NICU-TO-HOME TRANSITIONS FOR ADOLESCENT MOTHERS

Understanding NICU-to-Home Transitions for Adolescent Mothers: Theory, Methods and Research

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LAY ABSTRACT

Pregnancy and parenting during adolescence and care transitions from neonatal intensive care unit (NICU) to home are relatively complex experiences. While each have been explored separately, very little is known about when these experiences intersect. This thesis examines theory and methods related to this complex intersection and describes findings of research exploring NICU-to-home care transitions for adolescent parents.

ABSTRACT

Each year in Canada there are nearly 13,000 infants born to women under the age of 20 years (Statistics Canada, 2016). Infants born to adolescent mothers are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a neonatal intensive care unit (NICU) shortly after birth (DeMarco et al., 2021; Fleming et al., 2013; Shrim et al., 2011). Admission of their infant to the NICU creates an increasingly complex situation, as adolescent mothers and their children often already experience multiple social, psychological, and economic difficulties (Fleming et al., 2015). Additionally, adolescents are still developing important cognitive functions, such as advanced reasoning and decision-making, thus making their ability to navigate complex systems such as the NICU particularly challenging (Blakemore & Choudhury, 2006). However, the unique experience of the adolescent mother within the context of the NICU and their transition-home following discharge is poorly understood. Therefore, the overall purpose of this thesis was to explore the issue of transition-home from NICU for adolescent mothers with infants admitted to the NICU.

Three overarching goals guided this thesis work, these goals were to: (a) understand the transition experiences of adolescent mothers with infants in the NICU from a theoretical perspective; (b) understand how to best collect rich qualitative data among study participants experiencing marginalization or stigma; and (c) conduct research to further understand the phenomena and how to begin to address transition-related issues. Findings related to each of these goals are presented in four manuscripts that make up this sandwich thesis, including a critical review of theory, an exploration of methods, and an interpretive description study exploring NICU-to-Home transitions. The work presented in this thesis emphasizes the complexity of the NICU-to-home transition for adolescent mothers. Findings highlight the need for strategies within the NICU to mitigate the negative influence of this experience and opportunities for more integrated models of care within the NICU and extending into the community. Implications for research, policy, and nursing education and practice are discussed.

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LIST OF ABBREVIATIONS

ACE(s)	adverse childhood experience(s)
aRR	adjusted relative risk
BCHCP	British Columbia Healthy Connections Project
CI	confidence interval
ED	Emergency Department
FCC	family centred care
FiCare	family integrated care
HiREB	Hamilton Integrated Research Ethics Board
HPPD	hours per patient day
KT	knowledge Translation
MRI	magnetic resonance imaging
NFP	Nurse-Family Partnership
NICU	neonatal intensive care unit
NP	Nurse Practitioner
OR	odds ratio
PHN(s)	public health nurse(s)
PHN-PREP	Public Health Nursing Practice, Research, and Education Program
PHU(s)	public health unit(s)
PTTM-R	positivity toward teen mothers-revised
RN	Registered Nurse
RR	relative risk

RTA	reflexive thematic analysis
SDOH	social determinants of health
STI	sexually transmitted infection
SW	Social Worker
US	United States
WHO	World Health Organization
YPSS	Young Parent Stigma Scale

DECLARATION OF ACADEMIC ACHIEVEMENT

This sandwich thesis consists of four manuscripts that have been prepared for publication (chapters 4 & 5) or published in peer-reviewed journals (chapters 2 & 3). The student, Ms. Elizabeth Orr, is the first author on all four of these manuscripts and as such was responsible for: generation of research questions, research design, data analysis, interpretation of findings, writing of manuscripts, and revisions based on committee feedback and journal reviewers. Co-authors of the manuscripts include thesis supervisor, Dr. Susan Jack, and thesis committee members, Drs Marilyn Ballantyne and Andrea Gonzalez. All co-authors contributed to the study design, interpretation of findings, revising of manuscripts and approval of final manuscripts for publication.

CHAPTER ONE

Introduction

Each year in Canada there are nearly 13,000 infants born to women under the age of 20 years (Statistics Canada, 2016). Across the country, births to adolescent females aged 10-19 years account for 3.2% of all live births. Geographical differences exist with the lowest adolescent birth rates in British Columbia and the highest in Nunavut; proportions of births to mothers aged 10–17 and 18–19 years range from 0.8% and 1.8% (of all live births) in British Columbia to 8.4% and 10.6% in Nunavut respectively (Public Health Agency of Canada (PHAC), 2017). When compared to women who give birth between the ages of 20-35 years (representing 76.2% of all live births), Canadian adolescent mothers are more likely to have low-socioeconomic status (with household income as an indicator), be non-immigrants, be without a partner, and preferred to delay their pregnancy until later in adulthood (i.e., pregnancy was un-planned) (Al-Sahab et al., 2012). Infants born to adolescent mothers are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a neonatal intensive care unit (NICU) shortly after birth (DeMarco et al., 2021; Fleming et al., 2013; Shrim et al., 2011). Admission of their infant to the NICU creates an increasingly complex situation, as adolescent mothers and their children often already experience multiple social, psychological, and economic difficulties. Additionally, adolescents are still developing important cognitive functions, such as advanced reasoning and decision-making, thus making their ability to navigate complex systems such as the NICU particularly challenging (Blakemore & Choudhury, 2006).

However, the unique experience of the adolescent mother within the context of the NICU and their transition-home following discharge is poorly understood.

Background

The following sections outline developmental characteristics of adolescents, risk factors and consequences associated with unplanned pregnancy in adolescence, health-harming behaviours among pregnant adolescents that lead to poor health outcomes as well as the adverse neonatal outcomes associated with adolescent pregnancy. This overview will serve to highlight the complexity and vulnerability associated with adolescent motherhood and contextualize the potential challenges of transitioning-home from the NICU for this population.

Adolescence: A Brief Overview

Adolescence is commonly understood as the life stage when a child develops into an adult (Merriam-Webster, 2018). The ages associated with the life stage prevail from Erikson's (1950) proposed developmental stage and range from puberty to the late teenage years (e.g., 13-19 years). Adolescence is marked by significant physical, emotional, intellectual and social changes including the physical transformations of puberty, intense interest in peer activities, increased novelty seeking, increased risk taking and decreasing dependence on one's parents (Aruda & Burke, 2013; Johnson et al., 2009). While the presence of secondary sex characteristics and engaging in sexual activity gives the appearance of being more mature, the adolescent brain is still developing – with findings from longitudinal Magnetic Resonance Imaging (MRI) studies of the adolescent brain confirming what has been observed behaviourally for many years

(Aruda & Burke, 2013; Giedd, 2008; Leany, 2013). The prefrontal cortex is the fastest and largest region of brain development in adolescence, it is responsible for advanced reasoning, including the ability to plan, understand cause and effect, think through scenarios and manage impulses. Knowledge that this area is still developing throughout adolescence serves to highlight a biological component important in the understanding of pregnancy in adolescence. For example, this immature cognitive functioning can lead to distortions in judgement leading the adolescent to believe that pregnancy could not happen to them, or when their pregnant state is identified, adolescents may find it difficult to employ abstract decision making or planning for the future (Aruda & Burke, 2013; Leany, 2013). While this is simply one example of how the unique developmental issues that characterize adolescence have an impact on health and related behaviours, it emphasizes the demand for a specialized approach for supporting individuals in this life stage when they intersect with the health and social care systems.

