Nurses’ Experiences with Providing Newborn Screening Education to Mothers in the Hospital: An Exploratory, Qualitative Research Study

by

Diana Ann An

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Institute of Health Policy, Management and Evaluation
University of Toronto

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Abstract

Newborn screening (NBS) parent education is an important component of a well-functioning NBS program. Postpartum nurses are in an important position to educate parents about NBS, but their experiences have not yet been captured in the literature. This qualitative study sought to explore nurses’ experiences with providing NBS education to mothers on the postpartum unit by conducting one-on-one interviews with postpartum nurses and nursing leaders. An explanatory framework was developed which showed that although postpartum nurses were actively involved in providing both written and verbal information about NBS to mothers and viewed it as their responsibility, organizational factors and nurses’ desire to be responsive to mothers’ perceived preferences and needs limited the amount of time postpartum nurses spent on this education and the depth to which they provided it. This research illuminated the context in which NBS education occurred and suggests several research and policy implications.
Dedication

I dedicate this thesis to my wonderful parents
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Chapter 1
Introduction

1 Introduction

Newborn screening (NBS) is a program that is offered in many jurisdictions around the world in an effort to improve health outcomes in children affected by serious disorders through early identification and treatment. Although the main components of NBS include specimen collection (usually a blood sample from a heel prick shortly after birth), follow up of newborns who screen positive for diagnostic testing, and treatment where required, education is also recommended as one of the core components of NBS (Therrell, Panny, Davidson, Eckman, Hannon, Henson et al., 1992). Many types of health care providers care for mothers and newborns, but because the majority of babies are born in hospital in North America, most mothers receive at least some care from postpartum nurses and thus postpartum nurses may have a role to play in NBS education. It is known that in some jurisdictions such as in Ontario, postpartum nurses are providing the bulk of NBS education to mothers but we do not yet know their experiences with it. Thus, this study explored the provision of NBS parent education by postpartum nurses.
1.1 Background

NBS was first introduced in the 1960s as a test for one genetic disorder, Phenylketonuria (PKU), which, without early treatment, usually leads to intellectual disability, seizures, and other medical problems (Guthrie & Susi, 1963). Since then, a range of factors has encouraged expansion. For example, advances in genetic science led to the characterization of a growing number of rare diseases that could potentially be identified at birth (Seymour, Thomason, Chalmers, Addison, Bain, Cockburn et al., 1997), and technological advances such as tandem mass spectrometry made it possible to screen for these conditions on a mass population basis (Schulze, Lindner, Kohlmüller, Olgemöller, Mayatepek, Hoffmann, 2003). Though NBS programs may vary in the number of disorders screened, whether informed consent is necessary to participate, the setting of the screening test (i.e. home or in hospital), and the providers involved, stakeholders claim that informing parents about each part of the NBS program is important (Kaye & Committee of Genetics, 2006; Arnold et al., 2006; Davis et al., 2006; Little & Lewis, 2008). While a variety of providers could potentially be involved in NBS education, research has shown that health care providers who collected the blood sample for NBS were routinely and consistently involved (Araia, Wilson, Chakraborty, et al., 2012; Detmar, Hosli, Dijistra et al., 2007; Kerruish, Webster & Dickson, 2008; Kim, Lloyd-Puryear, Tonniges, 2003).

This means that in the North American setting, NBS education may often occur in hospital, on the postpartum unit, by postpartum nurses. Recent research in Ontario shows that this is the case (Araia, Wilson, Chakraborty, et al., 2012).

In Ontario, which is the location of this research study, newborn screening is coordinated through a single laboratory centre in Ottawa. It is recommended that heel prick blood samples be collected any time after 24 hours of life (Newborn Screening Ontario [NSO], n.d.a, para. 3). At the time of sample collection, a health care provider fills out a demographic information section on the screening card about the mother and the newborn for the purposes of accurate processing and quick follow-up of newborns who screen positive for a disorder or require repeat testing (NSO, n.d.a, para. 4). The sample is collected onto a special filter paper by the responsible provider (postpartum nurse, hospital technician, midwife, etc.) and mailed to the centralized laboratory in Ottawa for processing. Results are typically not available until after families have been discharged, which means that the newborn's health care provider in the community will be contacted to follow up should there be a screen-positive result or if repeat testing is required. The
NBS program tests for 29\(^1\) treatable disorders such as, inborn errors of metabolism, cystic fibrosis, and sickle cell disease.

NBS in Ontario is offered under an implied consent model, which means that explicit parental consent is not required (Downie & Wildeman, 2001; NSO, n.d.b, para. 3). However, the Ontario Newborn Screening Program (ONSP) still encourages prenatal providers to communicate several key messages about NBS to expectant parents\(^2\). These messages include, communicating the importance of the test, the serious nature of the diseases and the consequences of not implementing early treatment, the inability to tell upon physical examination whether newborns have one of the 29 diseases, clarifying the misconception that newborns who lack a family history of the disease are at lower risk, and communicating what follow up processes parents can expect should their newborn require further testing (NSO, n.d.c)

Postpartum nurses are implicated in NBS parent education before mothers and their babies are discharged, and research shows that postpartum nurses play a very important role in the provision of NBS education to mothers in Ontario (Araia, Wilson, Chakraborty, et al., 2012; Hayeems, Miller, Little, Carroll, Allanson et al., 2009). In a 2012 survey by Araia and colleagues involving mothers who had recently experienced NBS in Ontario, the majority of parents reported receiving information about NBS in the postnatal period. More specifically, among the mothers who reported receiving information about newborn screening, 72% received the NBS education during the period after birth and up to the time of screening, and nurses were the primary source (69%) of this education (Araia, Wilson, Chakraborty, et al., 2012). These findings are not surprising given that postpartum nurses are well-positioned to provide education to mothers in the hospital due to the amount of time they spend with them (DeLuca, Zanni, Bonhomme & Kemper, 2013; Little & Lewis, 2008; Martell, 2003), and because patient education is considered an integral part of nursing practice (Close, 1988; Nolan, Nolan & Booth, 2000; Tilley, Gregor & Thiessen, 1987). Further, there is increased attention in the literature to involving and equipping nurses in the education of parents about NBS (Anderson, Rothwell & Botkin, 2011; DeLuca, Zanni, Bonhomme & Kemper, 2012; Hayeems, Miller, Little, Carroll, 2009).

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\(^1\) At the time of data collection, NBS tested for 28 different disorders

\(^2\) Currently there is no discussion guide available specifically for postnatal providers on the ONSP website
Allanson et al., 2009). Yet, various factors may hinder NBS parent education on the postpartum unit. For example, hospital stays for uncomplicated vaginal and caesarean sections are short and are on average, between one and three days (Canadian Institute for Health Information [CIHI], 2004) and it is usually during this period that the NBS blood specimen is collected (NSO, n.d.d, para 5). Given the importance of nurses’ role, and of understanding how it is influenced by unit practices and policy, it is important to capture the views and experiences of nurses.

1.2 Purpose of the study

The objective of this study was to gain a clearer understanding of the provision of NBS parent education by postpartum nurses on the postpartum unit. The perspectives of postpartum nurses who were implicated in bedside delivery of NBS education and the perspective of nursing leaders who were responsible for setting expectations for postpartum nursing practice on the postpartum unit were sought. The research question addressed was, what are nurses’ experiences with providing NBS education to mothers in the hospital? NBS education was not explicitly defined in the literature nor did this research study attempt to define NBS education. Thus, postpartum nurses and nursing leaders were free to interpret NBS education as they wished and to speak to their experiences with it.

1.3 Relevance

This research adds to the existing but scant literature on the experiences of postpartum nurses who are directly involved with providing NBS education to parents. Results from the study will inform policy makers and other decision makers on the current challenges to providing effective NBS education to mothers and may assist them in building a better NBS education program for the public. Also, efforts to support or expand nurses’ role in NBS education should begin with awareness and understanding of their experiences as well as the facilitators and barriers they perceive. Finally, the results of the study can inform professional health care organizations on the importance of developing guidelines that define the scope of patient education for preventative health services such as NBS so that postpartum nurses are clear about what information they are responsible for communicating to mothers.
Chapter 2
Literature Review

2 Purpose of the literature review

Two bodies of literature informed this research study on the experiences of nurses with NBS parent education: namely the NBS literature and the nursing literature. In the NBS literature, studies exploring the rationales for providing NBS education to mothers/parents in general and those reviewing the status of NBS education for mothers in different NBS programs around the world were examined. Exploring the rationales for NBS education was important because it related specifically to the research study problem. Understanding the provision of NBS education in different jurisdictions allowed for consideration of the potential relevance and applicability of study findings to other contexts.

In the nursing literature, studies exploring the role of patient education in nursing practice as well as studies exploring the postpartum nursing environment were reviewed. Since the experiences of nurses in providing patient education about NBS was the focus of this research, it was important to understand better how patient education activities fit into postpartum nursing. Thus, the nursing literature was used to learn more about the views of nurses on their role in patient education. Also, given that postpartum nurses in Ontario are delivering NBS education to mothers in the hospital setting, it was important to learn more about the environment of postpartum units and the factors that may affect postpartum nurses’ provision of patient education. Gaps in each of the respective domains of literature were identified and helped to inform the research questions.
2.1 Rationales for parent education in NBS

Several reasons for the provision of NBS education are identified in the NBS literature: firstly, NBS education is expected to meet mothers/parents’ desire for NBS information; secondly, NBS education before screening may help combat anxiety associated with receiving a false-positive result or the need for repeat screening; and lastly, the need for informed consent for participation in NBS in some jurisdictions necessitates NBS education. Each of these rationales will be discussed further below.³

In general, studies suggest that mothers want to receive information about NBS. Studies report that mothers wanted basic information about NBS (Davis, Humiston, Arnold et al., 2006; Tluckyzok, Orland, Nick, et al., 2009) and more specifically, they wanted information about the purpose and importance of the test, disorders included in testing, whether screening was beneficial, the possible need for their baby to be retested, and how they would be informed about the need to retest and the importance of acting quickly (Tluckyzok, Orland, Nick, et al., 2009). Mothers in some jurisdictions did not want health care providers to go into detail about any one disorder (Bailey & Murray, 2008; Davis, Humiston, Arnold et al., 2006). However, parents have stated their desire for more information about NBS if the program were to be expanded and especially if they were required to make a decision about their infant’s participation in an expanded NBS program (Detmar, Hosli, Dijkstra et al., 2007).

In addition to wanting to know essential information about NBS, several studies report that mothers preferred to learn about NBS in the prenatal setting (Davis, Humiston, Arnold et al., 2006; Detmar, Hosli, Dijkstra et al., 2007; Hasegawa, Fergus & Ojeda, 2011; Parsons, King & Bradley, 2007), with mothers generally not thinking the postpartum setting was an ideal time to learn about NBS. Mothers receiving NBS education during the immediate postnatal period were unsatisfied because they felt that it was information overload (Parsons, King & Bradley, 2007) and because they were exhausted from the birth and were not in the optimal condition to receive patient education about NBS (Arnold, Davis, Humiston et al., 2006; Davis, Humiston, Arnold et al., 2006; Hasegawa, Fergus & Ojeda, 2011; Tluckyzok, Orland, Nick et al., 2009).

³ In addition, the argument that information provision has value by showing respect for persons in health care settings, irrespective of desire for it or its instrumental value, offers another rationale for NBS education (Manson, 2010)
Exhaustion and information overload during the postpartum period when NBS education is often given may affect mothers’ ability to retain knowledge about NBS.

