p. 753). Reis, Rempel, Scott, Brady-Fryer & Van Aerde (2010) use the term ‘negotiated partnership’ (p. 677) to describe the relationship between nurse and parent where the nurse uses skillful actions in order to attain the common goal of optimal care for the infant. This partnership is built upon a foundation of clinical knowledge, teaching and procedural skills, providing encouragement and promoting parental independence.

Teaching was a second subtheme interpreted from the findings in this study. Reis et al., (2010) revealed that parents believed the most ideal nurses were those who fulfilled the roles of a

teacher, guardian, and facilitator. Being involved in care and being shown how to perform routine care procedures are extremely important to parents. Reis et al., (2010) found that nursing actions parents found engaging and positive were, “granting parents “permission” to care for their baby, nurses encouraging parents to participate in their infant’s care, and nurses creating an environment where parents felt like there was room to learn (p. 680).” Herbst & Maree, (2006) found that, “The participants wanted to participate in their children’s care, “to hold them and care for them”, and “to do what parents are supposed to do for their children” (p. 8).” The researchers found that providing opportunities for parents to participate in their infants care and perform routine tasks such as diaper changes and taking the temperature led to feelings of empowerment and resulted in parents feeling like they were partners in the care of their infant.

In their work on family-centered care in the NICU, Beveridge, Bodnaryk & Ramachandran (2001) found that a key element to family-centered care was that parents should be prepared for the future. They should be kept one step ahead by being informed of the potential outcome of their infant’s care. Cleveland (2008) found that parents were empowered when they were prepared for the future. They felt like partners in care and were able to make more informed decisions when they were taught about potential procedures and outcomes.

Encouraging oral feeding is a significant component of parental teaching because mastering feeding is usually the final step before discharge home. The ability to fully orally feed their infant is perceived as one of the most important skills for mothers to attain. However, this skill can be difficult to achieve due to numerous factors such as the stressful nature of the NICU, fatigue and anxiety associated with having an ill infant and conflicting and inaccurate knowledge about breastfeeding or bottle-feeding (Bernaix, Schmidt, Jamerson, Seiter & Smith, 2006). In their study on mothers’ experiences on breastfeeding in the NICU, Boucher, Brazal, Graham-

Certosini, Carnaghan-Sherrard & Feeley (2011) found that mothers reported nurses teaching them was pivotal in providing positive reinforcement, learning new feeding techniques and making them feel more at ease with breastfeeding. They wrote, “The mothers described the nurses as an important resource for them during this learning process. Mothers stated that nurses provided information about taught them techniques that promoted effective breastfeeding (p. 24).”

Advocacy was a third subtheme identified in the findings. Advocacy is a key component of primary nursing. In their study on nurse and parent relationships, Reis et al., (2010) stated:

Consistency of nursing personnel has been identified by parents as a key factor affecting their ability to develop effective nurse/patient relationships. Additionally, parents report the nurse/ parent relationship as the factor that most greatly influences the parents’ satisfaction with their NICU experience (p. 675).

Likewise, Macquire & Botting (1990) found that primary nursing resulted in increased knowledge of specific patients, greater continuity of care and increased job satisfaction among nurses, which led to increased quality of care. In a study conducted by Goode & Rowe (2001), nurses reported that when they were primary nursing, they felt greater responsibility, more accountable and more driven to ensure the best quality of care for their primary patient. Nurses developed close relationships with their primary patients and went that extra step to advocate for them and ensure they received a high standard of care. Similarly, in their study on mothers of chronically ill infants and primary nursing in the NICU, Scharer & Brooks (1994) found primary nurses were of utmost importance in the NICU setting where infants are unable to speak for themselves and parents often need a supportive voice to advocate for their infant.

Voicing parental concerns is also an important part of advocating for infants and their families. Actively listening to parental concerns and then acting by either sharing information to alleviate the concerns or bringing the concerns to the attention of the healthcare team are nursing actions that facilitate parental empowerment and support (Hurst, 2001). Similarly, McAllister & Dionne (2006) found that listening to and respecting parents perspectives are action-specific nursing actions, which lead to effective nurse/parent partnerships that work to ensure the infant receives the best possible care.