Risk Factors and Consequences Associated with Unplanned Pregnancy in Adolescence

There are multiple social, psychological, and economic risk factors associated with an unplanned pregnancy in adolescence. Similar factors are considered outcomes or consequences associated with adolescent pregnancy making it difficult to determine the direction of causality in most situations. Globally, girls aged 15-19 years from the lowest socioeconomic groups are three times more likely to give birth in adolescence than their economically better-off peers (Dillon & Cherry, 2014). Similarly, in Canada the odds of becoming a teenage mother increases as household income decreases with many adolescent mothers living in poverty (Al-Sahab et al., 2012). Lower educational attainment is also considered a risk factor for adolescent pregnancy, with dislike of school identified as key aspect of young parents' accounts of their lives before becoming pregnant (Fleming et al., 2015; Harden et al., 2009).

While low socio-economic status is a risk associated with adolescent pregnancy and parenting, these adolescents also have a higher risk of having experienced adverse events in childhood and childhood disadvantage (Smith et al., 2018). Exposure to adverse childhood experiences (ACEs) is associated with many unfavourable outcomes including, smoking, alcohol abuse, suicide attempts and high-risk sexual behaviours (Hillis et al., 2004). These ACEs are associated with unintended pregnancies in all-aged women including pregnancy in adolescence (Hillis et al., 2004). Adverse childhood experiences include verbal, physical and sexual abuse (including neglect); exposure to intimate partner violence; household substance abuse; mental illness in the household; divorce or separation and an incarcerated household member (Hillis et al., 2004). One study conducted in the United States (US) demonstrated a clear dose response relationship between ACEs and adolescent pregnancy, with the prevalence of adolescent pregnancy increasing from 16 to 53% as the number of ACEs increased from zero to eight experiences (Hillis et al., 2004). The relationship between adolescent pregnancy and experiencing ACEs also places the infant at risk for adverse neonatal outcomes, as women experiencing ACEs have been found to have infants with lower birth weights and gestational ages than women without ACEs (Smith et al., 2016). Focusing specifically on exposure to violence, a Canadian study found that a history of abuse at any point in a young woman's life is also strongly associated with adolescent pregnancy and the adolescent mother is two times more likely to have reported physical or sexual abuse/violence within the previous two years when compared to the average-aged mother (Odds Ratio [OR] = 2.24, 95% Confidence Interval [CI]: 1.53–3.29) (Al-Sahab et al., 2012).

Mental health disorders, including depression, post-traumatic stress disorder, anxiety and substance misuse are common amongst pregnant adolescents, and can be considered a risk factor for pregnancy in this age group (Fleming et al., 2015). In a population-based study exploring the age-specific fertility rate for young women (age 15-19 years), those diagnosed with major mental illness within 5 years preceding pregnancy had a fertility rate of 44.9 per 1000 (95% CI: 43.3–46.7) compared with 15.2 per 1000 (95% CI: 15.1–15.3) in young women unaffected by major mental illness; meaning fertility rates are 3 times higher in adolescent girls with major mental illness than unaffected adolescents, these data suggest that a mental health diagnosis acts as an antecedent factor to adolescent pregnancy (Vigod et al., 2014). However, the direction of causality in the relationship between mental health and adolescent parenthood is particularly complicated, as factors associated with adolescent pregnancy including history of child abuse, chaotic home environments and limited social support networks have also been strongly associated with adverse mental health outcomes (Hodgkinson et al., 2014).

Adolescent childbearing, often compounded by the above-mentioned risk factors, is associated with negative outcomes for the adolescent mother including lower educational attainment and difficulty finding stable employment when compared to older mothers. Consequently, girls and young women face several socioeconomic problems as a result of pregnancy in adolescence including poverty, residential instability, violence and less social support than older mothers (Letourneau et al., 2004; Ruedinger & Cox, 2012). Whether antecedents to adolescent pregnancy or consequences of young parenthood, these conditions contribute to poor health outcomes among this vulnerable population. Poor maternal and infant health outcomes can also be accentuated by specific health harming behaviours among pregnant adolescents including, higher levels of substance use, smoking, unprotected intercourse leading to sexually transmitted infections (STIs) and lower levels of prenatal care (Thompson, 2016). These health behaviours and the relevant literature will be discussed in the following paragraphs.

Health Harming Behaviours in Pregnant Adolescents Leading to Poor Maternal Health Outcomes

In Canada, smoking and substance use rates are both higher in pregnant adolescents than their adult counterparts (38.8% vs. 11.9%; $p < 0.001$; and 11.7% vs. 5.1%; $p < 0.001$ for smoking and substance use respectively) and the use of alcohol and drugs by pregnant women can result in significant maternal, fetal, and neonatal morbidity (Fleming et al., 2013; Wong et al., 2011). In general, adolescents are at a greater risk for STIs because of the increased likelihood of having multiple sexual partners, experiencing unprotected intercourse, and being biologically more vulnerable to these types of infections. Pregnant adolescents are at an even greater risk as they are less likely to wear condoms during intercourse when compared to non-pregnant adolescents. STIs have been associated with adverse perinatal outcomes including, preterm delivery, chorioamnionitis, and postpartum infections (Fleming et al., 2013; Thompson, 2016).

Health behaviours seen as protective or preventative, are also lower in pregnant and parenting adolescents. Pregnant adolescents have significantly lower rates of first-trimester antenatal visits (adjusted relative risk [aRR] 0.53, 95% CI 0.51 to 0.55) when compared to adult women (Fleming et al., 2013). This delay in seeking care is often multifactorial with reasons including lack of knowledge related to the importance of prenatal care, desire to hide pregnancy, fear of social services involvement, contemplation of abortion services, societal attitudes toward adolescent pregnancy and financial barriers (Fleming et al., 2015). Standard prenatal care improves outcomes in adolescent pregnancy and has been shown to be protective against fetal and infant mortality in young pregnant women. Furthermore, approaches to prenatal care designed to meet the specific needs of the pregnant adolescent (e.g., addressing developmental needs, STI screening, contraception and return to school) lead to even better outcomes including, reductions in preterm birth, low birth weight and NICU admissions (Fleming et al., 2015; Malabarey et al., 2012). Following delivery, adolescent mothers have lower rates of breastfeeding – a health behaviour important for the nutrition, immunologic protection, growth and development of their infants and toddlers (Fleming et al., 2015). A Canadian study comparing women’s maternity experiences and practices found that just over 83% of adolescent mothers initiated breastfeeding compared to 91% of mothers over age 25 (Kingston et al., 2012). Young mothers were also significantly less likely to be exclusively breastfeeding beyond 3 months of age (34.1% breastfeeding ≥3 months in mothers age 15-19 compared to 53.3% of mothers ≥ 25 years), which is short of the global recommendation of exclusive breastfeeding during the first six months following birth (WHO, 2017).