Further, low levels of patient knowledge regarding NBS were evident in the NBS literature (Davis, Humiston, Arnold et al., 2006; Detmar, Hosli, Dijistra et al., 2007; Hasegawa, Fergus & Ojeda, 2011; Tluczek, Orland, Nick, et al., 2009; Parsons, King & Bradley, 2007). Davis and colleagues conducted a study on parental, provider, and expert opinion on providing effective NBS education and found that parents were not unaware of the term, "newborn screening" although some were familiar with the terms "PKU" and "heel prick" test. Among those who were familiar with the term "PKU" test, many were not aware that the NBS test screened for more than just PKU (Davis, Humiston, Arnold et al., 2006). In another study, Newcomb and colleagues surveyed postpartum women from five hospitals in one state to assess their basic knowledge about NBS (2013). Although most women in the sample knew that NBS could identify newborns with serious disorders, 91.3% of women did not know how they would receive their results. In addition, the literature has reported that many parents were uninformed or misinformed about the purpose of screening (Detmar, Hosli, Dijistra et al., 2007; Tluczek, Orland, Nick, et al., 2009; Parsons, King & Bradley, 2007).

A second rationale for providing NBS education to mothers/parents, in addition to meeting mother/parental desire for information, is more instrumental. It has to do with the potential for prior parent knowledge about NBS to help mitigate the stresses and potential psychosocial harms of infant screening arising from such things as requests for repeat screening tests (e.g., when a second sample is needed due to technical problems with a first), or false positive results (e.g., when confirmatory test results after an initial screen positive result show that the child is unaffected). A few studies have demonstrated that parents who knew the purpose of a repeat screening test reported lower stress levels compared to parents who did not know the correct reason for a repeat screen when these requests were received (Gurian, Kinnamon, Henry & Waisbren, 2006; Tluczek, Orland, Nick et al., 2009). Several other studies suggest that improving parents’ prior knowledge about NBS may help reduce parental anxiety due to false-positive results (Green, Hewison, Bekker et al., 2004; Hewlett & Waisbren 2006; Morrison & Clayton, 2011; Tluczek, Koscik, Farrell & Rock, 2005). Thus, it appears that prior knowledge about NBS may be instrumentally beneficial in reducing mother/parental anxiety and stress associated with false-positive results and the need for repeat testing.
A third rationale for providing parental education about NBS relates to the fact that some jurisdictions require explicit consent in order to participate in NBS. In many countries in Europe, such as Austria, France, Italy, Spain, Sweden, Switzerland, and the United Kingdom, informed consent is required prior to participation in the NBS program (Loeber, Burgard, Cornel, et al., 2012). In North America, by contrast, explicit informed consent is less common (Therrell, Johnson, & Williams, 2006). The majority of US states (38 of 51 NBS programs) notify parents about NBS but their explicit consent is not required since these NBS programs make testing mandatory (Mandl, Feit, Larson et al., 2002). NBS in Canada is also a routine part of care⁴. In Ontario, the NBS program is considered a standard of care and unless a parent explicitly requests to opt out of the program, their newborn will receive screening (Downie & Wildeman, 2001; NSO, n.d.a, par. 3).

Although the rationale for NBS education is clear, the capacity to deliver NBS education in Ontario and many other jurisdictions remains limited. The next section will review the status of the provision of NBS education to mothers/parents.

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⁴ Hanley (2005) and Downie and Wildeman (2001) found that while most provinces and territories have implemented routine NBS practices, one province, Saskatchewan, has gone one step further and mandates NBS for two conditions. However, on the current Saskatchewan NBS website, it appears that NBS is considered a routinized procedure in the hospital, thus challenging the findings of these studies.
2.2 The provision of NBS education

The delivery of NBS education is inconsistent and it appears that many jurisdictions struggle with the provision of effective NBS education, including Ontario. In this section, some of the challenges noted in the literature facing the provision of NBS parent education are reviewed. These challenges relate to variations in how parents received information about NBS, the diffused responsibility for NBS education among several provider groups, and capacity issues such as a lack of knowledge or confidence about NBS education among some providers.

A first challenge is that parents may receive information about NBS from many sources (Davis, Humiston, Arnold et al., 2006; Detmar, Hosli, Dijistra et al., 2007; Hayeems, Miller, Little et al., 2009; Parsons, King & Bradley, 2007). Receiving information from different sources could be problematic as it is uncertain whether each source is providing accurate NBS information. Tluczuk and colleagues found that some parents learned about NBS from a health care provider, while others learned it from watching the television, reading a book, or through their prenatal class (2009). In some cases, parents reported not receiving any information about NBS from their health care providers at all. For example, in a qualitative study conducted in the Netherlands, parents reported not receiving any explicit information about NBS from their health care providers but rather learned about NBS after screening through a brochure when registering their newborn (Detmar, Hosli, Dijistra et al., 2007).

Another potential challenge in the provision of education to parents relates to the fact that different health care providers, such as midwives, family physicians, obstetricians, pediatricians or nurses (Davis, Humiston, Arnold et al., 2006; Hayeems, Miller, Little et al., 2009; Parsons, King & Bradley, 2007) could be involved with NBS education at different times, from pregnancy through to the post-birth experience. Indeed, Clayton (2005) argues that this state of affairs diffuses responsibility to educate mothers about NBS, creating a lack of ownership and uptake by any one provider group. This argument is supported by several studies. For example, Davis et al (2006) show that providers’ willingness to be involved with NBS education is conditional on this not impeding their routine practice (Davis, Humiston, Arnold, et. al, 2006). As well, an Ontario study highlighted differences between the perceived responsibility to inform parents about NBS and actual involvement among providers who were routinely involved with prenatal care or care of newborns up to and during the time of screening (Hayeems, Miller, Little et al.,
Specifically, while 79% of nurses perceived a professional responsibility to inform parents about NBS, only 47% of them reported being consistently or usually involved with this practice. Compared to the 72% of family physicians who perceived a professional responsibility to inform parents about NBS, only 17% reported being consistently or usually involved (Hayeems, Miller, Little et al., 2009).

Finally, a third challenge relates to capacity barriers health care providers face in the provision of NBS education to parents. Several authors have reported a lack of knowledge or confidence about NBS among providers as an impediment to their involvement (Burke & Kirk, 2006; Davis et al., 2006; Dunn, Gordon, Sein & Ross, 2012; Hayeems et al., 2009). Hayeems and colleagues (2009) showed providers were 40% to 70% less likely to discuss NBS with parents if they experienced this barrier, and nurses reported experiencing a greater lack of knowledge about NBS than other prenatal providers. Other factors included not having enough time (Miller, Hayeems, Carroll et al., 2010; Tarini, Burke, Scott, Wilfond, 2008) and not being adequately trained (Hayeems, Miller, Little et al., 2009).

It appears that NBS parent education is challenging for several reasons—reasons related to variations in the sources of NBS information for parents, variations in actual involvement among provider groups, and capacity issues such as a lack of knowledge or confidence about NBS among various provider groups, including nurses. However, in order to understand the context under which NBS education occurs in Ontario, an overview of the postpartum nursing culture will be provided.
2.3 Postpartum nursing

Three components of the nursing literature relevant to the provision of NBS education by postpartum nurses on the postpartum unit are reviewed. These components include the influential role of the Family-Centred Care (FCC) philosophy on patient education, the centrality of patient education in nursing practice, and specific factors and challenges that may be relevant to implementing NBS education on the postpartum unit.

The philosophy of FCC, which is integral to the practice of postpartum nursing, emphasizes the value of patient education. FCC can be described as, “a way of caring for children and their families within health services which ensures that care is planned around the whole family, not just the individual child/person, and in which all the family members are recognized as care recipients” (Shields, Pratt & Hunter, 2006). This means that postpartum nurses who care for mothers and babies in hospital should ensure that their care is reflective of the core principles of FCC, which includes the partnership relationships between families and health care professionals (Harrison, 2010; Shields, Pratt & Hunter, 2006) and the information sharing and collaboration that occur within these relationships (Zwellings & Phillips, 2001). Family members are defined as any persons the mother identifies as family, regardless of their biological relation (Zwellings & Phillips, 2001). The reported benefits of developing a successful partnership between nurses and families include improved health outcomes and more knowledgeable and confident parents (Trajkovski, Schmied & Vickers et al., 2012), as well as improvements in parent-provider communication, family satisfaction with care, and increased confidence in caring for their infant (Petersen, Cohen & Parsons, 2004).

Another component theorized to influence patient education activities on the postpartum unit relates to the centrality of patient education to nursing practice in general. Patient education is considered an essential component of patient care and it is advocated that nurses take responsibility for providing patient education since they have the most contact with them, have greater health knowledge than the layperson, are considered an authoritative source of medical information by patients, and have experience tailoring their interventions to patients (Close, 2006).

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5 Although the FCC philosophy applies to families, mothers were the focus of this study because mothers would be the constant family member present during the newborn’s hospital stay and when NBS education was provided.
Thus, many nurses, researchers, nursing philosophers, and national nursing bodies view patient education as an integral part of a nurse’s role (Close, 1988; Friberg, Granum & Bergh, 2012; Nolan, Nolan & Booth, 2000; Tilley, Gregor & Thiessen, 1987). Patient education can be defined as the improvement of patient understanding (Henderson, 1966), which means that nurses are implicated in the role of teacher and that patients are implicated in the role of learners (Close, 1988). The purpose of patient education is to provide patients and their families with the knowledge and skills necessary to equip them to make the best decisions they can for themselves (Kelo, Martikainen & Eriksson, 2013). However, given the amount of information postpartum nurses could potentially relay to mothers during their postpartum stay, it is argued that nurses should allow patients to direct their teachings so that patients’ learning needs are met (Field & Renfrew, 1991). The postpartum period marks a time of important physical, psychological, and practical transitions in the lives of mothers, their newborns, and their families as they recover physically from the birthing experience, adapt psychologically to the transition to parenthood, and negotiate new family dynamics and roles (Weiss & Lokken, 2009). As such, it is important for postpartum nursing care to focus on teaching families how to successfully navigate this transitional period (Weiss & Lokken, 2009; Zwellings & Phillips, 2001). Examples of some teaching topics prioritized by mothers on the postpartum unit include self-care management, information on infant feeding and signs of ill health (Beger & Cook, 1998; Bowman, 2005; Martell, 2001; Ruchala, 2000).

While FCC is the philosophy of care for postpartum nursing practice and patient education is a key component to nursing practice, there are some challenges to implementing patient education and FCC on the postpartum unit, which can ultimately impact the provision of NBS education by postpartum nurses. One such challenge relates to the short length of hospital stays by mothers and babies on the postpartum unit. The trend towards short postpartum hospital stays has become the norm in many places around the world (Centers for Disease Control, and Prevention, 1995; Health & Social Care Information Centre [HSCIC], 2013; Wen, Liu, Marcoux, & Fowler, 1998) and may interfere with a nurse’s ability to provide quality patient care. Mainly due to hospital efforts to cut back on spending, postpartum hospital stays have decreased drastically over the past few decades. Where postpartum hospital stays were previously upward of one week on average, today, postpartum hospital stays of a few days or less are not uncommon (HSCIC, 2013; Public Health Agency of Canada [PHAC], 2009; Weiss, Ryan,
Lokken, & Nelson, 2004). For example, in Ontario, the average length of stay for uncomplicated vaginal births and caesarian sections is one to three days (CIHI, 2004; Health Canada, 2000). Further, mothers do not receive routine nursing community follow up upon discharge, so the first few days in the hospital after birth are a crucial time for mothers to receive information that will help them care for their newborns and themselves at home (Beake et al, 2010). Although many nurses agree with the principles of FCC (Coyne, O’Neill, Murphy et al., 2011; Petersen, Cohen & Parsons, 2004), there are reports of inconsistencies and differences in its implementation due to a multitude of reasons (Corlett & Twycross, 2005; Trajkovski, Schmied, Vickers, et al., 2012). Studies show that factors such as poor communication, ambiguity about parents’ and nurses’ roles, and lack of negotiation about these roles, together with busy workloads, result in inconsistent ways of implementing FCC (Kuo, Houtrow, Arango et al., 2012; Trajkovski, Schmied & Vickers et al., 2012). Furthermore, organizational factors such as a lack of education have also been reported (Kuo, Houtrow, Arango et al., 2012; Trajkovski, Schmied & Vickers et al., 2012) as a barrier to providing quality patient education and to practicing within a FCC model of care.