Many of the participants in this study described the challenges they experienced functioning in the NICU due to the fact that English was not their first language. Ardal, Sulman & Fuller-Thomson (2010) wrote:

Following the birth of a healthy term baby, parents usually assume total responsibility for their infant, but in an NICU, their role is supplanted by technology, and they have to entrust the care of their fragile infant to professionals. The situation is even more difficult for families who are not of the dominant language and culture because they lack easy access to information and support (p. 89).

In their study on Latino families with limited English proficiency in the NICU, Miquel-Veges, Donohue & Boss (2010) found that language barriers interfered with medical follow-up arranged by the NICU and parents with limited English proficiency faced barriers to understanding their infant's medical needs and to obtaining appropriate medical services. Likewise, Wiebe & Young (2010) found immigrant mothers who spoke limited English expressed anxiety about understanding others and being understood. There were numerous inaccuracies in parents' understanding of their infant's condition and treatment and some parents were too afraid to ask questions or felt the staff was withholding information from them. These parents identified

several strategies such as speaking slower and teaching by demonstration as means of overcoming language barriers.

Another subtheme identified in this study was participants had a lack of knowledge about the NICU. Ardal et al., (2010) stated, “NICU norms that are readily discernible or easily questioned by parents who speak English are often a mystery to those who do not (p. 95).” They found that immigrant parents often lacked knowledge about the basics of how the NICU functioned, what resources were available to them and what was expected of them while their infant was in the NICU. Wiebe & Young (2010) found that the healthcare system of an immigrants’ country of origin could often influence how they function in a new healthcare system. They wrote, “Many immigrants mentioned the poor quality of services available in their home countries, unsanitary conditions, and the requirement to pay for services (p. 80).” As a result, immigrants were less likely to question care or bring up concerns because they felt gratitude and appreciation for the high-quality health care services available to everyone in Canada. In her work on the traditional practices of neonatal care in India, Schwoebel (1998) wrote, “India’s nursing profession lacks status. Its’ practice and education are hospital-centered, while medicine dominates the health care delivery system and nurses function primarily as physicians’ handmaidens (p. 30).” As a result, many South Asian immigrant families may come to Canada and not know how to interact with the nursing team. In addition, they may not question the physicians because they are viewed as the ultimate authority and decision-maker.

A more comfortable NICU was a final subtheme identified in this study. All the participants interviewed in the study expressed that a single room unit design would make the NICU more comfortable to parents. They all felt single room units would allow for privacy, relaxation and allow more alone time for them to spend with their infant. Cone (2010) stated:

The single family room has appeal for number of reasons, including the positive impact of developmentally appropriate care on infant outcomes, increased importance placed on breast-feeding and kangaroo care, better infection control practices, increased family involvement, as well as the mandate to assure patient privacy (p. 68).

As discussed earlier, the chaotic nature of the NICU environment also adds to parents feeling fearful and anxious about their parental role. Some studies have shown that the open ward design of the NICU can perpetuate these negative feelings. Darbyshire (1994) found that parents felt like they were “parenting in public” (p. 101). As a result, their very private feelings about their child and their parenting behaviors become common property of other parents and nurses on the unit. White (2003) found that single family rooms gave parents a sense of belonging in the NICU environment. Mothers felt more comfortable nursing their infant, singing or talking “baby talk” and fathers especially felt more at ease to interact with their infant in a more private setting. In addition, parents could rest and personalize the room in order to make it a “home away from home.”

Implications of Findings

The findings of this study have implications for clinical nursing practice and nursing research, which will be discussed in separate sections.

Implications for Nursing Practice

Many implications for nursing practice emerge from the findings of this study. Most of these implications are not new information for most nurses, but it is hoped that this research will inspire all nurses to examine their interactions with all immigrant families in order to provide care that is holistic and individualized to the needs of their immigrant patient. When providing care to South Asian immigrant women, it is essential that nurses not make any assumptions about

their patient's understanding of the healthcare system, NICU policies and procedures and what their role is during their NICU stay. Nurses may need to outline details of how the NICU unit works, encourage mothers to be involved in the care of their infant and encourage them to ask questions to the entire healthcare team.