In summary, social determinants of health inequities and co-existing risk-oriented health behaviours can have a significant impact on the health of the young mother and her infant. Smoking, substance use and STIs, all with higher rates on average among pregnant adolescents, can result in significant maternal, fetal and neonatal morbidity; and early prenatal care and breastfeeding, which can be protective against poorer health outcomes, has lower attendance/initiation rates in pregnant adolescents than their adult pregnant counterparts (Fleming et al., 2015; Thompson, 2016). Therefore, to fully understand the health context of the adolescent mother-infant dyad, it is important to also understand the adverse neonatal outcomes associated with adolescent pregnancy, these will be discussed below.

Adverse Neonatal Outcomes Associated with Adolescent Pregnancy

Globally, stillbirths and infant death before one week of age are 50% higher in infants born to adolescent mothers when compared to mothers age 20-29 years; also, an inverse relationship exists between maternal age and risk of death during the neonatal period (i.e., the first month of life), with infants born to the youngest mothers at highest risk (Dillon & Cherry, 2014). Risk of adverse neonatal outcomes among infants born to adolescent mothers are not exclusive to developing nations – lower socio-economic status and education, exposure to ACEs and maternal mental health concerns also contribute to poorer outcomes among young women and their children in developed nations – with social determinants of health inequities likely at the root of negative health outcomes in adolescent mothers and their children when compared to maternal age alone (Smith et al., 2016; Thompson, 2016). However, even when controlling for significant sociodemographic factors, infants born to adolescent mothers are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a NICU shortly after birth (Fleming et al., 2015; Shrim et al., 2011).

Preterm birth, low birth weight and congenital anomaly. Adolescent mothers and their infants are at an increased risk for poor health outcomes; however, it has been debated whether young maternal age is intrinsically a risk factor for poor health outcomes in this population or if the increased risk is related to the socio-economic circumstances leading to and following pregnancy for this group (Paranjothy et al., 2009). Several researchers have conducted studies with results providing insight to this debate, including a recent systematic review and meta-analysis exploring the prevalence of low birthweight, premature birth, and stillbirth among pregnant adolescents in Canada. In this review DeMarco and colleagues (2021) reviewed primary research articles reporting birth outcomes for adolescent women and found a 56% increase in the prevalence of low birthweight (pooled odds ratio [OR] 1.56; 95% CI 1.24 to 1.97), a 23% increase in pre-term birth (pooled OR 1.23; 95% CI 1.06 to 1.42), and a 20% higher prevalence for stillbirth (pooled OR 1.2; 95% CI 1.05 to 1.37) amongst adolescent pregnancies compared to adult pregnancies. Included in this review was a retrospective population-based cohort, where, Shrim et al (2011) found higher rates of prematurity (OR 2.3; 95%

CI 1.6-3.2) and extreme prematurity (OR 4.5; 95% CI 2.5-8.1) (<37 weeks' gestation and <28 weeks' gestation respectively) in the adolescent mothers (age <20 years) compared with adult mothers (age 20-39). This study also found increased rates of low-birth-weight ratio (birth weight divided by the average weight for the gestational age) (P=0.004) and higher rates of congenital anomalies (OR 1.8; 95% CI 1.2-2.6). This study did not however adjust for socio-economic factors. Also included in the DeMarco et al review, was another retrospective cohort study examining adolescent pregnancy outcomes in the province on Ontario; in addition to a significantly higher risk of being born very or extremely preterm (< 32 weeks' gestation) (aRR 1.6; 95% CI 1.02 to 1.31) infants born to adolescent mothers also had significantly higher risk of admission to the NICU (aRR 1.08; 95% CI 1.02 to 1.14). Importantly this study adjusted for sociodemographic risk factors (such as incomes and education status) and the risk of adverse birth outcomes remained (Fleming et al., 2013). Internationally, similar studies have reported comparable findings. In the United Kingdom, Jolly et al (2000) found pregnancy in women less than 18 years old was associated with increased risk of preterm labor before 32 weeks' gestation (OR 1.41; 99% CI 1.02, 1.90); in the US Chen et al (2007) found that risks of very and extremely preterm delivery (gestational age < 32 weeks), preterm delivery (gestational age , < 37 weeks), very low birthweight (< 1500 grams), and low birthweight (< 2500 grams) increased with decreasing maternal age, even when analysis was restricted to account for known cofounders; and in Sweden, even after adjusting for socio-economic factors, mothers less than 20 years of age still had an increased risk of preterm birth compared to older mothers (age 20-24). While these studies suggest that biological age plays a role in adverse pregnancy outcomes, a systematic review of social determinants of health and adverse maternal and birth outcomes in adolescent pregnancy found experiences of socio-economic deprivation among pregnant adolescents resulted in a higher prevalence of poor pregnancy outcomes when compared to more well-off counterparts (Amjad et al., 2019). This review suggests certain sub-groups of adolescent mothers may be at higher risk of poor pregnancy outcomes.

In addition to preterm birth and low birthweight, certain congenital anomalies are associated with young maternal age. Of note, gastroschisis (a congenital abdominal wall defect which results in the extrusion of the developing fetal intestines into the amniotic space) is among the most common structural birth defects, and while its cause remains unknown, the most widely observed association of gastroschisis occurrence in pregnancy is its inverse relationship with maternal age (relative risk [RR]= 7.0 in women < 20 years of age and RR=2.4 in women 20-24 compared to women 25-29) (Skarsgard et al., 2015). The prevalence of gastroschisis in Canada is approximately 1 per 2200 births with this rate rising threefold in the previous 10 years (Skarsgard et al., 2015). Understandably, an infant born with gastroschisis requires admission to an NICU. The risk for gastroschisis, as well as the above-mentioned risks of preterm birth, low birthweight and other congenital anomalies increases the likelihood of infants born to adolescent mothers requiring specialized care following birth and thus admission to the NICU.