In sum, several aspects of postpartum nursing culture may influence the provision of NBS parent education on the postpartum unit. These aspects include the central role of FCC and its emphasis on patient education, the central role of patient education for nursing practice (including the focus on having patients prioritize their learning), and barriers to the provision of parent education on the postpartum unit, notably short hospital stays. In the following section, a brief recap of the NBS literature and the nursing literature, followed by a brief discussion of the overlap of the two key areas of this research study will be provided to give further justification for the necessity of this study.
2.4 Postpartum nurses and NBS education

While there has been increased interest in the education of mothers and their families about NBS, there are many challenges to providing this education. Postpartum nurses have an important role to play in NBS education, and have been shown to be the major source of such information in Ontario. To date, however, the views and experiences of postpartum nurses have received very little attention in the NBS literature. Existing nursing literature provides important insight into the ways in which postpartum nurses might engage with NBS education, and the barriers that they might face in doing so. In the following, the methods of this qualitative study of postpartum nurses in Ontario are reviewed.
Chapter 3
Methods

3 Overview

This qualitative study investigated the experiences of postpartum nurses involved with providing NBS education to mothers in the postpartum unit of the hospital as well as the views of nursing leaders who were directly involved with setting policy for the postpartum unit. The research design was descriptive and exploratory, although it started off as a comparative case study. Interviews were used to collect data on nurses’ views, perceptions, and experiences with NBS parent education. Nursing leaders were interviewed to learn about their expectations of postpartum nurses with regard to NBS parent education and to provide insight into facilitators and barriers to postpartum nurses’ involvement in NBS education. Interview data were then analyzed using thematic analysis and interpretive descriptive approaches and an explanatory framework was developed comprising three themes relating to the research question. In addition, a variety of tools were used to enhance the quality and rigour of the study and to minimize researcher bias. This section concludes with a brief overview of the steps that were taken to ensure ethical conduct of the study.
3.1 Research design

The design of the study was descriptive and exploratory, and a qualitative approach was used. This study was originally designed to follow a comparative case study design which would have allowed for the comparison of the experiences of nurses at two birthing hospitals to determine whether external differences in hospital organization and nurse and patient demographics would influence nurses’ experience with providing NBS parent education. However, as the study progressed and interview data were collected and analyzed, it became apparent that the findings among participants at both hospitals were similar. As well, after having asked nursing leaders about potential sources of organization specific NBS documents that could inform the study but identifying none, the team decided that continuing with a comparative case study research design was not most relevant and a qualitative descriptive and exploratory research design was pursued instead. Pursuing a descriptive exploratory research design meant that nurses’ responses were grouped together and analyzed as a whole. Also, the primary source of data collection was focused on conducting one-on-one interviews rather than collecting data from multiple sources.

Since the aim of this research study was to understand the experiences of nurses in the provision of NBS education, a previously mostly underexplored phenomenon, a qualitative approach to conducting the study was taken because qualitative research provides a way to explore and understand phenomena that are poorly understood (Creswell, 2009). This approach, which focuses on the meaning individuals attribute to certain problems, supports rich and detailed descriptions of the phenomena under investigation (Creswell, 2009; Morse, 2012). More specifically, the semi-structured interview was the data collection technique of choice because it allowed for the exploration of participants’ opinions, perceptions, beliefs, and motives on the topic of interest (Barriball & While, 1994) and encouraged participants to address issues of particular interest and concern to them (Britten, 1995). By interviewing participants, a rich and detailed description of nurses’ experience with the provision of NBS education would be possible since the data collected would explain this phenomenon from the perspective of the health care providers who were directly involved (Brink, 1998).
3.2 Research setting

Two hospitals from the Greater Toronto Area (GTA) were selected for this study due to their large maternity programs and their differences in academic affiliation (Ayanian & Weissman, 2002) and geographic location (Wright, Causey, Dienemann, Guiton, Coleman, & Nussbaum, 2013). The selection of two distinct settings was intended to permit exploration of whether differences in hospital organization and nurse and patient demographics, as well differences in the acuity of patients at each hospital, would impact the experience with NBS education by nurses. Both hospitals were located in areas that had a high immigrant population; however, the first hospital, site A, was located in an area that was comparable to the City of Toronto's average population of recent immigrants and income status; whereas, the second hospital, site B, was located in an area that had higher than the City of Toronto's average number of recent immigrants, visible minorities, and low-income and unemployed (Hutfless, Kim, Nabi, & Rajan, 2011). There were other differences noted in terms of the highest level of acuity of patients each hospital accepts, the programs they offer, and the affiliations with academic institutions.

Site A was a large, urban hospital with approximately 6,700 births per year. It housed a Special Pregnancy Program and a high-risk pregnancy program. This hospital employed dedicated postpartum registered nurses (they were not cross-trained to provide care for patients in labour and delivery). A separate postpartum unit existed where mothers with uncomplicated births were transferred shortly after birth. This hospital was an academic hospital, affiliated with the local university. Site B was a large, suburban hospital with approximately 5,000 births per year. It housed a level two nursery and an early pregnancy assessment clinic. The hospital had two satellite campuses where mothers could give birth. Although both satellite sites used cross-trained and dedicated postpartum nurses, one of the satellite campuses employed more dedicated postpartum nurses, had a larger pool of nurses to draw from, and was geographically closer for me to make site visits on a regular basis. Due to these reasons, active recruitment efforts occurred at only one of the two satellite campuses at Site B (accounting for approximately 2700 births per year).
3.3 Research participants

Postpartum nurses and nursing leaders were the focus for this research. Postpartum nurses were the most appropriate participants to include in this study since they were directly involved in providing postpartum care to mothers and newborns shortly after birth and before discharge. This meant that they would be implicated in collecting the NBS blood sample at some point during the mothers’ stay in hospital. Nursing leaders included nurse managers, nurse educators, and clinical nurse specialists. It was important to include nursing leaders in this study because they were directly involved with developing policies influencing postpartum nursing practice in the postpartum unit and would provide us with a better understanding of their expectations regarding postpartum nurses’ involvement in educating parents about NBS.

For the purposes of providing an opportunity for most postpartum nurses to participate in the study, the inclusion criteria were broad and allowed for regular full-time, part-time, and casual postpartum nursing staff with all levels of postpartum nursing experience to participate in the study. The exclusion criteria included temporary nursing personnel such as contract or agency postpartum nurses and new staff hires still undergoing orientation. Contract and agency postpartum nurses may not have as much exposure to NBS as regular staff, so including them may not have yielded detailed descriptions of their experience with NBS education.
3.4 Recruitment strategy

Separate recruitment strategies were used to recruit postpartum nurses and nursing leaders into the study. For postpartum nurses, a multi-component recruitment strategy was used to increase participation (Broyles, Rodriguez, Price, Bayliss, & Sevick, 2011). The components included posting study advertisements around the unit (Appendix A), emailing postpartum nurses about the study (Appendix B), and making site visits to approach postpartum nurses who were working on the days this researcher was on site. The poster advertisements were posted around the unit for two weeks, an email reminder was sent, and postpartum nurses were approached directly and had the study details described to them. All but one postpartum nurse who was approached agreed to participate in the study, stating that she was too busy. Verbal and written informed consent was obtained prior to their participation in the study. All postpartum nurses included in the study were recruited through face-to-face interaction. It was uncertain whether the recruitment of these participants occurred solely because of the face-to-face interaction or whether the passive recruitment strategies, i.e. poster and emails, prepared them to agree to participate in the study.

A convenience sampling strategy was used to recruit nursing leaders into the study with the intent of recruiting nursing leaders who were involved with influencing postpartum nursing practice on the unit. Once a nursing leader contact was made at each organization, they were asked to identify other nursing leaders who would be appropriate to approach to include in this study. Once the list was compiled, this researcher approached each of the nursing leaders and asked if they wanted to participate in the study. One nursing leader declined to participate in the study stating that she was new to the role and was still adjusting to her role. A small honorarium in the form of a $5 coffee card was provided to the postpartum nurses and nursing leaders who consented to take part in the study.
3.5 Data collection

Two types of data were collected: the first was interview data using two different interview
guides, depending on whether a postpartum nurse or nursing leader was interviewed, and the
second was demographic data, collected through a short questionnaire before the interview. Data
were collected over a 3-month period: February 2012 to May 2012. Interviews averaged
approximately 20 minutes for postpartum nurses and 45 minutes for nursing leaders.

Once participants agreed to participate in the study, interviews took place in a private
room located at the hospital for the majority of the participants. The participants were given a
choice as to whether they preferred to be interviewed on-site or off-site and when they wanted
the interviews to occur. All but one preferred that they be interviewed during their regular work
hours and all but two interviews were conducted in private rooms. One interview was conducted
over the phone and two interviews were conducted in the nursing lounge at the participant’s
request.

One-on-one interviews were conducted with all participants, except for two nursing
leaders who preferred to be interviewed together. Development of the postpartum nurses'
interview guide (Appendix C) and the nursing leaders' interview guide (Appendix D) was
informed by the literature and expert opinion. Specifically, the postpartum nurses’ interview
guide was informed by the gaps identified in the literature and by the expert opinion of
researchers who were familiar with qualitative research. Two nursing colleagues who were
familiar with qualitative research, had experience working in maternal-child nursing care, and
were able to provide feedback, reviewed it. This review by nursing colleagues helped to clarify
the interview guide questions. The nursing leader interview guide was informed by the expert
opinion of one researcher who was familiar with the topic and with qualitative research. The
guide was tailored to each nursing leader to personalize the interview approach and thus to
maximize the opportunity for rich data to be collected. The nursing leader interview guides were
not piloted because asking other nursing leaders to review the questions would have limited an
already small sampling pool.

The interview guide questions for postpartum nurses focused on topics such as nurses’
experience with providing NBS education, views on their scope of responsibility with respect to
NBS education, perceived facilitators and barriers to providing NBS education, and how NBS
education compared to other types of postpartum parent education. The interview guide questions for nursing leaders focused on their expectations for nurses with respect to patient education generally and NBS education in particular on the postpartum unit. As the study progressed, questions that were not clearly understood by participants or that did not elicit in-depth responses were modified and either rephrased or deleted while retaining the main themes of the interview guide. Edits were made to the interview guides as necessary so that concepts of interest could be explored further and so that data redundancy could occur. These edits did not change the content of the interview guide but gave me an opportunity to focus the interview on the main themes to be explored and to bring clarity to some questions by reframing them (Rowley, 2012).

The second source of data was each participant’s socio-demographic information, collected before or after the start of each interview (Appendix E). The purpose of including demographic information in this study was to generate a clear picture of who was involved in the study and to support consideration of the transferability of these findings to other settings. Information about each participant’s length of experience providing postpartum nursing care, highest level of education completed, age, and employment status was obtained.

Data collection and data analysis was an iterative process and data collection continued until data redundancy in emerging themes was achieved (Lincoln & Guba, 1985; Patton, 2002).
3.6 Data analysis

Both interpretive descriptive and thematic approaches to analyzing the interview data were used. Both approaches support low inference description of the data with the focus on thematic categories that collate the data into higher order categories. The interpretive descriptive approach is a strategy for “excavating, illuminating, articulating, and disseminating the kind of knowledge that sits somewhere between fact and conjecture” (preface, Thorne, 2008) and this analytic method was chosen because it goes beyond describing the data to making interpretations of the data. The thematic approach is a method of identifying, analyzing, and reporting patterns or themes within data (Braun & Clarke, 2006). This approach was selected because it provided more structure to analyzing the data. The use of both these data analytic strategies was necessary as they were complementary in areas that proved to be useful to me as a novice researcher. For example, the process of organizing data into patterns and themes was more explicit with the thematic analysis approach than with the interpretive description approach.