Nurses should also be aware of any cultural assumptions they may have about South Asian immigrant women. There is often a tendency to attribute lack of knowledge about the healthcare system or barriers to services to the cultural beliefs or practices of the vulnerable groups such as, shyness or cultural beliefs about disease prevention and causality. This culturalist attitude does not help immigrant families obtain adequate health care and only further adds to the underlying problems of racism, gender and class (Culley, 1996). Nurses should dismiss any stereotypical cultural beliefs they may have about South Asian immigrant women such as believing they are subordinate to their husbands, only desire male children or are compliant and passive. Nurses should be aware that although certain similarities may exist among individuals of a particular cultural group, each individual is unique and thus, nursing care should be individualized to the needs of the patient.

According to Kirkham & Anderson (2002), "the social and moral mandate of nursing is now seen to include illumination of the experiences of those marginalized within society and within health care (p. 2)." Thus, nurses should adopt a stance to their practice that takes into account the many dimensions of their patients, especially vulnerable groups such as South Asian immigrant women and by doing so promote ethical nursing practice. Nurses can promote equality of care and ensure that South Asian immigrant families are receiving optimum care and are not being ignored because they may not question care, not fully understand the care being given to their infant or do not speak or understand English. Promotion of care can be achieved

by ensuring interpreters or a family member/healthcare professional that speaks Punjabi or Hindi is present during daily rounds and at care conferences. In addition, nurses can reinforce to South Asian immigrant families the importance of asking questions and clarifying the reasoning behind procedures.

Nurses should be aware that health is multi-dimensional and that numerous factors influence the health status of immigrants (Raphael, Bryant, Rioux, 2006). Dunn & Dyck (1998) reiterate this fact by stating, “The most important antecedents of human health status are not medical care inputs and health behaviours (smoking, diet, exercise, etc.), but rather social and economic characteristics of individuals and populations (p. 1).” Thus, nurses should be aware of how factors like socioeconomic status, social isolation and education can affect a South Asian immigrant women’s NICU experience. Nurses can help alleviate the impact of some of these factors by linking South Asian immigrant families with a social worker in order to obtain food vouchers and housing close by the hospital. Nurses may also need to link South Asian immigrant women to other resources such as interpreters, cultural liaison groups and community support groups. In addition, since extended family members are an integral component of South Asian women’s lives, it is important that nurses include these family members in decision-making but only when the women desire it (Grewal, Bottorff & Hilton, 2005).

Finally, nurses can reflect on how their own values and beliefs surrounding marginalized groups affect their daily interactions with such groups and nursing practice overall.

Discriminatory attitudes of nurses can impact the illness experience of individuals under their care (Johnson, Bottorff, Browne, Grewal, Hilton & Clarke, 2004). Nurses should be aware of the way they interact with South Asian immigrant patients and use of language and stereotypes when referring to another cultural group. Nurses should help extinguish both active and passive

racism by monitoring their own attitudes and pointing out others discriminatory actions, language or attitudes. Nurses as the healthcare providers can be viewed as dominant over typically vulnerable groups such as South Asian immigrant women (Razack, 1998). As a result, positions of domination and subordination can reinforce discriminatory behaviours and should not be tolerated.

Implications for Nursing Research

Finally, this study has implications for nurse researchers who work to uncover new findings in order to ensure nursing practice is based on evidence. Tingen, Burnett, Murchison & Zhu (2007) state:

The information obtained by a nurse researcher can be disseminated to nurses who work directly with the individuals to whom the research applies. Practice that has shown to be effective through research allows nurses to advocate for patients and provide the best possible care (p. 169).

Thus, in order to better understand the immigrant experience and allow practicing nurses to deliver effective care to immigrant families, nurse researchers should continue conducting studies that examine the experience of immigrant families in clinical settings. For example, experiences of South Asian immigrant families in other clinical settings and in the public health arena would shed light on the health disparities and barriers faced by this population. In addition, studies examining how components such as family and religion may influence South Asian immigrant women's health beliefs may also provide valuable information on how they experience and interact with the Canadian healthcare system.