It is important to note that there is a higher risk of preterm birth among Black women than among white women in both the US and Canada (McKinnon et al., 2016). Higher risk of preterm birth also exists among Canada’s Indigenous population (He et al., 2017; Luo et al., 2010; Seventh Generation Midwives Toronto, 2018). In addition, Indigenous women in Canada have higher rates of adolescent pregnancy (8% in Indigenous women compared to 1.3% in non-Indigenous women age 15-19 years) (O'Donnell & Wallace, 2011). While race is not the focus of this thesis, these data underscore the importance of recognizing structural racism as a determinant of health within maternal-child health contexts. For Black and Indigenous mothers, experiences of discrimination, racism, and historical trauma intersect with the above-mentioned constellation of health and social inequities, thus posing further risk of poor health and developmental outcomes among these women and their infants.

Admission to the NICU. In 2019, nearly 15,000 infants were admitted to the 32 healthcare organizations that form the Canadian Neonatal Network (Canadian Neonatal Network (CNN), 2019; Fallah et al., 2011). For infants born to adolescent mothers there is an increased risk of NICU admission cited in two Canadian studies (aRR 1.08; 95% CI 1.02-1.14; OR 2.1, 95% CI 1.5-3.0) (Fleming et al., 2013; Shrim et al., 2011), however, there is limited data related to what percentage of NICU admissions are infants born to Canadian adolescent mothers. American study findings offer a possible estimate of this number; in a study evaluating a NICU teen parent support program, authors cite that 15% of infants admitted to the 75-bed, level IV, NICU in the large American city are born to mothers between the ages of 13 and 19 years (Walsh & Goser, 2013). Fifteen was also the percentage of mothers aged 14-18 years with infants admitted to the NICU in a study examining these admission rates among 233,844 mothers from 19 US hospitals between 2002 and 2008 (de Jongh et al., 2012).

Despite the absence of an exact number of young women affected by admission of their infant to the NICU, these young women are part of the NICU parent population, yet little is known about their unique experience (Christopher et al., 2000; Rosenstock & van Manen, 2014). For these young mothers, admission of their infant to the NICU exacerbates an already complex situation. In addition to the above-mentioned social, psychological and economic difficulties associated with adolescent motherhood, the NICU environment coupled with the fragile condition of their critically-ill infant are frequent sources of stress, anxiety, depression, and grief as well as the need for increased social and professional support – for all-aged parents (Ballantyne et al., 2017; Boykova & Kenner, 2012; Lakatos et al., 2019). These emotional and psychological outcomes are pervasive and continue well beyond the infant's discharge from the NICU; with studies reporting ill-effects up to seven years post-discharge (Feeley et al., 2011; Lefkowitz et al., 2010; Schecter et al., 2020; Treyvaud et al., 2014). While the experiences of older parents in the NICU are well documented, the unique experience of the adolescent mother within the context of the NICU is poorly understood.

In a review of the literature on adolescent parenting in the NICU, Rosenstock and van Manen (2014) found the majority of studies focused on parental stress and parenting practices among adolescent parents with infants in the NICU (with adolescent parents often a sub-population within the study sample), a few studies examined communication practices, parental needs and intervention programs and only one qualitative study focused specifically on the experience of the adolescent mother within the NICU. Bocock (2012) used a phenomenological approach to explore the experiences of four adolescent mothers whose infants required admission to a small New Zealand NICU. From the analysis, three themes were developed: (a) the need to do mothering (b) the NICU being a safe place and (c) the NICU experience as an emotional rollercoaster; a key finding of the study was that despite their developmental stage, adolescent mothers had similar experiences of the NICU compared to older mothers. The study's breadth of focus combined with a small sample does however limit the depth and application of the findings. The other study using qualitative methods focused specifically on the adolescent mother's understanding of their infant's diagnosis. Boss et al. (2010) used qualitative interviews and descriptive analysis and compared this data with chart data to ascertain how much adolescent mothers knew about key components of their infant's illness. They found that while most adolescent mothers were able to identify the names of their infant's diagnoses and treatments, they often underestimated the severity of their infant's illness, therefore, highlighting the need for healthcare providers to ensure effective communication that enhances understanding in this population of young mothers. These studies, while limited in scope, shed some light on the adolescent parenting experience within the NICU. There is, however, a particular void related to understanding the transition home experience for this unique and potentially vulnerable group of infant/adolescent-mother dyads.

Transition Home from NICU

Transition to home following discharge from the NICU has been the topic of a number of explorations within the literature. These discussions and studies range in focus from preparing for or facilitating discharge among this population of infant/parent dyads

(Boykova, 2016; Boykova & Kenner, 2012; Green et al., 2021; Jefferies, 2014; Lopez et al., 2012; Raffray et al., 2014); describing the development, implementation and evaluation of discharge programs or interventions (Brodsgaard et al., 2015; Broedsgaard & Wagner, 2005; Feehan et al., 2020; Garfield et al., 2016; Mills et al., 2006; Pineda et al., 2020; Sauers-Ford et al., 2021; Schlittenhart et al., 2011; Toral-Lopez et al., 2016); and documenting parental perspectives, experiences or emotional responses related to discharge and transition-home both qualitatively and quantitatively (Aydon et al., 2018; Brenner et al., 2015; Enlow et al., 2014; Garfield et al., 2014; Lakshmanan et al., 2019; Raines, 2013; White et al., 2017). Despite the coverage given this topic, an adolescent focus within the related literature is essentially absent, additionally many of the participants in these studies are significantly older than the adolescent age-group. While it is possible to apply adult-focused findings to the adolescent population, failure to consider the unique developmental stage of the adolescent mother and the relative complexity of her pregnancy and parenting situation could lead to care that is un-informed and unable to meet her needs and the needs of her infant. Additionally, premature infants born to adolescent mothers have an increased likelihood of rehospitalisation and emergency department visits following their initial discharge from NICU (OR= 3.57, 95% CI 1.81–7.05; OR= 3.67, 95% CI 2.11–6.39), underscoring this need for an age-specific understanding of the transition-home experience (Ray et al., 2010).

The preceding sections highlight the many complexities associated with adolescent motherhood, including risks for poor outcomes for both mother and infant, making them a vulnerable dyad. This vulnerability may be increased when the infant requires admission to the NICU shortly after birth, and the risk-oriented factors associated with adolescent motherhood intersect with the known challenges associated with the NICU experience. The following sections describe why this is a problem requiring further understanding.

Problem Statement

Admission to the NICU interrupts, fragments and complicates the usual transition home experience for the adolescent mother, where there is a focus on engagement with public health services and availability of programming grounded in the principles of health promotion and prevention and services designed to address social determinants of health (SDOH). This atypical transition is further compounded by the above-mentioned emotional and psychological consequences of an NICU admission. Additionally, the young mother is faced with the complexities of caring for an infant who is potentially medically fragile and at risk for developmental delay. These many layers of complexity require healthcare professionals to be informed of the distinct circumstances, experiences and needs of the adolescent mother when discharged home from the NICU. Lack of understanding of this phenomenon renders healthcare professionals ill-equipped to support these mothers within the NICU and beyond, therefore, leaving adolescent mothers and their infants at risk of not receiving, or engaging with, the health and social care services required to promote the optimal growth and development of the adolescent mother and her infant. Therefore, the overall purpose of this thesis was to explore the issue of transition-home from NICU for adolescent mothers with infants admitted to the NICU.