The first step to data analysis involved familiarizing myself with the data (Braun & Clarke, 2006) and allowing myself a chance to react to the data (Thorne, 2008). Authors of both approaches recommend that researchers transcribe at least some of the interview data themselves in order to facilitate this process of familiarization. The interviews were digitally recorded and listened to at least twice. Next, half of the interviews were transcribed by this researcher and the other half were transcribed by a professional transcriptionist, who signed a confidentiality agreement. The transcripts were read at least twice and were crosschecked with the digital recording to ensure internal consistency. As the transcripts were read or the recordings listened to, memos and notes of this researcher’s reactions to the data were documented.

The second step involved coding the data. Codes can be applied to lines, paragraphs, or sections of the data (Braun & Clarke, 2006). Thorne recommends that in the early coding process, codes should be broad enough to capture similar items so that researchers can understand the overall shared intent of each data piece (2008). Thus, codes were applied to lines and sections of the data for all the interview data that related to the study objectives. Codes were developed based on the terms participants used or based on the ideas identified within the data.

The next step involved identifying patterns and themes by sorting codes into related groups (Braun & Clarke, 2006). Braun and Clarke recommend the use of visual display to assist
in grouping and identifying emerging patterns and themes from within the data (2006). Several diagrams and multiple tables were created to organize this researcher’s thoughts and to identify and confirm patterns within the data.

The final step involved identifying relationships between the groupings (Braune & Clarke, 2006; Thorne, 2008), and moving towards building a clearer sense of the whole (Thorne, 2008). For this step, the research team was consulted to help identify relationships within the data. Relationships between groupings of data were discussed and analyzed by organizing and reorganizing bits of information. Through that process, interactions between the themes were identified and were suggestive of an explanatory framework.

Throughout the data analysis process, this researcher had regular discussions with her thesis committee team to confirm what was being identified in the data and to seek further guidance. As a result, there was strong agreement on the themes that were identified and the relationships between them. In addition to describing in detail how this study was conducted, it is also important to describe some of the steps this researcher took to enhance the quality and trustworthiness of the study findings.
3.7 Rigour

Ensuring quality and rigour is as important with qualitative research as with any type of health research. As such, a critical appraisal skills program (CASP) qualitative research assessment tool (CASP International Network [CASPin], 2013) was used to ensure that key issues of a qualitative study were addressed and reported on in the thesis. Although the assessment tool was not meant to be a definitive guide, it was used as a guiding framework. This tool consists of ten questions and addresses three broad issues of rigour, credibility, and relevance of a study. Questions cover areas such as sampling, data collection methods, reflexivity, ethical issues, and data analysis. In conjunction with the tool, the four criteria as outlined by Lincoln and Guba were applied to evaluate the strength of naturalistic inquiry studies (1985). These criteria were credibility, transferability, dependability, and confirmability. Credibility refers to the degree to which the study findings represent the experiences of participants or context in a believable way and is considered the most important criterion in establishing trustworthiness; transferability refers to the degree to which the findings can be applicable to other settings; dependability refers to the likelihood that the same results would occur if the study were to be repeated under the same circumstances, using the same methods, and the same participants; and confirmability refers to the extent to which the findings are the participants' experiences and ideas versus the researchers’ (Lincoln & Guba, 1985).

Enhancing the trustworthiness of the findings of qualitative research is critical and requires reflexivity to reduce bias and to strengthen the understanding and analysis of study findings. Reflexivity is a process whereby researchers determine how their own positions and interests affect all stages of the research process (Hsiung, 2008; Primeau, 2003). There was a potential for researcher bias in conducting this study given the following factors: this researcher had previously practiced as a postpartum nurse, postpartum nurses were being approached for recruitment from a hospital where this researcher had worked, and there was a personal interest in contributing to the nursing literature on the educational role of postpartum nurses. Recognizing this bias and wanting to avoid conducting the research and interpreting the findings based on this researcher’s own experiences and ideas, it was important to undergo the process of reflexivity throughout the research process. For example, frequent discussions were held within a research team context with non-nurses from different sectors and the team’s input was used to inform all stages of the research project, such as during the time when the research
question and interview guide questions were developed, and when the data were analyzed.
3.8 Research ethics

Research Ethics Board (REB) approval was received from the University of Toronto and the two participating hospitals within the Greater Toronto Area\(^6\). Once REB approval was obtained, participant recruitment began and data were collected. Each participant read and understood the consent form (Appendix F), knew that their participation in the study was voluntary, and understood that their confidential information would not be shared with anyone other than core members of the research team. In the case of the telephone interview, verbal consent was sought before the start of the interview and written consent was obtained after the interview.

Confidentiality was maintained by replacing personal names with anonymous ID codes, and ensuring that no participant identifiers were attached to any notes, memos or transcripts. All recordings of the interviews and notes taken during the interviews were kept in a locked office at the university and no one except core members of the research team had access to this information.

The ID codes were used as follows: PNSub100x quotes were from postpartum nurses at the suburban hospital; PNUrb200x quotes from postpartum nurses at the urban hospital; NLSsub300x quotes from nursing leaders at the suburban hospital; and NLUrb400x quotes from nursing leaders at the urban hospital.

\(^6\) REB approval forms were not included in this thesis in order to protect the anonymity of the organizations that participated in this research study
Chapter 4
Findings

4 Findings overview

This section presents the demographic information of the postpartum nurses and nursing leaders who participated in this research study and the findings from this research study.

4.1 Participant description

31 postpartum nurses and six nursing leaders participated in this study. There were more similarities between the postpartum nurses at both these sites than there were differences. Differences included more full-time nurses from the urban hospital (n=12) than the suburban hospital (n=7) and the employment of cross-trained nurses at the suburban site but not at the urban site. Cross-trained nurses were those who were trained to provide both labour and delivery care as well as postpartum care on the unit and could one day be practicing as a labour and delivery nurse and on another day practicing as a postpartum nurse. The dedicated postpartum nurses at the urban site were only trained to provide postpartum nursing care and only practiced on the postpartum unit. Cross-trained nurses and dedicated postpartum nurses are referred to as ‘postpartum nurses’ in this thesis.

Nursing leaders included participants such as nurse educators and managers. There were an equal number of nursing leaders who participated from each site and all nurses were full-time. The main difference between the participants was in the number of years of postpartum nursing leadership experience. Nursing leaders at the urban hospital had, on average, more years of postpartum leadership experience (10 years) than nursing leaders at the suburban hospital (3.3 years).
Table 1 - Participant demographic characteristics: Postpartum nurses

<table>
<thead>
<tr>
<th>Description</th>
<th>Postpartum Nurses</th>
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</thead>
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<td>Urban</td>
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</tr>
<tr>
<td>Total # (n)</td>
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<tr>
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<td></td>
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<td></td>
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<tr>
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<tr>
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</tr>
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</tr>
<tr>
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<td>6</td>
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<tr>
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Table 2 - Participant demographic characteristics: Nursing leaders

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</tr>
<tr>
<td>Total # (n)</td>
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<td>3</td>
<td></td>
</tr>
<tr>
<td>Postpartum nursing experience (years)</td>
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<tr>
<td></td>
<td>Average: 10</td>
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<tr>
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<tr>
<td>35 - 49</td>
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<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>
4.2 Themes identified within the data

The purpose of this study was to explore nurses’ experience with providing NBS education to mothers on the postpartum unit. An explanatory framework (Figure 1) was developed, which highlighted three themes.

**Figure 1: Explanatory framework of findings**

Theme one addressed how postpartum nurses engaged with NBS education and showed that although postpartum nurses were actively involved with providing NBS education to mothers, provided both written and verbal information, and viewed NBS parent education as their responsibility, their engagement with NBS parent education was limited. NBS education was a brief encounter and postpartum nurses did not provide in-depth information about NBS to mothers. In speaking with the postpartum nurses and the nursing leaders, it became clear that there were organizational factors and nurses’ desire to be responsive to mothers’ preferences and needs (themes two and three) that limited postpartum nurses’ engagement in NBS education.

Theme two related to organizational factors that contributed to minimizing the attention to NBS parent education such as the perceived priority of breastfeeding education. Theme three related to mothers’ perceived desire for other, higher priority information before NBS, such as infant feeding, self-care, and baby-care information, and mothers’ concern with the procedural aspect of the NBS test. The main components of each theme are presented below (Figure 2).

---

7 Written information refers to the NBS education pamphlets developed by the ONSP and/or the tear-away sheet attached to the NBS filter paper. The tear-away sheet is a one-page double-sided sheet given to mothers at the time of heel prick. On one side of the sheet, information about the purpose of the test, meaning of possible test outcomes e.g. screen positive, screen negative, and repeat testing, and who mothers can contact for more information is provided. On the other side of the sheet, information about protecting each newborn’s privacy and confidentiality, the number of diseases screened, the possibility of detecting carrier results, and a section on declining screening for newborns is provided.
Figure 2: Main components of each theme

**Theme 2:**
Organizational factors

- Breastfeeding education priority
- Unit factors: short lengths of stay, language barrier, timing

**Theme 1:**
Nurses’ engagement with and views on NBS education

- Patient education priority
- Actively involved
- Limited in time and depth
- Best providers on the postpartum unit

**Theme 3:**
Patient responsiveness

- Breastfeeding education priority
- Heel prick concerns
- Basic information satisfaction
- Avoiding information overload and anxiety
4.3 Theme one: Nurses’ engagement with and views on NBS education

Postpartum nurses were actively involved in providing NBS education to mothers on the postpartum unit but their engagement with NBS education was limited. Nursing leaders and postpartum nurses viewed patient education as an important component of postpartum nursing practice and implemented several initiatives to support this practice. With respect to NBS parent education, postpartum nurses were involved with the provision of both written and verbal information to mothers. More specifically, mothers were provided with NBS pamphlets by postpartum nurses and also received verbal information about the purpose, types of disorders screened, and when results would be available. NBS information was communicated to mothers at various times during mothers' postpartum stay and the education sessions were described as brief. In addition, postpartum nurses viewed themselves as playing an important educational role in NBS since they collected the blood sample for the test, perceived other providers to not have the time for NBS education, and already spent a lot of time with mothers. These points are reviewed in detail below.

Patient education priority

Postpartum nurses and nursing leaders viewed patient education as an important component of postpartum nursing practice. For example, nursing leaders said that patient education was a core aspect of the practice of postpartum nursing and expected postpartum nurses to be actively engaged in it. One nursing leader described some of the tools on the unit that reminded postpartum nurses about the topics they should review with mothers before discharge:

I think it’s a very big part of their job. In terms of preparing a new family to take home a baby, there’s a lot of education that goes into that. Even on their clinical documentation tools, they have checklists of information that they either need to initiate or review with patients through the course of their stay, which is a short stay, so it’s a fairly intensive kind of education. NLSub3003

Nursing leaders described different initiatives they implemented on the unit that supported the centrality of patient education to postpartum nursing practice. For example, at one hospital, nursing leaders spoke about two initiatives that supported this practice. The first was having
whiteboards installed in each patient’s room so that mothers could write down what they wanted to learn when it came to mind. The second initiative was to have postpartum nurses check in on mothers on an hourly basis so that they were proactive in identifying and responding to mothers’ needs. The purpose of these initiatives was to help postpartum nurses prioritize mothers’ learning needs.

…I think all the staff on the postpartum floor recognize that 80% of their time is spent educating in some way, so they play a huge role in it…So it is, [with] all of the different initiatives, we are seeing a change; that the nurses are able to spend time where they need to spend time. NLSsub3001

The importance of identifying mothers’ learning needs was summed up by one nursing leader who said that this was important to do since different mothers will come in with varying levels of understanding and knowledge about different things.

[Patient education is] so specific to the individual family, because a lot of people will come in knowing some things and not knowing others so you would… the nurse needs to be able to get to the information she needs, based on her own assessment skills and also based on the patient’s identified needs…. so it has to be individualized and postpartum nurses are good at figuring out what they need to know and getting the information. I would expect that from a postpartum nurse. NLSsub3003

Postpartum nurses in turn said that it was important to be responsive to mothers’ learning needs since, as expressed by the nursing leaders, different mothers will vary in their knowledge and learning needs in general, but also so they could help to minimize anxiety that may result because of mothers’ unanswered questions or concerns in general.