Differences in the NICU experience or any other healthcare experience between first-generation and second-generation South Asians could also pinpoint specific needs for each

population. Research that aims to find strategies that make the Canadian healthcare experience could be made more manageable, accessible and easier for South Asian families would also provide support for the changes that are needed. Finally, research that explores how South Asian immigrant women experiences with breastfeeding, death, and decision-making around a very premature infant or infant with disabilities would also prove useful.

Limitations

Some of the limitations of the study related to the methodology. Interpretive description is a relatively new and emerging methodology in qualitative research. Therefore, there are very few resources and examples of research conducted using this methodology to guide the research process. As a result, this lack of resources on the methodology was a limitation to the study. However, the material supplied by Thorne et al., 1997 and Thorne et al., 2004 were extremely coherent and informative. However, the degree of interpretation needed to illuminate the phenomenon under study and answer the posed research questions was unclear. According to Sandelowski & Barosso (2002), researchers must take a risk and commit to making an interpretation during the analysis process. Researchers must take ownership of their interpretation, which can be the most challenging part of interpretative description especially for those who are new to the research process. I tried to overcome this limitation by continually comparing interpretations to secondary data sources such as relevant literature and by consulting other South Asian health care professionals.

Nurse researchers should develop their own qualitative research traditions because the nature of knowledge that nursing practice theory demands can be quite different from the kind of “cause and effect” knowledge highlighted by quantitative research (Carter, 1985). For example, this study is not attempting to highlight a relationship between South Asian immigrant women

and the NICU environment. It is also not attempting to generalize findings of this study to the South Asian immigrant population or any other population, which would be inappropriate for a qualitative study.

Other major limitations of the study were sample-related. I did not anticipate such difficulty with recruiting participants and as a result, ended up with a smaller sample size than initially proposed. Although I could have continued to recruit participants, it was felt that the data obtained from the five participants was sufficient to elicit an interpretation of South Asian immigrant women's experiences in the NICU. However, additional interviews would have been helpful in order to allow for more data.

There is much anecdotal evidence about particular challenges, differences and similarities in the South Asian immigrant women's healthcare experience that were not reflected in the findings. Although I am of South Asian origin, reiterated that confidentiality would be maintained and encouraged participants to speak freely, they still did not speak openly during the interview process. It was noted that during the majority of interviews, participants would speak more freely and share their negative NICU and overall negative healthcare system experiences with the researcher once the audio recorder was turned off. Participants would share stories of specific nurses who had not done a particular task or had not shared information with them. In addition, participants would relay negative experiences about other aspects of the healthcare system such as other NICUs they had stayed in or inadequate pregnancy care.

Other limitations were related to the sample criterion. Because the participants all had to speak conversational level English, the sample is not reflective of the entire South Asian immigrant community. Non-English speaking South Asian immigrants experience language barriers, which lead to a multitude of health challenges such as delays in receiving pertinent

health-related information and misunderstanding of treatment and diagnosis (Roberts, 2003). In addition, non-English speaking immigrants and recent immigrants (which is also not reflected in the study sample as all the participants have been in Canada for at least five years) may not yet have fully integrated with the Canadian system and thus may have more specific cultural needs and may not be aware of resources available to them (Newbold, 2009). As a result, the unique healthcare challenges and needs experienced by non-English speaking South Asian immigrant women and recent immigrants may not be reflected by the study sample.

Because the study was only conducted at BCWH NICU, the findings cannot be generalized to an overall NICU experience. In addition to basic differences in care, procedures, routines and resources among different NICUs, there are also definite differences among NICUs located in different geographic areas including socio-cultural, socio-economic and philosophical differences. This phenomenon is especially significant because many of the participants had stayed in other NICUs in British Columbia and relayed how different their experience was there compared to the NICU at BCWH. This study could not capture the potential influences of these differences between various NICUs and provides insight for the NICU at BCWH.

Conclusions

The findings of this study illustrate the NICU experience of South Asian immigrant women is similar to that of all individuals regardless of their ethnic background. Fear of the unknown, is a feeling expressed by most parents who have an infant admitted in a stressful environment such as the NICU. Likewise, trust, teaching and advocacy are all components of nursing care valued by both adult patients and parents who have a sick infant or child. The ideas suggested by participants to make the NICU more comfortable for parents are also echoed by other parents in the NICU.