Approach to Understanding NICU-to-home Transitions for Adolescent Mothers

Three overarching goals for understanding NICU-to-home transitions were identified at the outset of this thesis work; these goals directed the approaches and outputs documented in this dissertation. These goals were:

1. To understand the transition experiences of adolescent mothers with infants in the NICU from a theoretical perspective;
2. To understand how to best collect rich qualitative data among study participants experiencing marginalization or stigma; and
3. To conduct research to further understand the phenomena and how to begin to address transition-related issues.

Theoretical Understanding

The purpose of research within any discipline is to create knowledge – and it has been noted that research without theory often results in discrete data or information that does not add to the accumulated disciplinary knowledge base – thus, examining theory is integral to the research process (McEwen & Wills, 2014). At the outset of this thesis work, I completed a critical analysis of theory to contribute my understanding of the phenomena from a theoretical perspective and to ensure my proposed research was theory-informed.

Five theories within the nursing and developmental literature were analyzed and contributed to the overall theoretical understanding of NICU-to-Home transitions (see

Table 1 for an overview of each of the theories). First, from Meleis' Transitions Theory, I understood that transitions are periods characterized by uncertainty and disconnectedness, where there are losses of networks and social supports, and therefore individuals experiencing transitions are in a vulnerable state – often requiring intervention to facilitate healthy transition and enhance healthy outcomes following transitions (Meleis, 2010). Additionally, in examining and applying Transitions Theory's concepts to the NICU-to-home transition for adolescent mothers the importance of understanding the number and types of transitions experienced by this group of young women was highlighted. Specifically, an adolescent mother at the time of discharge from the NICU with her infant is simultaneously experiencing (a) the transition to motherhood; (b) parenting an infant with complex health needs and risk for developmental delay; (c) transitioning from the critical care environment to home and (d) all within the context of transitioning to adulthood. Therefore, examination and application of four additional theories, associated with each type of transition, served to deepen the understanding of the transition-home experience for this unique population of adolescent mothers. For example, Mercer's theory of Becoming a Mother elucidated the process of transitioning to the role of mother and achieving one's maternal identity (Mercer, 1985); the uncertainty experienced by parents when their infant is born ill and requires care in the NICU was explained by Mishel's Uncertainty in Illness theory (Mishel, 1988); Kenner's Transitions from NICU model provided insight into the care needs of parents as they transition home from NICU with the previously-ill infant (Kenner & Lott, 1990); and

Arnett's theory of Emerging Adulthood provided developmental or life-stage context (Arnett, 2000).

Using theory to explore the transition-home from NICU as experienced by adolescent mothers offered a unique perspective for understanding the issue and served to highlight the complexity of the problem that was not elucidated in the existing literature. However, simply combining the concepts from the multiple theories did not create a comprehensive understanding of the unique transition-home phenomenon experienced by adolescent mothers with infants discharged from NICU. Thus, knowledge-generating research to inform health care professionals of the distinct circumstances, experiences and needs of the adolescent mother when discharged home with their infant from the NICU was warranted. Specifically, this exploration of theory supported the argument for a proposed grounded theory study to develop a mid-range substantive theory to explain how adolescent mothers transition-home following discharge of their infant from the NICU. This theoretical exploration and subsequent understanding served as the basis for the first published manuscript in this sandwich thesis.

Data Collection Considerations

With qualitive methodology – specifically constructivist grounded theory (Charmaz, 2014) – informing the design decisions for this emerging study, in-depth interviews were an intuitive choice for data generation. The interview is one of the most common ways of producing knowledge in the health, human and social sciences (Brinkmann, 2017), with semi-structured or in-depth interviews dominating the methods used by qualitative researchers in the applied health fields. In-depth interviewing: (a) seeks deep information and understanding (e.g., a way to learn the meanings of participant's actions); (b) relies on open-ended questions; (c) goes beyond common-sense explanations or understandings of events, activities or places; and (d) generates deep understandings – allowing researchers to grasp and articulate multiple views, perspectives and meanings (Charmaz, 2014; Johnson & Rowlands, 2012). Researchers use in-depth interviews to study topics about which the participant has had substantial experience; during the interview the participant talks and the researcher encourages, listens and learns (Charmaz, 2014).

However, the quality and depth of data required can be difficult to operationalize among participants who feel stigmatized by health and social care systems and/or mistrust practitioners, including researchers (Bonevski et al., 2014; MacDonald et al., 2011). Additionally, obtaining high quality data can be challenging in the presence of certain cognitive factors; such as the immature cognitive functioning associated with the different developmental stages (Aruda & Burke, 2013; Leany, 2013). In an effort to mitigate the potential for data collection challenges among adolescent mothers – who are often a marginalized group in society and experience stigma from providers within the health and social care systems and society at large (SmithBattle, 2020) – arts-based visual methods were explored during the study design phase and incorporated into the data collection methods for the proposed study. This methodological work served as the basis for the second published manuscript in this sandwich thesis.

Knowledge-generating research

The Proposal

As highlighted above, the lack of understanding of transition home from NICU for adolescent mothers combined with the complexity of overlapping and intersecting transition experiences warranted knowledge-generating research. Research findings would inform practices and policies – beginning in the NICU and continuing beyond the acute care setting – to address the complex biopsychosocial care needs of this unique group of mother/infant dyads and ensure focused and holistic care based on methods that ensure the participants voices are sufficiently heard. Therefore, a qualitative, grounded theory study to develop a mid-range substantive theory to explain how adolescent mothers transition-home following discharge of their infant from the NICU was proposed. A constructivist grounded theory approach informed plans for sampling, data collection and data analysis (see Figure 1, original study structure).

This proposed study obtained ethical approval January 2, 2019 and recruitment began soon after. The proposed study included two types of participants, mothers and health care or social care providers. In the original proposal these participants were to be recruited sequentially with mothers being recruited first and then providers would be recruited based on recommendation from the mother participants. In October 2019, based on slower than anticipated recruitment of mother participants, the decision was made to recruit providers simultaneously with mother recruitment. This amendment was approved in December 2019 and recruitment of providers began immediately with good response. This change also saw an improvement in the recruitment of mothers as more providers became aware of the study through their own participation. In early 2020, recruitment and data generation for the study appeared to be revived, and then on March 11, 2020 the

World Health Organization (WHO) declared a global pandemic related to the global spread of the COVID-19 virus; this was quickly followed by a declared state of emergency in Ontario. Researchers, including graduate students, were first forced to pause research efforts for a period of approximately 3 weeks; then faced decisions regarding how to pivot their study procedures while navigating strict and frequently changing public health guidelines with little precedence or guidance on how to do so – all while balancing the fear and uncertainty of daily life in the early pandemic.