Some [parents] are anxious and need a lot, a lot of teaching and coaching and just your presence there. PNUrbd2014

Postpartum nurses and nursing leaders both viewed the identification of mothers’ learning needs as an important part of postpartum nursing practice.
Active involvement

Nursing leaders not only expected postpartum nurses to be involved with patient education activities in general on the postpartum unit, they also expected postpartum nurses to be specifically involved with NBS education. When asked about their expectations, nursing leaders said that they expected postpartum nurses to be involved with providing both verbal and written education.

I think they should be ensuring parents are given the front sheet, they’re [mothers] understanding what they’re consenting to, their questions are answered, they perform the tests and they have to have the proper documentation to back it up. NLSUB3001

Postpartum nurses in turn said that they were actively involved with providing both written and verbal information about NBS to mothers on the postpartum unit. Postpartum nurses talked about providing NBS print materials to mothers, which they expected mothers to read. Postpartum nurses provided NBS pamphlets or referred mothers to look at the tear away information sheets for more information about NBS, and also referred mothers to the NBS website.

So, we give them a sheet on it [sic] that comes with the blood test, so they have that to read. But, we also explain to them that it tests for I think it’s twenty-eight different disorders. PNSUB1013

Postpartum nurses also described what they would normally say to mothers. Nurses communicated basic information; they talked about the technical aspects of how the test would be done, the number of tests that NBS screened for, and provided some information about what the follow up process would be like. Details about the different disorders screened for were not communicated.

…with the newborn screening, it’s more like, “ok, well we’re going to take blood work for [the] baby and it’s going to test for you know, a variety of things”. But we don’t really get into, you know the [sic] specifically what it is, or what the consequences would be, or how to address it or anything. It’s just more like, “ok, blood’s going to be taken, the results will come back to your doctor in a few weeks if there are any, if not, there’s nothing to worry about”. PNURB2008
Postpartum nurses noted different times during a mother’s hospital stay during which NBS education could occur: on the time of admission when mothers were being oriented to the unit; on the day the blood test would occur when postpartum nurses would encourage mothers to read information provided to them about NBS; and/or at the time of heel prick, where specific NBS information would be provided.

…it’s kind of like, in the morning, when I come, or if I’m admitting a patient, I’ll mention that it’s going to be happening; if I get a patient in the morning, then I’ll go in and say hello and I tell them what’s going to be happening during that day. I mention it and then when I do it, I’ll talk about it, that’s pretty much it. PNUrb2011

Limited in time and depth

Nursing leaders indirectly supported the practice of postpartum nurses by saying that it was important for postpartum nurses to provide basic information to mothers about NBS, such as why the test was being done, where the sample is sent, and when the results would be ready. However, they did not expect postpartum nurses to explain to mothers all of the disorders tested, but to simply know that there were multiple disorders screened for.

For newborn screening, yes, I do think that there is a role, but there are 21 different, 28, 21, 28… different metabolic disorders that are screened for with that one test, and would I expect the nurses to know enough about each of them to recite them or to be able to address each one? I don’t think that’s reasonable especially…like I think they owe it to the patient to at least give them a piece of paper that describes it or to direct them to a website, which I believe we do in our education material, the written material. And to have enough knowledge to say to the patient, “this is the test I’m doing, this is why I’m doing it, if you need more information, there’s a good website, and I encourage you to access that website” and you know, if need be, make the website available to them while they’re here as an inpatient. But most patients, to be honest, don’t in my experience, they don’t ask to look into that right away. NLSub3003

As this nursing leader suggested, she did not expect NBS education to involve a lot of time or energy; instead, the education of mothers about NBS was often described as a brief patient education session by postpartum nurses.
There’s not a lot of newborn screening teaching… it’s really brief. PNUrb2015

**Best providers on the postpartum unit**

Despite the limited nature of the education, postpartum nurses viewed themselves as playing an important role in NBS education because they were the ones collecting the blood sample for NBS.

So, I think if they [mothers] were to get a [sic] teaching, I think it should have been from the nurses who actually do it. So, before they do it or after they do it, we should be able to explain it to them. PNSub1011

Postpartum nurses also did not perceive that other providers on the postpartum unit would have the time to spend on educating mothers about NBS.

Because we are the primary nurse at the bedside. I mean the doctors are only in, what, the room for only a few minutes? They don’t really explain it. They may mention it in their newborn exam, very briefly, just mentioning like, “oh you know, your nurse will be in to check you and do the blood work in 24hours, she’ll let us know if there’s anything wrong.” That’s pretty much their spiel, they don’t really say anything beyond that, so the onus is on us… PNUrb2001

Furthermore, postpartum nurses viewed themselves as the best provider on the postpartum unit to provide this education to mothers since they already spent a lot of time with them and were already educating them on a variety of topics.

We’re the ones who spend the most time with them. And, we’re educating them on so many things already, right?... We already have built that relationship with them. PNSub1008

In sum, patient education was considered an integral component of postpartum nursing practice and postpartum nurses were expected to be involved in NBS parent education. Although postpartum nurses viewed themselves as playing a primary role in the education of mothers about NBS on the postpartum unit, the time they spent on this education and the amount of information they provided about it was somewhat limited. In speaking with the nursing leaders
and the postpartum nurses, it became apparent that there were two main factors that influenced the amount of time and depth postpartum nurses spent providing NBS education to mothers. One related to organizational factors and the second related to nurses’ desire to be responsive to mothers’ preferences and needs. These two factors will be discussed in themes two and three respectively.
4.4 Theme two: Organizational factors on postpartum units minimized postpartum nurses’ attention to NBS parent education

Nursing leaders and postpartum nurses identified some challenges in the provision of NBS education on the unit. One major challenge related to nurses’ perception that breastfeeding education was a higher priority on the postpartum unit. Thus, postpartum nurses spent a lot of time on educating mothers about breastfeeding. In addition, challenges related to shortened length of stay, accessibility to NBS print material, language barriers, and the time at which NBS was conducted (the 24-hour mark) were also noted. The combination of these challenges contributed to minimizing postpartum nurses’ engagement with NBS education provision to mothers on the unit.

Breastfeeding priority

Nursing leaders and postpartum nurses talked about challenges in providing patient education on the unit. One major challenge to providing NBS education was that nurses perceived that it competed with higher priority teaching topics such as breastfeeding education. Postpartum nurses said that they perceived their organizations as prioritizing breastfeeding education since so much attention was given it.

...we’re a breastfeeding friendly hospital, we have a lot of supports, lactation consultants, a lot of education, like all of us had a lot of education about breastfeeding... There’s a breastfeeding course, that’s run by the hospital and I think, I’m pretty sure, I’m sure everybody on this unit all staff on this unit have done that course. And then a number of staff have become LCs [lactation consultants], and that’s really promoted so you always have colleagues to go to if you need anything, and the posters on the wall, everything is very geared towards breastfeeding. PN Urb2011

As a result, postpartum nurses’ involvement with breastfeeding was more extensive and demanded more of their time and attention.

For breastfeeding education it’s ongoing all the time while the patient is in the hospital, but for the newborn screening it’s like a onetime thing. You explain to them why you’re
doing it, and you do it…. but for breastfeeding and other baby care or mom’s care, it's like a [sic] ongoing, the whole time they stay in the hospital, it's like from the beginning till the discharge, it's like you know, it's ongoing all the time. PNSub1007

When nursing leaders were asked the question about how NBS education was prioritized compared to other topics on the unit, their responses varied. While some answered immediately that breastfeeding was a priority, others started off by saying that while all topics were important, feeding newborns took precedence over NBS education.

I don’t think you’ve got... can rank any one [patient education topic] more important than the other. I think it’s important that they get the information because the test is being done. If you’re going to take newborn screening information over having a... teaching them how to get their baby to feed, well, you’re going to go to the feeding first because that’s... you’ve got to get that baby to feed, but it’s still all part in parcel, things you can talk to. NLUrb4001

(Unprovoked) And, the teaching could involve anything from just your basic baby care through to immunizations, car seat safety, follow-up, how they feel generally. Breastfeeding’s a big... Breastfeeding’s one of the biggest things for teaching.

Unit factors

In addition to competing priorities, challenges such as the impact of short hospital stays affected postpartum nurses’ ability to provide comprehensive patient education. As a result, postpartum nurses were not always able to review everything they wished to review, nor give mothers the attention they wanted since their patient education sessions were rushed. For example, one postpartum nurse shared:

It’s quickened it. It’s a lot because they’re coming in and out a lot faster. So, it’s just everything has to happen very quickly and they have to process a lot more information faster. So, it’s... yeah, it’s just you’re doing a lot more in a shorter period of time. ... Sometimes you don’t get everything that you want done. And, sometimes you can’t even do all the education that you need to do… PNUrb2014
In addition, some nursing leaders said that another barrier to providing NBS education had to do with accessibility issues related to NBS print material in different languages.

Well, we don’t have those pamphlets [in different languages] anymore, and if you don’t remember the website, you’re not going to be able to access the different languages.

NLSUB3002

As well, nursing leaders identified language barriers as a factor that could challenge nurses’ provision of NBS education to mothers.

Probably one of the largest is just language barriers, communication because... I have a very multicultural staff, but it’s still sometimes hard to buddy up a Mandarin-speaking nurse with a Mandarin-speaking mom if I don’t have one booked that day. Or, I mean, we have a lot... we see a lot of languages come through. So, I think communication is one of the... I would say that’s probably the biggest barrier in a lot of things. It’s very difficult to get across some of your discussions when the person has very, very little English.

NLURB4001

While there were general issues described that affected the priority given to, or the time available for NBS education, there were also issues described that were specific to the way NBS education was conducted that limited its depth. NBS education occurred at or around the time of the heel prick test (24-hour mark). The context at that time may have made it difficult to educate mothers about NBS effectively since it was a hectic time and families were being prepared for discharge.

Sometimes it's really, really hard, because you're really really busy and everyone wants to go home at the same time, at the 24 hour exactly, then you're rushing, rushing a lot.

PNSub1007

Postpartum nurses and nursing leaders talked about the postpartum nursing environment and it was clear how providing NBS education in that environment and the challenges they faced, contributed to minimizing postpartum nurses’ engagement in NBS education. The third theme describes postpartum nurses’ perception of a professional responsibility to be responsive to patient’s learning needs and how practicing that way influenced the amount of time they spent on NBS education and also contributed to limiting the depth of NBS information nurses provided to mothers.
4.5 Theme three: Being responsive to mothers’ learning needs meant that postpartum nurses’ engagement with NBS was minimized

In addition to organizational factors that minimized postpartum nurses’ engagement in NBS education, postpartum nurses described a professional responsibility to be responsive to mothers’ learning needs. By being responsive to mothers’ learning needs, postpartum nurses focused their attention on topics mothers asked about and were sensitive to how much information they perceived mothers could handle. As a result, postpartum nurses perceived mothers to prioritize other topics ahead of NBS; where mothers were concerned with NBS, it mainly had to do with the process of providing the heel prick blood sample for the screening test. As well, nurses perceived mothers to be generally satisfied with the basic NBS information they received and referred to maternal exhaustion as a reason why mothers were not engaged in NBS education. Nurses recommended the prenatal setting as a better time for NBS parent education to first occur. Finally, to emphasize the routine nature of NBS and minimize patient anxiety, postpartum nurses were motivated to deemphasize in-depth NBS parent education. In sum, all these factors contributed to minimizing nurses’ engagement with NBS parent education on the postpartum unit.

Breastfeeding education priority

Postpartum nurses perceived mothers to prioritize self-care, feeding issues, and baby-care above other topics, and that mothers were not that interested in learning in-depth information about NBS. Responding to my question about why mothers prioritized learning about breastfeeding, one nursing leader responds that mothers are ill-prepared to deal with feeding issues since not much attention is given to breastfeeding prior to birth.