Language barriers are a challenge experienced by most immigrant groups in the healthcare system. The use of interpreters and other native-speaking healthcare staff are measures that can be used to overcome this challenge. However, more interpreters that are available at the point of service and at all times are needed in the NICU. Most parents lack knowledge of how the NICU functions, what resources are available to them and what is expected of them. However, as their length of stay continues, they become more comfortable and adept at functioning in the unit. South Asian immigrant women's lack of knowledge of the NICU may be compounded by their lack of knowledge of the Canadian healthcare system and may also be influenced by the healthcare system of their native country. As a result, measures are needed to make the NICU environment more navigable and user-friendly for this population group.

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APPENDIX B: RECRUITMENT POSTER

Are you a South Asian Immigrant Mother whose infant is/was admitted in the NICU at B.C Women's Hospital?

I am a South Asian masters of nursing degree student at the University of Victoria interested in the experiences of South Asian immigrant women with infants in the NICU. I would like to invite you to share your experience. You must speak English at a conversational level to participate in this study.

Only one interview will be conducted and the recording of your experience will take 1-2 hour(s) using a tape recorder. A written record will be made from the recording. Confidentiality and anonymity will be guaranteed. You may end your participation at any time. You will incur no costs as a result of your participation in this study. You may choose to not talk about any issues that you are not comfortable talking about. The interview will be in the form of a conversation at a time and place that you choose. All questions related to the interview, the recording process and the research study itself will be answered to your satisfaction before, during and after the interview. A signed consent form will be requested for participation in this study. In addition, demographic data such as date of birth, occupation, level of education, marital status, reason why your infant was admitted to the NICU etc. will be collected as part of the interview process.

If you agree, I will meet with you to review the study in more detail and the consent form. If you agree to participate, I will set up a time to conduct an interview that is most convenient for you.



Yes, I would like more information.

Please contact me at _____



No, I'm not interested.

Sincerely,

Deepshikha Wilson, B.Sc., BN, RN, MN (candidate) 778.863.7808/dgargawilson@gmail.com



APPENDIX C: SUBJECT INFORMATION AND CONSENT FORM

Understanding the Experience of South Asian Immigrant Women in the NICU: An Interpretive Description

Principal Investigator: Deepshikha G. Wilson, BSc., BN, RN, MN(candidate)
 UBC Division of Pediatrics & Neonatology
 British Columbia Children's & Women's Health Centre
 778-863-7808

Dr. Joan MacNeil, RN, BScN, MHSc, PhD
 University of Victoria, Faculty of Nursing
 250-721-7965

You are being invited to take part in this research study because you are a South Asian immigrant woman with an infant currently admitted in the NICU or that was admitted in the past five years at the BC Women's Hospital NICU and we would like to hear your account of your NICU experience.

Your participation is entirely voluntary, so it is up to you to decide whether or not to take part in this study. Before you decide, it is important for you to understand what the research involves. This consent form will tell you about the study, why the research is being done, what will happen to you during the study and the possible benefits, risks and discomforts.

If you wish to participate, you will be asked to sign this form. If you do decide to take part in this study, you are still free to withdraw at any time and without giving any reason for your decision.

If you do not wish to participate, you do not have to provide any reason for your decision not to participate nor will you or your infant lose the benefit of any medical care to which you or your infant are entitled or are presently receiving.

Please take time to read the following information carefully and to discuss it with your family, friends, and doctor before you decide.

WHO IS CONDUCTING THE STUDY?

The study is being conducted by Deepshikha G. Wilson, BSc., BN, RN, MN(candidate) who is a graduate student in the School of Nursing at the University of Victoria as part of the thesis requirements for a Master's degree in Science of Nursing.

WHAT IS THE PURPOSE OF THE STUDY?

The purpose of this research project is to gain a greater understanding of the experience of South Asian immigrant women with infants in the NICU.

Research of this type is important because it may help us better understand what challenges South Asian immigrant women who have sick infants in the NICU face. The information gathered from the individual interviews cannot be generalized to all South Asian and other immigrant populations nor is it the intent of this study. Instead, by examining the individual NICU experiences and challenges faced during this experience, it is hoped that patterns come out that will prompt neonatal nurses to examine their own practice toward immigrant families. On a broader scale, it is hoped that this research study will inspire all nurses to examine their interactions with all immigrant families in order to provide care that is meaningful and individualized to the needs of their immigrant patient.