The Pivot

A pivot from in-person to virtual data collection allowed many studies to proceed after the initial pause in March 2020. I too considered a shift to virtual data collection, however four main factors contributed to my decision to instead pause recruitment.

1. First, I considered my main participant population, the adolescent mothers. As outlined in the introductory paragraphs of this dissertation, young mothers with infants in the NICU are less likely to be well supported both socially and economically; virtual data collection through an application such as Skype, or Facetime would require access to both the hardware and software required for these applications as well as Wi-Fi and/or a phone with data capabilities. Even a telephone interview assumes access to a landline, which is becoming more and more uncommon, or enough minutes to conduct and in-depth interview. Additionally, through experience recruiting this population, text-messaging was the most preferred method of contact among participants to arrange and confirm interviews and discuss study details; telephone communication was rare.

2. Ensuring young mother participants felt safe during the interview was also at the forefront of the decision whether to pivot to virtual data collection. In-person interviews were conducted in a location of the participants choosing; allowing them the ability to decide on a location that felt safe for them to conduct the interview. While some interviews were conducted in the young mothers' homes, others were planned for public spaces like Tim Hortons. Due to the pandemic public health restrictions, virtual interviews would be forced into the home of the participant or the place where they were sheltering – removing the option to conduct the interview in the location of their choice.
3. The proposed data collection methods for this study also impacted the decision to go virtual (or not). During the proposal phase of the study, a strong argument was made to support the incorporation of drawing activities into the data collection process to enhance the depth of the data collected and mitigate challenges collecting data among certain participation population – including adolescents and marginalized groups. Without a major re-working of the data collection techniques and/or proceeding with unclear precedence related to the rigor of such methods in a virtual setting, the drawing components would be likely be lost in virtual data collection.
4. Finally, I needed to consider my secondary participants for this study, health care and social care providers. Many of my provider participants were nurses employed in NICUs and Public Health Units (PHUs). The healthcare sector was significantly impacted by the COVID-19 pandemic. Public Health Nurses were re-

deployed in large numbers to support the COVID-19 response effort, leaving those not re-deployed burdened with high caseloads and decreased resources. Re-deployment also occurred in the acute care settings with many nurses covering shortages due to staff illness and increasing ICU demands. Further burdening these providers with requests to participate in research felt unprofessional and perhaps even unethical.

These main factors led to the decision to pause recruitment for the proposed grounded theory study in April 2020. At this time, nine provider interviews had been completed and it was decided to limit the scope of the dissertation to the providers' perspectives: with a subsequent (post-dissertation/post-pandemic) study addressing the mother's perspective. Narrowing the thesis study led to a re-organization of the proposed grounded theory study – that included multiple design elements – to a multimethod qualitative approach consisting of two interpretive description studies that will eventually inform a final analysis aimed at developing a mid-range theory (see Figure 2, revised study structure). As pressure on health care teams eased, first in the NICUs and then for PHUs, an additional eight providers were recruited and interviewed for the revised study to explore and understand the NICU-to-home transition for adolescent mothers from the care provider perspective (see Figure 3, providers perspectives study structure). Findings from this study are presented in chapters four and five.

Interpretive Description

The revised study adopted interpretive description as a guiding methodological framework (Thorne, 2016). Designed for applied and practice disciplines (e.g., nursing) the methods employed in interpretive description studies are tailored to the knowledge needs of the discipline. The decision to use interpretive description was also based on its congruence with a number of the methodological decisions already proposed before the narrowing in focus related to the pandemic, for example, the use of in-depth interviews, concurrent data collection and analysis and constant comparison analytic techniques. Thorne (2016) also advocates for the use of the "thoughtful clinician" as a data source in qualitative health researcher design; citing the role of the expert practitioner who having seen many cases over time can speak to the variations and diversities that may be beyond the reach of most qualitative studies (p. 85). Findings of interpretive description studies are also relevant to the discipline and ready for application in the nursing context versus being considered too abstract or theoretical to be meaningful for practice.

Scaffolding

Scaffolding is a term adopted by Thorne (2016) and refers to the background knowledge and disciplinary orientation that one brings to a study. Interpretive description, as with most approaches within the qualitative research paradigm, both recognizes and capitalizes on the researcher's influence on the research process. It is imperative, therefore, for a researcher to be accountable for their theoretical allegiances upon entering the study, locate themselves within their disciplinary perspective and describe personal thoughts, perspectives or experiences that may have influenced the viewing-angle of the study. The following reflective statement considers these influences.

Researcher Reflective Statement

I am a neonatal intensive care nurse with over 13 years of clinical experience working in an NICU at a world-class pediatric hospital. This dissertation is undoubtably influenced by my experiences working in this environment. My research is also influenced by an awakening or re-orientation that I experienced when I returned to university to complete my graduate studies in 2011. Particularly, while working closely with my graduate supervisor, who operated from a strong health equity orientation, I was reminded of the importance of social factors and their relationship to health and well-being. From this point forward, my approach to care in the NICU changed. I still possessed the highly refined and specific skill set required to provide top quality care to one of the most fragile patient populations – but now I saw the influences of social determinants of health in the infants and families I cared for and the many systemic factors that resulted in inequity. Specifically, I could not shake the feeling that the care provided to young mothers, by myself and my NICU colleagues, was somewhat "less than" when compared to adult-aged mothers – especially when it came to preparing for discharge. This research endeavour was born out of this gut feeling that there was something going on here worth exploring further.

My research is also impacted by my position within the broader nursing discipline. Thorne et al. (2016) have written extensively on allowing nursing epistemology to guide qualitative study design decisions. One example of how nursing epistemology shaped my research work was the inclusion of providers as participants to explore their perspectives on transition home for NICU for adolescent mothers. Empirical knowledge is only considered part of the nursing knowledge base, which also includes personal, aesthetic, and ethical patterns of knowledge (Carper, 1978). The provider participants in my study (outlined in chapter 4) had extensive personal knowledge of supporting young women, including those experiencing the NICU-to-home transitions. It was my role as nurse-researcher to gather this knowledge in a meaningful way and commit to using it in support of the health of people or populations, as is nursing's mandate for knowledge use (Thorne et al., 2016).