Why do I think that is? Because it’s a postpartum population and 96% of our patients choose to breastfeed, so it is the one thing I think they need lots of education on, they get it prenatally, they get it in prenatal classes, they do reading but it, uh, I don’t believe it sinks in until they actually have a baby in arms. There’s too much, emphasis, correctly so, in there, on the whole labour process, you know, it’s that apprehension about labour and just wanting the delivery and that’s what they focus on, and then they have baby in arms.
and it’s not as clear cut as everybody makes it seem to be. So they do require a lot of 
support and education on breastfeeding. NLS3001

Heel prick concerns

Postpartum nurses also perceived the actual specimen collection process to be a source of anxiety 
for some mothers, leading them to wish to downplay NBS rather than emphasize it through a 
more extended educational intervention. One postpartum nurse described a situation where a 
mother had responded to learning how much blood was necessary and her own response to the 
mother, trying to reassure her that the test was necessary, and that the amount of blood needed 
was not great compared to the newborn’s body size.

Sometimes they go, “oh, I have a small baby and how much blood you take?”. When they 
see you doing that because it’s getting five blots, right, to them it’s a lot of blood. And, 
they worry about that, but, you know, all you have to do is explain to them, “you want 
this test to be done. You want to do it accurately. You need this amount of blood.” So, 
comparatively to the baby’s body, it’s not a lot. So, I try to reassure them. PNS1016

Basic information satisfaction

Aside from being concerned about the actual process of specimen collection, postpartum nurses 
perceived mothers to not be engaged with NBS education since mothers did not ask too many 
questions about NBS and were generally seen to be satisfied with the basic information received.

It’s just that the patient population, they, themselves, you know... For example, like, I 
would say ninety-five percent of them they don’t ask me what it is for…I think it’s also 
the patient population too; they don’t know too much, like, you know, about what the 
blood work is for, stuff like that. Like, whatever you tell them they kind of listen to you. 
PNS1011
However, when mothers did ask questions about NBS, it was very basic and consisted of questions about when the results would be available. As one postpartum nurse described it,

They don’t have too many questions about it because I think a lot of parents will ask their healthcare providers for it because the results don’t come to us; it’ll go to their physicians. PNUrb2015

*Avoiding information overload and anxiety*

Another reason nurses identified for what they perceived as mothers’ minimal engagement with NBS education related to their perception that mothers in the immediate postpartum setting were not in the ideal state to receive too much information about NBS since they would be too exhausted.

It’s just it’s such a short period of time that you’re trying to relay all this information, which is what I find probably the most challenging is that there’s a lot of information going out. And, it may be going out to the mother, but how much is the mother absorbing? How much is the family really understanding when you’re actually saying... They’ve just gone through labour and delivery. They’re tired. They have lots of visitors even though they’re only in for twenty-four hours. They just figure it’s a test, you know. So, the question is how much is the mothers really or the families really absorbing when you’re actually telling them, with anything you’re telling them? NLUrb4001

As a result, both postpartum nurses and nursing leaders said that NBS education should begin in the prenatal setting.

Yeah, so they know ahead. If they have questions, they can ask the doctor right away. Don’t wait until that day they’re exhausted. They’re tired. So, it’s hard for them to really get all your information. So, I think the newborn screening, you know, just... and just like any other health information, give it to them ahead. PNSub1016

Being cognizant of the mothers’ exhaustion and limited capacity to absorb new information, postpartum nurses wanted to avoid causing or escalating maternal anxiety by overwhelming mothers with too much information; thus, postpartum nurses focused on providing mothers with just enough information they perceived mothers could handle.
You want to make sure that the information that you’re giving to the patient is not going to overwhelm them and you also want to make sure that it’s supportive. So for instance, if I get a patient that is quite anxious. Ah just with years of experience, this is not the type of patient I want to give too much information at one time. This is the type of patient, let’s get back to newborn screening, I’d probably say, in about, after 24 hours your nurse will be doing some blood work, at that time, she will go through more thoroughly what the blood test is for. PNUrb2002

Postpartum nurses also liked to emphasize that NBS was a routine procedure so that mothers would not worry.

I think when you say, “routinely”, it just means, you know, it’s not that my baby is unhealthy or something [is] wrong with my baby, it’s that, you know, it’s a test that we do on everyone so you’re not centred out for any reason, your baby’s not ill or anything. PNUrb2010

As illustrated, mothers’ greater interest in other topics other than NBS, mothers’ concerns about the procedural aspect of the test, and their satisfaction with the basic information received about NBS, alongside nurses’ desire to minimize maternal anxiety by emphasizing the routine nature of NBS, contributed to minimizing postpartum nurses’ engagement in NBS education.

The overall findings of this research showed that postpartum nurses and nursing leaders’ views on NBS education were similar and that although postpartum nurses were actively involved with NBS education by providing basic information about NBS to mothers, organizational factors and nurses’ desire to be responsive to mothers’ preferences and needs contributed to minimizing postpartum nurses’ engagement in NBS education. In the next chapter, a discussion of the relevance of these findings to the current NBS and nursing literature and the implications of this research for future research and policy will be provided.
Chapter 5
Discussion

5 Discussion overview

NBS parent education is an important component of NBS programs around the world but authors have expressed concerns about parents receiving insufficient information about NBS (Davis, Humiston, Arnold et al., 2006; Detmar, Hosli, Dijistra et al., 2007; Hayeems, Miller, Little et al., 2009; Parsons, King & Bradley, 2007). The NBS literature indicates that postpartum nurses are involved with providing NBS education to parents in Ontario (Araia, Wilson, Chakraborty, et al., 2012; Hayeems, Miller, Little, Carroll, Allanson et al., 2009), yet there is limited empirical research about nurses’ experiences with the provision of NBS parent education. This qualitative study addressed this gap in the literature and explored nurses’ experiences with providing NBS education to mothers at two hospitals in the Greater Toronto Area. As well, nursing literature was reviewed in order to understand the context of care and nursing philosophies influencing nursing practice alongside NBS literature. This review of nursing literature was important in understanding some of the study’s key findings that spoke to nurses’ commitment to patient education and to being responsive to patients’ needs. The following sections will present a discussion of the findings, the strengths and limitations of the study, policy implications arising as a result of this work, and areas of future research.
5.1 Discussion of the findings

An explanatory framework was developed that highlighted three main themes. The first theme showed that postpartum nurse engagement with NBS parent education was limited. Although postpartum nurses were actively involved with providing both verbal and written information about NBS to mothers and viewed NBS parent education as their responsibility, these encounters were described as brief, with basic information provided. Themes two and three described the factors contributing to postpartum nurses’ limited engagement in NBS parent education. Specifically, theme two related to organizational factors such as the perceived priority of breastfeeding education. Theme three related to mothers’ perceived desire for other, higher priority information before NBS, mothers’ perceived satisfaction with basic NBS information received, and nurses’ desire to minimize mothers’ concern and anxiety by emphasizing the routineness of the test. Organizational factors and a desire to be responsive to the needs and preferences of mothers explained why attention to NBS education was minimized on the postpartum unit. These findings highlight the fact that the postpartum environment plays an important role in influencing the amount of time spent, and the depth to which nurses provide NBS education to mothers.

The study showed that nursing leaders and postpartum nurses viewed patient education as an integral part of their role, confirming previous research that has reported postpartum nurses’ involvement with NBS parent education to mothers (Araia, Wilson, Chakraborty, et al., 2012; Hayeems, Miller, Little et al., 2009). As well, this study makes a unique contribution to the NBS literature by identifying reasons for postpartum nurses’ active involvement with the provision of NBS parent education. These reasons include involvement with blood sample collection and the perception that they were the only ones available to fulfill the role on the postpartum unit. In this way, postpartum nurses in this study have stepped up to the role of educating mothers about NBS. Another unique contribution to the NBS literature was made by including nursing leaders in the study since they offered a new perspective on the role postpartum nurses should play in NBS education. Results showed that the nursing leaders all expected postpartum nurses to be involved with educating mothers about NBS. Since NBS is considered a routinized part of care not only in Ontario, but also in the majority of provinces and territories in Canada (Downie &
Wildeman, 2001), and given that most births are in hospital\(^8\), the findings of this research may be relevant to other nurses’ experiences and views on their role in NBS education in other jurisdictions across Canada. Furthermore, nurses in the US may also be routinely implicated in NBS parent education since NBS is mandated in most jurisdictions in the US (Downie & Wildeman, 2001), thus implicating nurses’ involvement in NBS. Thus, these study findings may also be a reflection of the educational role of postpartum nurses practicing in North America.

In addition to confirming the role postpartum nurses played in NBS education, the results of this study challenged the suggestion that limited commitment to NBS education by any provider is necessarily related to the diffused nature of professional responsibility. Specifically, Clayton (2005) has argued that when the responsibility to educate parents about NBS is diffused among multiple providers, it contributes to the lack of uptake by any one specific provider group. However, study findings showed that postpartum nurses and nursing leaders perceived NBS education as nurses’ responsibility in the immediate postpartum setting, which highlights the fact that nurses have taken some ownership of the provision of NBS education to mothers. This finding adds to the existing NBS literature that identifies nurses as being well-placed to be involved with NBS education (Deluca, Zanni, Bonhomme, et al., 2013; Hayeems, Miller, Little, et al., 2009) but goes further to show that the postpartum nurses also viewed themselves as being the best providers in the immediate postpartum setting to provide this education to mothers.

Additionally, although it was clear that postpartum nurses and nursing leaders viewed NBS parent education as the responsibility of nurses, the nurses in the study described this education as a brief intervention not requiring a great deal of time. NBS education to mothers consisted of providing a brief verbal overview of NBS and NBS brochures to read. Nurses perceived mothers to be satisfied with the basic information received and nurses were involved with responding to basic questions about NBS, such as when the test results would become

\(^8\) 377,636 births total in Canada in 2011 (http://www5.statcan.gc.ca/cansim/a26?lang=eng&retrLang=eng&id=1024502&paSer=&pattern=&stByVal=1&p1=1&p2=38&tabMode=dataTable&cid) and 372,968 births were in hospital in 2011 (http://apps.cihi.ca/MicroStrategy/asp/Main.aspx?evt=4001&reportID=A706B8E148E72193117B8F808CCB0F18) Therefore, 99% of births were in hospital.
available. Postpartum nurses did not describe NBS to mothers in depth. Further, nursing leaders did not expect detailed educational sessions about NBS on the unit. While this study does not illuminate whether the brevity of this intervention was due to a lack of NBS-relevant knowledge—a phenomenon that has been identified in another Ontario-based study (Hayeems, Miller, Little et al., 2009)—the study showed that there were contextual factors at play related to the organization and to nurses’ professional orientation to be responsive to patients’ needs. These challenges limited postpartum nurses’ engagement with NBS parent education, thus challenging the sufficiency of the cognitive deficit model for NBS education.

One contextual factor that minimized postpartum nurses’ engagement with NBS parent education was associated with the organizational factors unique to the postpartum unit. Postpartum nurses and nursing leaders perceived that breastfeeding education was prioritized. Thus, postpartum nurses spent more time teaching mothers how to feed their newborns, leaving less time to spend on other teaching topics, such as NBS education. There were also capacity issues, such as language barriers and short length of hospital stays, which were identified as influencing postpartum nurses’ ability to engage with providing NBS education to mothers and perhaps influencing the depth to which they provided it. It was not surprising that language emerged as a barrier to providing NBS education given the high immigrant population served by the hospitals from which the sample of nurses was drawn. This research showed that postpartum nurses perceived that short length of hospital stays limited the amount of time they had to review teaching topics with mothers. Postpartum nurses talked about the negative impact short length of stays had on their patient education experiences in general and specifically about how the quality of their patient education suffered because they felt rushed. Further, since many mothers were discharged around the time of NBS education, postpartum nurses described that time as particularly hectic. The finding that insufficient time was a limiting factor to providing adequate patient education is a strong theme within the literature (Hayeems, Miller, Little et al., 2009; Honan, Krsnak, Petersen, et al., 1988; Stamp & Crowther, 1994; Woody, 1984). Given the limited amount of time nurses perceived they had to spend not only on NBS education but also with other patient education topics, it was not surprising that nurses’ attention to NBS education specifically was limited.