STUDY PROCEDURES

If you agree to voluntarily participate in this research, your participation will include one 1-2 hour interview. To minimize any inconvenience to you, the interview can take place in your home or at my office at a time that works best for you. The researcher will take written notes and/or audiotape the interview. In addition, demographic data such as date of birth, occupation, level of education, marital status, reason why your infant was admitted to the NICU etc. will be collected as part of the interview process. The data will be transcribed by a third party and will be analyzed by the researcher. The findings will be documented in a written report that will be available to subjects.

POTENTIAL RISKS

Participation in this study may cause some inconvenience to you, including the time for the interview. However, every effort will be made to arrange the interview at a time and place that is convenient.

By participating in this research you may experience an emotional response to past experiences or the opening of sensitive wounds. To prevent or to deal with these risks the following steps will be taken:

- all questions will be respectful, appropriate and sensitively presented.
- subjects will be encouraged to answer only those questions they feel they are able to.
- if the subject becomes upset during any part of the interview, the researcher will pause, reschedule or end the interview altogether.
- if necessary the researcher will refer the subject to the NICU Social Worker or a counseling agency to deal with the emotional response.

POTENTIAL BENEFITS

The potential benefits of your participation in this research include the opportunity to explore and discuss your own experiences of being a South Asian immigrant woman with an infant in the

NICU. The findings of this study will hopefully result in nursing care that is more meaningful and individualized to the needs of not only South Asian immigrants but all immigrant families in the NICU. In addition, the state of knowledge in health care about South Asian immigrants may be informed, expanded, and promoted.

CONFIDENTIALITY

In terms of protecting your confidentiality, you will have face-to-face contact with the researcher but you will decide what personal identifiable information you wish to extend to the researcher. Audio recordings will be numerically coded and kept in a locked filing cabinet available only to the researcher. Audio recordings will be transcribed and tracked through number codes. Audio recordings will be erased after data analysis is completed. In published reports and presentations, subjects' names will be replaced with false names. One list of subjects' names, addresses, phone numbers, e-mail addresses (if applicable), and codes will be kept by the researcher for the purposes of communication with subjects. This list will be kept in a separate location from the transcribed data and will be destroyed at the end of the study.

Your confidentiality and the confidentiality of the data will be protected by restricting audio recordings and transcribed data to only the researcher. All data will be kept in a locked filing cabinet and password protected computer. A paid transcriptionist who will also uphold ethics of confidentiality and sign a contract will transcribe interviews. Confidentiality will be upheld if research findings are shared in any publications or presentations. Data from this study will be disposed of by erasing audio recordings after data analysis is completed. The only copy of the subject list will be destroyed at the end of the study. Transcribed data will be kept for the possibility of secondary analysis because this research is the first of a series of studies with the phenomenon of understanding the experience of South Asian immigrant women in the NICU.

Please check if subject agrees to have the interview data used for secondary analysis.

It is anticipated that the results of this study will be shared with others in the following ways. When my thesis is completed, the final document will be kept at the University of Victoria and will be accessible to faculty and students. Sections of the thesis may also be published in scientific journals/books or publicly presented while adhering to ethics of anonymity and confidentiality.

CONTACT FOR INFORMATION ABOUT THE STUDY

If you have any questions or desire further information with respect to this study, you may contact Deepshikha G. Wilson, BSc., BN, RN, MN(candidate) by email (dgargawilson@gmail.com) or by telephone (778-863-7808). You may also contact my supervisor Dr. Joan MacNeil at the University of Victoria School of Nursing by email (joanm@uvic.ca) or by telephone (250-721-7965).

CONTACT FOR CONCERNS ABOUT THE RIGHTS OF RESEARCH SUBJECTS

If you have any concerns about your rights as a research subject and/or your experiences while

participating in this study, contact the Human Research Ethics Office at the University of Victoria by email (ethics@uvic.ca) or by telephone (250-472-4545) or the Research Subject Information Line in the University of British Columbia Office of Research Services by email (RSIL@ors.ubc.ca) or by telephone (604-822-8598) (Toll Free Number 1-877-822-8598).