Summary of Thesis Chapters

This thesis consists of two published articles and two prepared manuscripts linked together by the overall goals of this dissertation work:

1. To understand the transition experiences of adolescent mothers with infants in the NICU from a theoretical perspective
2. To understand how to best collect rich qualitative data among study participants experiencing marginalization or stigma
3. To conduct research to further understand the NICU-to-home transition for adolescent mothers and how to begin to address transition-related issues

Chapter 2 - The Complexity of the NICU-to-Home Experience for Adolescent Mothers Meleis' Transitions Theory Applied

Chapter two is a manuscript published in *Advances in Nursing Science*. This article briefly reviews the middle range nursing theory developed by Meleis' and colleagues, Transitions Theory (Meleis, 2010). The theory is then applied to increase the theoretical understanding of the transition experiences of adolescent mothers who have had infants in the NICU. Meleis' Transitions Theory offers a unique theoretical perspective for understanding this transition experience and serves to highlight the complexity of the NICU-to-home transition for this population of young mothers that is not currently elucidated in the literature. The full citation for this article is:

> Orr, E., Ballantyne, M., Gonzalez, A., & Jack, S. (2020). The complexity of the NICU-to-home experience for adolescent mothers: Meleis' Transitions Theory applied. *Advances in Nursing Science*, 43(4), 349-359. DOI: 10.1097/ANS.0000000000000299

Chapter 3 - Visual Elicitation - Methods for Enhancing the Quality and Depth of Interview Data in Applied Qualitative Health Research

Chapter three is a manuscript published in *Advances in Nursing Science*. This methods article explores the issue of generating rich data from qualitative interviews when difficulties such as establishing rapport, power imbalances, and participant factors threaten the interview process and quality of data. The article, (a) discusses the value of incorporating visual elicitation tools or tasks within semi-structured or in-depth qualitative interviews to enhance the depth of data generated and (b) provides a specific example of how this is planned and executed within the context of an applied qualitative health research study. The full citation for this article is:

> Orr, E., Ballantyne, M., Gonzalez, A., & Jack, S.M. (2020). Methods for Enhancing the Quality and Depth of Interview Data in Applied Qualitative Health Research. *Advances in Nursing Science, 43(3), 202-213*. doi: 10.1097/ANS.0000000000000321

Chapter 4 – Understanding the context of care for adolescent mothers in the Neonatal Intensive Care Unit: An interpretive description of care providers' perspectives

Chapter four is a manuscript prepared for submission to an academic nursing journal focused on qualitative research methods and evidence. From the providers' perspectives, this article seeks to understand the NICU context of care and, from providers' perspectives, how this context influences adolescent mothers' NICU experiences. We used interpretive description methodology and asked expert providers caring for adolescent mothers in the NICU how the context of care influences mothers' experiences during an NICU stay. We learned from providers that the NICU was perceived as a traumatic experience for many mothers; but that experiences of judgment from care providers or feelings of being treated differently compounded this experience particularly for adolescent mothers. Ways to mitigate the impact of the NICU experience are discussed, including the addition of mental health practitioners and public health nurses within the NICU care team and the adoption of trauma- and violence-informed care principles within the NICU care framework.

Chapter 5 – Transition home from the Neonatal Intensive Care Unit for adolescent mothers and their infants: An interpretive description of care providers' perspectives

Chapter five is a manuscript prepared for submission to an academic journal in the applied health field focused on qualitative methods and evidence. This article presents a qualitative study asking the question, what can be learned from care providers' perspectives about the experience of transitions from NICU to home for adolescent mothers? Providers interviewed for this study offered critical insights into the NICU-to-home transition experience for adolescent mothers and we learned that understanding the impact of the NICU on young mothers, establishing therapeutic relationships, and facilitating supportive partnerships, supported care providers in their overarching goal of successful NICU-to-home transition for adolescent mothers or mobilizing forward.

Chapter 6 – Key Contributions, Implications, and Recommendations

In the final chapter, I discuss the key contributions and implications of this dissertation work including recommendations for policy, education and practice. This chapter will also outline the knowledge translation approaches for the dissemination of these findings. Additionally, ongoing and future research stemming from this dissertation work will be discussed. Finally, strengths and limitations of this work are considered.

Table 1: Theories Underpinning NICU-to-Home Transitions for Adolescent Mothers

Theory	**Purpose**	**Definitions & Concepts**	**Theory Development**
Transitions Theory	To describe, explain and predict human experiences in various types of transitions (Im, 2014)	*Transition* – "a passage or movement from one state, condition, or place to another"(Schumacher & Meleis, 1994, p. 119). *Defining characteristics* (Chick & Meleis, 1986): a) process, in that transition involves a sense of movement or flow; b) disconnectedness, or a disruption in the associations on which one's feelings of security depend; c) perception, transition and its attributed significances vary between persons, communities and societies; d) awareness, persons must have some awareness that change is occurring *Types of transitions* (Schumacher & Meleis, 1994): 1. developmental transitions (e.g., becoming a parent); 2. situational transitions (e.g., discharge from hospital); 3. health-illness transitions (e.g., end of life); and 4. organizational transitions (e.g. introduction of new care technology). *Transitions conditions* (Im, 2014): factors that may facilitate or constrain the process of healthy transition (e.g., socioeconomic status, cultural beliefs surrounding transitions and knowledge about transition experiences)	3 decades of work by Meleis and colleagues Extensive review of transitions literature as well as empirical testing of the developing framework (Im, 2018)
Becoming a Mother	To describe the process of having an internalized view of oneself as a mother or maternal	*Maternal Identity* – "the movement to the personal state in which the mother experiences a sense of harmony, confidence, and competence in how she performs the role" (Mercer, 1981, p. 74). *Stages:* 1. commitment and preparation 2. acquaintance, practice and physical restoration 3. approaching normalization; and	Extensive research beginning in the 1960's by Rubin and continued by Mercer Influenced by role, developmental and systems theories (Meighan, 2018)