The second contextual factor that minimized postpartum nurses’ engagement with NBS education was postpartum nurses’ commitment to be patient responsive, which is an essential

Given the centrality of FCC philosophy in postpartum nursing practice, it was not surprising that the nurses in this study focused on identifying and responding to patients’ needs and priorities. Postpartum nurses focused their attention on teaching topics that were prioritized by mothers and nursing leaders encouraged this practice, which meant that topics such as self-care and baby-care were given higher priority than NBS education. The concerns of authors in the NBS literature about the insufficiencies of NBS education currently imply that health care providers should be providing more comprehensive information to mothers about NBS. However, the findings from the study suggest that if postpartum nurses are responsive to mothers’ highest priorities for learning, NBS will be de-emphasized in the postpartum period.

It also appeared that postpartum nurses were sensitive and responsive to minimizing maternal anxiety. Postpartum nurses perceived that mothers were more concerned about the procedural aspect of NBS - a finding not previously reported in the literature - which meant that a more extended NBS educational intervention was avoided. Also, postpartum nurses tailored their teaching to minimize maternal anxiety, and suggested that the prenatal period was a better time for mothers to first learn about NBS, which is consistent with the NBS literature (Davis, Humiston, Arnold et al., 2006; Detmar, Hosli, Dijkstra et al., 2007; Hasegawa, Fergus & Ojeda, 2011; Parsons, King & Bradley, 2007). In addition, these research findings raise questions about the adequacy of NBS parent education, since it does not appear to be consistent with the principles of FCC where families can truly collaborate with providers, receive information about their newborn’s care, and participate in the care of their newborn. Although postpartum nurses were meeting the expectations of their organizations and the perceived needs of their patients by providing the very information that both parties expected and wanted, the timing for mothers to learn about NBS was not optimal. The postpartum unit was a challenging environment for NBS education, given competing priorities such as breastfeeding education; as well, mothers were not seen to be well-placed to receive this education on the postpartum unit. NBS parent education may be inadequate because it may be difficult for postpartum units to truly reflect the attributes of ‘health literate health care organizations’ – that is, where organizations make every
opportunity to maximize patient education to help patients use information and services to better their health (Brach, Keller, Hernandez, Baur, Parker, Dreyer et al., 2012).

The findings of this study add to the current literature by offering the views of postpartum nurses and nursing leaders involved with NBS parent education, confirming some findings of prior research and adding new insights not previously reported in the literature. Further, this thesis locates these findings within a body of nursing scholarship that helps to make sense of the professional norms and contextual realities illuminated by the data. In the next section, the strengths and limitations of the study will be discussed.
5.2 Strengths and limitations

Several strengths and limitations of the study will be discussed. Strengths included using a qualitative approach to answer the research question, shifting from a comparative case study to an exploratory descriptive design approach, and using the CASP tool as a guide to strengthen the quality of the study. Limitations included the inclusion of nursing leaders, who may have been motivated to give what they perceived as the most desirable responses about their expectations, the workplace setting in which the interviews took place, and the active recruitment of nurses only during the day.

Using a qualitative research approach to address the research question was the first strength of the study. This approach was useful in identifying and exploring new areas of postpartum nurses’ practice and nursing leaders’ views and experiences with the provision of NBS parent education, which may not have been possible with a quantitative approach. As well, this research study was, to the researcher’s best knowledge, the first study of its kind to explore the experiences of postpartum nurses and nursing leaders, known to be implicated in NBS parent education, using a one-on-one interview approach.

Another strength was the shift from a comparative case study approach to the exploratory descriptive approach in response to early evidence that despite external differences between hospitals in terms of patient population and academic affiliation, the views and experiences of nurses on the provision of NBS parent education were similar. With comparative case study approaches, multiple sources of information are gathered to provide a rich description of each case. However, after noticing that participant responses to the interview questions were similar along with the lack of organization specific NBS source documents that could be used for this research, a decision was made to abandon the comparative case study design since there was little benefit in pursuing it further. While this researcher cannot be definitive on the matter, this suggests that external differences in hospital location, patient population, and academic affiliations did not lead to internal differences in how NBS parent education was run at each hospital. This finding may add to increasing the transferability of the study findings to other settings.
A final but very important strength of the study was the use of several strategies to enhance the credibility, transferability, dependability, and confirmability of the study findings. In order to enhance the credibility of the data, a strong rapport with participants was established because it was believed to be an important step in ensuring that the data reflected nurses’ real experiences and perceptions. Site visits were made and postpartum nurses were spoken with on a casual basis before this researcher asked them to participate. As more frequent site visits were made, the postpartum nursing staff at both hospitals became familiar with this researcher. Their increasing familiarity and growing trust in this researcher enabled for quick recruitment of study participants and allowed for the participation of a range of postpartum nurses with different levels of experience. The use of the convenience sampling method meant that there was the possibility for nurses who were already interested in the topic to have accepted participation in the interviews. However, it is believed that this approach was beneficial because strong rapport was established with the nurses, and this may have contributed to the participation of a wider range of postpartum nurses, including those who normally might not participate in research studies.

In addition to taking steps to enhance the credibility of the study findings, steps to enhance the trustworthiness of the findings were taken. This occurred through ensuring that the themes identified demonstrated data redundancy. Also, the data from the nursing leaders supported the data from the postpartum nurses, which reinforced the confidence in the study findings. In order to enhance the transferability of these findings to other settings, the thesis provides relevant information pertaining to the study, such as the settings in which interviews took place, and is transparent about the sites selected for the study. In addition, demographic data were collected from the participants in the study so that a basic description of the nurses could be provided to readers. This will allow readers to determine how similar or dissimilar the sample was to nurses and nurse leaders within other organizations and thus judge the relevancy of these findings to other settings. Further, in order to enhance the dependability of the study findings, transparency about the shifts in the research design were communicated as well as the changes made to the interview guide that served as a form of audit trail. Finally, to enhance the confirmability of the study findings, reflexive practice, in the form of recording initial impressions of the data and having frequent debriefing sessions with the team, were undertaken in order to address the potential for researcher bias at any stage of the research process. These
activities provided an opportunity to check this researcher’s potential research bias and helped examine the data in new ways. In addition, this research was presented at several research events so there were opportunities for peer scrutiny and constructive feedback.

In addition to these strengths, there were three limitations of the study worth discussing. One related to the sample included—notably, the inclusion of nursing leaders—and the tension observed between their professional and personal views. On the one hand, nursing leaders were approached because they were expected to present their organization’s views and expectations for postpartum nurses. On the other hand, a discrepancy was noted between their personal views and their professional views in discussions about whether breastfeeding education took priority on the unit. Direct questions about whether breastfeeding education took priority on the unit were met with the response that no one education topic was prioritized over others; whereas, in unprovoked conversations about whether breastfeeding education was a priority, nursing leaders commented that it was, in fact, most important. However, despite these discrepancies, one should expect individuals representing their organization to be inclined to give the “right” response. What is learned from these interviews is that despite the fact that nursing leaders may have experienced tension between their professional and personal views, the fact that their responses were similar suggests a uniformity of their experiences in the hospital, the strong culture of patient education on postpartum units, and provides a glimpse of the worldview of postpartum nursing in the hospital.

Another limitation of this study related to the setting in which interviews took place. Interviewing some of the postpartum nurses at work may have interfered with the level of openness or the depth to which they shared their experiences with NBS education. Perhaps that is why interviews on average for postpartum nurses took about 20 minutes. For example, since they still had their patient workload and they were being interviewed during work hours, their attention could have been divided. However, participant responses were similar across respondents. Also, this researcher informed participants that their responses would be confidential, waited for postpartum nurses to be ready for their interview, so they had time to prepare themselves by handing off their patients to their colleagues and preparing themselves mentally for the interview, and noted that most interviews were not interrupted and participants appeared focused and at ease.
A third limitation related to the fact that this researcher was only able to recruit nurses during the day time due to strict hospital policies not allowing visitors to be present on the units after a certain time. This restriction could mean that dedicated night nurses, such as those who only work the evening/night shift, would not have had the same opportunity to be approached to participate in the study. Given that NBS education and testing could occur at any time after the 24 hour mark, day or night, these providers may have distinct insights that were not reflected in the study. However, given that most nurses work an equal number of night shifts and evening shifts as part of their hospital agreement, it is believed that the nurses in this study would have been able to identify any notable differences in their experiences with the provision of NBS education during the day or night if there had been any.

In sum, there were several notable strengths of the study that enhance the quality of the findings and allow for a unique contribution to be made to the current literature and may prove useful to decision makers involved in postpartum nursing practice. As well, three key limitations were discussed which highlight potential areas of future investigation and research.
5.3 Next Steps

5.3.1 Policy implications

Given that NBS parent education is considered an essential component of a well-functioning NBS program (The Changing Moral Focus of Newborn Screening, 2008; Therrell et al., 1992), these findings have practical implications for program planners. Specifically, this study suggests that postpartum nurses have an important role to play in the education of parents about NBS. However, it suggests also that postpartum nurses should not be the only ones involved with providing NBS education. The provision of NBS education on the postpartum unit does not appear to be an ideal time for mothers to first learn about NBS; in addition, current educational approaches may not meet the principles of FCC, nor reflect the attributes of health literate health care organizations. Thus, it may be important to consider other educational strategies for NBS in Ontario – specifically, ones that include the involvement of health care providers in the antenatal context. This will become an even more significant issue if Ontario’s NBS education strategy changes such that more education is expected to be provided to parents by postpartum nurses. This is likely if new screening activities in the early postpartum period, such as routine pulse oximetry screening for critical congenital heart defects (Copeland et al., 2012; Ewer, 2013), are introduced in Ontario. In future, policy makers and program planners should carefully consider the role of postpartum nurses in NBS education to take best advantage of the capacity and willingness that exists, while realistically accounting for existing constraints.

5.3.2 Research implications

Future research should focus on defining the scope of NBS education of postpartum nurses, with the knowledge that this is a provider group willing and capable of providing this education to mothers in the postpartum setting. As well, in the era of constrained resources and short hospital stays, future studies should explore how the effectiveness of individual health care providers who collaborate to meet the educational needs of pregnant women, mothers, newborns, and families can be maximized. Further, attention should be paid to how to best coordinate postpartum nursing care in general given that two main factors that are theorized to influence and limit postpartum nurses’ role in providing NBS education are organizational factors and nurses’ desire to be responsive to patients’ needs. Thus, research on how to deliver patient education in general in this setting should be explored.
Chapter 6
Conclusion

This qualitative study sought to explore postpartum nurses’ and nursing leaders’ experiences with providing NBS education to mothers on the postpartum unit at two hospitals in the GTA using a semi-structured interview approach. This research resulted in an explanatory framework that showed that although postpartum nurses were actively involved with providing both verbal and written NBS information to mothers and viewed NBS education as their responsibility, nurses’ engagement with NBS parent education was limited and nurses did not provide in-depth information about NBS to mothers. Organizational factors such as nurses’ perception that breastfeeding education was a higher priority on the unit, capacity barriers such as language barriers and short length of stay, and nurses’ desire to be responsive to mothers’ preferences and needs, limited the amount of time nurses spent on NBS parent education and the amount of information they provided about it. This research made a unique contribution to the current NBS and nursing literature because it provided a glimpse into the world of postpartum nursing from the perspective of postpartum nurses and nursing leaders in the hospital, and on the factors that strongly influence the amount of time nurses spend on certain patient education activities and the depth of information they provided. This study also offered several research and policy implications that should be considered by researchers wishing to extend the findings and by policy makers and decision makers involved with influencing practice and education agendas in NBS and postpartum nursing. In particular, the consideration of adopting an alternate NBS parent education strategy is warranted in light of these research findings.
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Appendices

Appendix A: Recruitment strategy poster

Attention Postpartum Nurses

Do you have 30 to 60 minutes to help me understand the educational roles and responsibilities of postpartum nursing?