CONSENT

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy to the care received by you or your infant during their stay in the NICU or any subsequent follow-up care.

Your signature below indicates that you have received a signed and dated copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

Subject Signature

Date

Printed Name of the Subject signing above

Date



APPENDIX D: CONTRACT FOR TRANSCRIPTION OF INTERVIEW TAPES

You have agreed to be a transcriptionist in a study entitled, “*Understanding the Experience of South Asian Immigrant Women in the NICU: An Interpretive Description*” that is being conducted by Deepshikha G. Wilson, BSc., BN, RN, MN(candidate).

I am a graduate student in the School of Nursing at the University of Victoria and you may contact me if you have further questions by email (dgargawilson@gmail.com) or by telephone (778-863-7808). As a graduate student, I am conducting this research as part of the requirements for a Master’s degree in Science of Nursing. You may also contact my supervisor at the School of Nursing if you have any questions: Dr. Joan MacNeil by email (joanm@uvic.ca) or by telephone (250-721-7965)

If you have any concerns about your rights as a research subject and/or your experiences while participating in this study, contact the Human Research Ethics Office at the University of Victoria by email (ethics@uvic.ca) or by telephone (250-472-4545) or the Research Subject Information Line in the University of British Columbia Office of Research Services by email (RSIL@ors.ubc.ca) or by telephone (604-822-8598) (Toll Free Number 1-877-822-8598)

This contract for transcription of interview tapes constitutes an agreement between Deepshikha G. Wilson, Principle Investigator, and _____, transcriptionist. In agreeing to this contract, I _____ agree to the following:

- Audiotapes are to be transcribed verbatim, and in detail, according to the formal instructions of the principle investigator.
- As the transcriptionist, I will maintain the confidentiality and privacy of the participants. I will repeat no part of the participant dialogue and if I am aware of the identity of participants, I will not reveal this information to anyone.
- The audiotapes, disks, and hardcopies of the data, when not being actively used by me for transcription, will be kept in a locked filing cabinet or a locked box supplied to me by the principle investigator.
- Once tapes and transcriptions (disks and hardcopies) are returned to the principle investigator, I will erase any and all computer files pertaining to this research.
- Payment will be made upon completion of transcripts at a rate of \$20.00 per hour of work. It is expected that each one-hour tape will require three to four hours of transcription time.

Your signature below indicates that you understand the above contract conditions and that you have had the opportunity to have your questions answered by the researcher.

Name, Address & Phone Number of Transcriptionist

Signature of Transcriptionist

Date

Name, Address & Phone Number of Researcher

Signature of Researcher

Date

Name, Address & Phone Number of Witness

Signature of Witness

Date

A signed and dated copy of this consent form will be left with you, and a copy will be taken by the researcher.

APPENDIX E: DEMOGRAPHIC DATA

Subject Number: _____

Month & Year of Birth of Subject: _____

Country of origin: _____

Number of years in Canada: _____

Reason for immigration to Canada: _____

Number of children: _____

Family in Canada: _____

Occupation: _____

Education level: _____

First language: _____

Proficiency level of English: _____

Marital status: _____

Support people at time of NICU admission: _____

Health status of narrator at time of NICU admission: _____

Diagnosis of Infant upon admission: _____

Is/was this your first time having an infant admitted to the NICU? _____

Is/was this your first extended encounter with the Canadian Healthcare system?

Anything else subject would like to tell me about herself:

APPENDIX F: SAMPLE INTERVIEW QUESTIONS

1. When did you first visit your baby in the NICU? What was this experience like for you?
2. Who were the health care providers that you interacted with most during your baby's stay in the NICU?
3. Describe a situation where a nurse was helpful for you?
4. Can you think of a situation where a nurse was not helpful?
5. What challenges have you experienced as a South Asian immigrant women with the overall NICU experience.
6. What improvements do you think are needed with any aspect of the NICU from nursing care, the equipment, the resources available etc. that could make the NICU experience better or easier for South Asian immigrant women?