Why is this research being done?

- As a former postpartum nurse, I want to explore nurses’ role in family education, with a focus on newborn screening (NBS).
- This research is for my Masters’ thesis in the Health Services Research program at the University of Toronto

What would your role be?

- An interview of approximately 30 to 60 minutes at a time and place that is convenient to you
- If you agree to participate, the interview will be recorded so that the transcript can be analyzed later
- All your answers will be kept confidential

A small token of appreciation will be provided to all participants at the end of the interview.

Please contact Diana An if you are interested in participating or if you have any questions, comments, or concerns.
Appendix B: Recruitment strategy email to postpartum nurses

Attention Postpartum Nurses

My name is Diana An and I am a former postpartum nurse. As part of my Masters program, I am hoping to conduct a research study that involves a one-time, 30-60 minute interview with 15 to 20 postpartum nurses at [unnamed] Hospital.

Postpartum nurses are underrepresented in the literature, which means that the public, such as researchers, other health care professionals, and policy makers are generally unaware of the amount of work postpartum nurses are responsible for. I would like to take this opportunity to help the public understand the experiences of postpartum nursing, but I need your help.

My research focuses on one critical aspect of postpartum nursing—family education. In particular, I am interested in learning about your experiences with newborn screening (NBS) education.

Please contact Diana An if you are interested in participating in the study or if you have any questions, comments, or concerns. Your participation is completely voluntary and confidential. You may also withdraw from the study at any time.

A small token of appreciation will be provided to all participants at the end of the interview.

Thank you so much for your consideration.

Sincerely,

Diana

Diana An, BScN, CRA (c) MSc (c)
University of Toronto
Institute of Health Policy, Management and Evaluation
155 College St. 4th floor
[email]
[phone number]
Appendix C: Postpartum nurse interview guide

Introduction: To start, can you tell me a bit about how you got started in postpartum nursing?

Theme 1: Experience with newborn screening (NBS)

I’d like to learn more about the experiences of postpartum nurses who practice in the immediate post-birth setting. In particular, I am interested in learning more about the educational roles and responsibilities of postpartum nurses as it relates to NBS. Would you describe what your experience has been with the NBS program so far?

- Would you provide an example of what a typical nurse-parent(s) NBS encounter would look like?
- How much time do discussions related to NBS normally take?
- What are your thoughts in having postpartum nurses involved with the NBS process?
- Do you feel comfortable discussing NBS with parents? Why/not?

Theme 2: Attitudes towards providing NBS education to parents

I’m curious to learn what your thoughts are on having postpartum nurses involved with NBS education. NBS emphasizes shared responsibility among health care professionals for parental education of NBS; what role, if any, should postpartum nurses play?

- Who do you think are the ideal people to be involved with educating mothers and parents about NBS?

Theme 3: Comparing NBS to other educational activities on the postpartum unit

If you were to compare NBS education to other educational activities on the unit, such as, breastfeeding and hyperbilirubinemia education, what would you say?

- What are your thoughts on having postpartum nurses involved with these other types of educational activities on the postpartum unit?
- How comfortable are you with discussing a range of topics with mothers and parents?
- Do you feel that there is enough time to cover all the material you would like to cover?
- How prepared do you feel to discuss this range of topics with parents?
- What do you think is the most ideal way to organize and deliver these preventative and hands on educational sessions?

Theme 4: Barriers and facilitators in providing NBS education to parents.

What do you think are some of the barriers/facilitators in providing education to parents on the postpartum unit?

- Would you describe what other competing priorities there are?
- How do you deal with these competing priorities?
- Do you feel like there are resources you can turn to, should you need them? If so, where? Who?
**Theme 5: Final thoughts**

Given our discussion on the educational responsibilities of postpartum nurses, would you like to make any concluding remarks as to how NBS education fits or doesn’t fit into postpartum nursing?

- What message would you send to decision makers both at the hospital and outside of the hospital with respect to postpartum nursing?
Appendix D: Nursing leader interview guide

Introduction: To start, can you tell me a bit about how you got started in becoming a postpartum nursing leader?

Theme 1: Thoughts on the role of postpartum nurses with NBS

To start, I’d like to learn more about what the educational roles and responsibilities of postpartum nurses in preventive health services. Would you share with me a bit about the current role postpartum nurses are playing in NBS?

- What are your thoughts on having nurses involved in both the technical and teaching aspect of NBS?
- Do you think it is appropriate to involve postpartum nurses in these activities?
- Would you describe what an ideal nurse-patient NBS education interaction would look like?

Theme 2: Implementation of the NBS program

If you could take me back to the time of when NBS was implemented on the unit, would you talk a bit about what that experience was like for you and the leadership team?

- Who assisted with the implementation of the NBS program? In hospital? Outside of hospital?
- Are there any NBS guidelines and policies available on the unit?
- Do you remember what the nurses’ reaction was like? Was there anything else that was going on at the time that might have influenced their reaction?
- How did the team prepare the nurses to handle this additional responsibility?

Theme 3: Comparing NBS to other educational activities on the postpartum unit

If you were to compare NBS education to another similar and dissimilar educational activities on the unit that postpartum nurses might be involved in, what would you say?

- What do you think is the best approach for managing and implementing all these nursing educational activities?

Theme 4: Attitudes towards postpartum nursing education

How important is it for postpartum nurses to engage in parental education of preventative health services, such as, hyperbilirubinemia?

- How should postpartum nurses prioritize their educational roles and responsibilities?
- What do you think should be the scope of postpartum nursing education?

Theme 5: Barriers and facilitators in providing NBS education to parents
What do you think are some of the barriers/facilitators to providing parental education on a postpartum unit?

- What are some of the other competing priorities?
- How should these competing priorities be addressed?

**Theme 6: Priorities**

The nurses in our study so far have said that ... (educational roles and responsibilities play a in/significant) what do you think about this?

- Do you dis/agree? Why or why not?
- What message would you send to decision makers both within the hospital and outside of the hospital?
Appendix E: Demographic information

1. The following is a list of work settings. Check the category that best describe(s) the setting where you see most of your patients.
   - Academic hospital
   - Community hospital

2. Approximately how many years of postpartum nursing experience do you have? _______________

3. Do you provide the following types of care? (Please check all that apply)
   - Prenatal care
   - Intrapartum care
   - Infant care
   - Care of children
   - Care of adults

4. What is your professional role?
   - Registered Nurse
   - Registered Practical Nurse
   - Nurse Practitioner
   - Nurse Educator
   - Nurse Manager
   - Other (please specify): _______________

5. Do you function in both a clinical role and a nursing leadership role? If so, what percentage of your time (approximately) is spent providing patient care? _______________

6. What is your highest level of education completed?
   - Diploma
   - Baccalaureate (e.g. BScN)
   - Masters (e.g. MScN)
   - Doctoral

7. Please indicate your current employment status:
   - Full time
   - Part time
   - Casual

8. Please indicate which age category you fall under:
   - <25 years
   - 26-34 years
   - 35-49 years
   - 50+ years
Appendix F: Informed consent form

INTRODUCTION

You are being asked to take part in a research study. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish. Participation in this study is voluntary.

The University of Toronto and the investigator, Diana An, are not under contract with a Sponsor for this study and thus are not receiving compensation to cover costs of conducting the study.

BACKGROUND AND PURPOSE

WHY IS THIS RESEARCH BEING DONE?

Newborn screening (NBS) programs test infants for serious conditions to try to prevent disease or disability. Providing NBS education to parents is important but there is evidence that not a lot of parents are receiving it. Given the role of postpartum nurses in education, these providers have a potential role to play in NBS education.

WHAT IS THE PURPOSE OF THIS STUDY?

You have been asked to take part in this research study because we want to know how health care providers think, feel, and engage with NBS education. This study is intended to explore the role of nurses in providing NBS education to parents in Ontario in order to understand the role they currently play and want to play, and the contextual factors influencing their involvement with providing NBS education. This research will also explore the general role health care providers play in providing other types of family education on the postpartum unit—namely hyperbilirubinemia education and breastfeeding education. By understanding the educational experiences of other similar and different educational activities that might occur on the postpartum unit, we hope to better understand the context in which NBS education operates.
HOW MANY PEOPLE WILL BE IN THIS STUDY?

About 30 to 40 interviews from two hospitals will be in the study. About 15 to 20 will come from x Hospital.

STUDY DESIGN

WHAT WILL MY RESPONSIBILITIES BE IF I TAKE PART IN THE STUDY?

We would like to have a one-on-one interview with you about your experiences, attitudes, and opinions about the issues described above. The interview would be conducted by telephone or in person, and would last approximately 30 to 60 minutes (at your convenience and discretion). Your interview will be digitally recorded and transcribed word-for-word by a professional transcriptionist who has signed a confidentiality agreement. You will also be asked to fill in a short questionnaire.

WHAT ARE THE POSSIBLE RISKS AND DISCOMFORTS?

There are no medical risks if you take part in this study, but being in this study may make you feel uncomfortable. You may refuse to answer questions or stop the interview at any time if there is any discomfort.

WHAT ARE THE POSSIBLE BENEFITS FOR ME AND/OR FOR SOCIETY?

You may or may not receive any direct benefit from being in this study. Results from this study will be of great value to the research team, and publications may help other researchers and policy-makers.

CAN PARTICIPATION IN THE STUDY END EARLY?

Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your employment status. You may refuse to answer any question you do not want to answer, or not answer an interview question by saying “pass”.

We will give you new information that is learned during the study that might affect your decision to stay in the study.
IF I DO NOT WANT TO TAKE PART IN THE STUDY, ARE THERE OTHER CHOICES?

An alternative to the procedures described above is not to participate in the study and continue on just as you do now.

WHAT INFORMATION WILL BE KEPT PRIVATE?

All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law. Any information about you that is sent out of the hospital will have a code and will not show your name or any information that directly identifies you. You will not be named in any reports, publications, or presentations that may come from this study.

The information that is collected for the study will be kept in a locked and secure area by the co-investigator, Dr. Fiona Miller, for 10 years. Only the study team or the people or groups listed above will be allowed to look at your study information. You are welcome to listen to your recording or review your transcript at any time. The audio files will be retained for up to 6 months following the conclusion of the study, to allow us to check and cross-check the accuracy and adequacy of the written transcript and then will be destroyed. The transcripts will be destroyed ten years following the conclusion of the study.

WILL I BE PAID TO PARTICIPATE IN THIS STUDY?

We offer a $5 gift card to Second Cup as a small token of thanks for your time.

WILL THERE BE ANY COSTS?

Your participation in this research project will not involve any additional costs to you. The main cost to you is the time you take to participate in the interview. We will pay for any telephone charges or travel costs associated with your participation.

WHAT HAPPENS IF I HAVE A RESEARCH-RELATED INJURY?

If you become ill, injured or harmed as a result of taking part in this study, you will receive care. The reasonable costs of such care will be covered for any injury, illness or harm that is directly a result of being in this study. In no way does signing this consent form waive your legal rights nor
does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You do not give up any of your legal rights by signing this consent form.

**IF I HAVE ANY QUESTIONS OR PROBLEMS, WHOM CAN I CALL?**

If you have any questions, concerns or would like to speak to the study team for any reason, please call: Diana An at x.

If you have any questions about your rights as a research participant or have concerns about this study, call x Hospital Research Ethics Board (REB) or the Research Ethics office number at x. The REB is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to take part in this study.

__________________________  _____________________  ____________
Print Study Participant’s Name  Signature  Date

(You will be given a signed copy of this consent form)

My signature means that I have explained the study to the participant named above. I have answered all questions.

__________________________  _____________________  ____________
Print Name of Person Obtaining Consent  Signature  Date