	identity (Mercer, 1985)	4. integration of maternal identity (Mercer, 2004, p. 231). *Influences:* - Microsystem influences (e.g., family functioning, mother-father relationship, social support, stressors, economic status and family values - Mesosystem influences (e.g., work and places of worship) - Macrosystem (e.g., social, political, cultural) - Maternal traits (e.g., empathy, sensitivity to infant cues, self-esteem) - Infant traits (e.g., temperament, ability to send cues, appearance, responsiveness)	
Uncertainty in Illness	To explain how patients cognitively process illness-related stimuli and construct meaning in these events (Mishel, 1988)	*Uncertainty* – "the inability to determine the meaning of illness-related events" (Mishel, 1988, p. 255) *Uncertainty variables* (Mishel, 1988): a) Stimuli frame – the form, composition and structure of the stimuli that a person perceives: symptom pattern, event familiarity, and event congruence b) Cognitive capacity – the information processing ability of a person. Can reduce the ability to perceive the concepts in the stimuli frame, leading to situations being perceived as uncertain. c) Structure providers – the resources available to the person to assist in interpretation of the stimuli frame (e.g., education, social support and credible authority) (Bailey & Stewart, 2018). *Appraisal of uncertainty* (Mishel, 1988): - Uncertainty can either be appraised as danger or opportunity requiring coping to either reduce or maintain the uncertainty - Conditions of enduring uncertainty may lead to probabilistic perspective on life, where the nature of uncertainty is accepted as the natural rhythm of life	Draws on information processing models, personality research, and tenants from chaos theory Extensive empirical testing supporting theoretical concepts (Bailey & Stewart, 2018)
Kenner Transition Model	To describe parental responses to caring for infants in the home following their infant's discharge from	Five main parental transitional challenges were identified in the immediate post discharge period: 1. Informational needs – providing routine care for their infant, recognizing normal infant characteristics and understanding infant development) (Boykova et al., 2014). 2. Anticipatory grief – continued worry post-discharge related to potential sickness or death of their recently discharged infant (Kenner & Lott, 1990).	A series of studies by Kenner and colleagues classified parental post–hospital challenges and concerns

	the NICU (Kenner & Lott, 1990)	3. Parent-child role development –parental lack of confidence in their ability to care for their child; feelings that the health care team knew their child better than they did (Kenner & Lott, 1990). 4. Stress and coping – stress related to alterations in the parental role; coping with this stress was dependent on resources (informational, material and social) (Boykova et al., 2014). 5. Social interaction – necessary for mastery of parenting skills; parents felt they needed support with feeding, normal infant care, decision making and change of lifestyle prior to discharge from the NICU (Kenner & Lott, 1990).	
Emerging Adulthood	To describe an additional developmental stage in the life course between adolescence and adulthood (Arnett, 2000)	*Identity explorations* – when young people explore the variety of options for their lives (e.g., love, work, worldviews); become more independent of their parents but have not yet entered the stable, enduring commitments typical of adult life (Arnett, 2000). *Instability* – Identity explorations contribute to not only a rich life-stage but also one that is exceptionally unstable (e.g., frequency of changing residence) (Arnett, 2014) *Self-focus* - Few ties entail daily obligation or commitment to others thus allowing for skill development and practiced self-sufficiency (Arnett, 2014). *Feeling in-between* – In between the restrictions of adolescence and the responsibilities of adulthood lie the explorations and instability of emerging adulthood; Emerging Adulthood accounts for the process of developing the qualities associated with adulthood (Arnett, 2014) *Possibilities/optimism* –the age of possibilities and a time when little about a person's direction in life is decided for certain; Emerging Adulthood offers the greatest range of choice for how to live than any previous life-stage and therefore the fulfillment of their hopes seems possible (Arnett, 2014)	Theoretical and empirical evidence to support emerging adulthood as a unique developmental stage Based on demographic shifts in later entry to stable adult roles

Figure 1: Original Study Structure

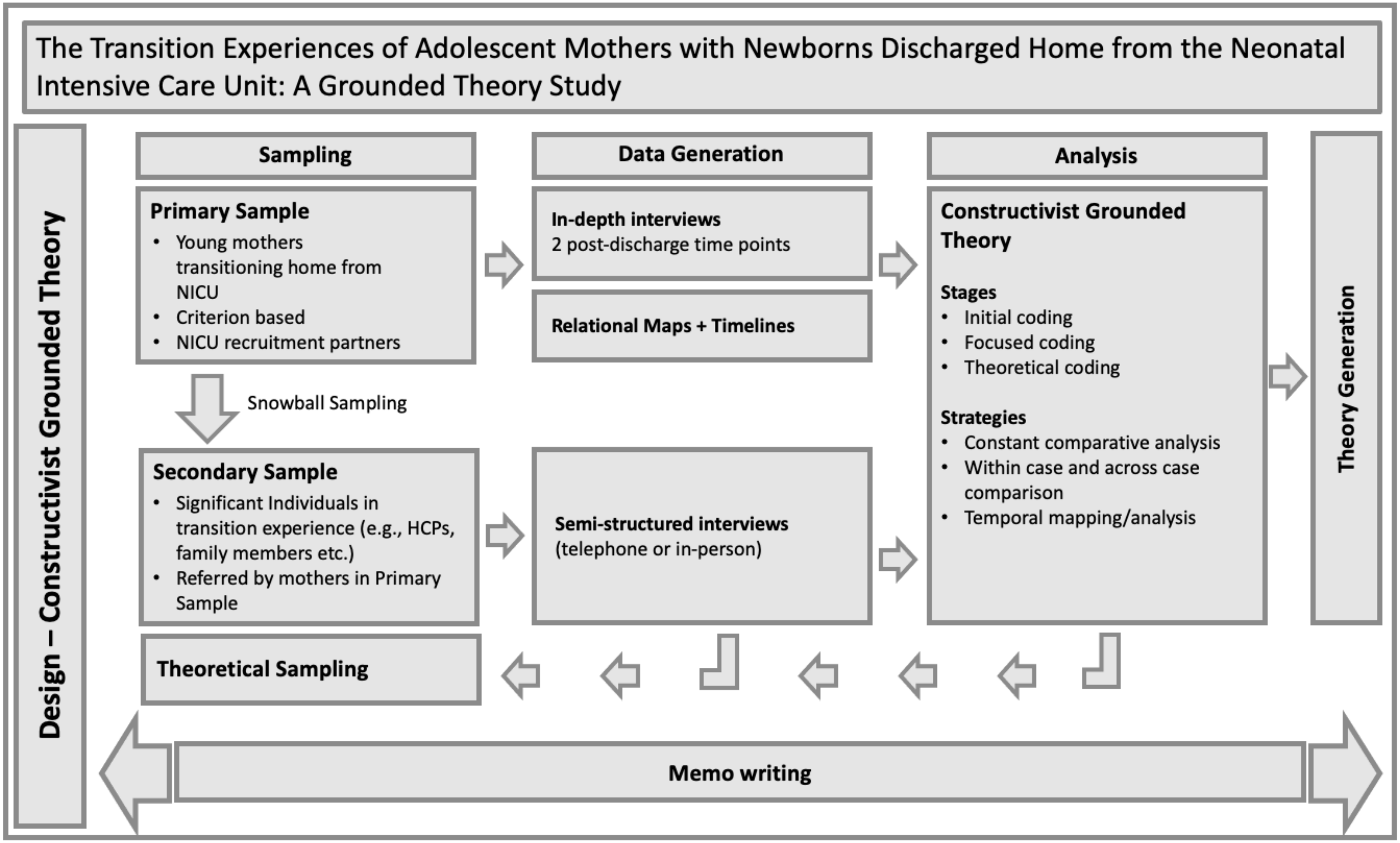


Figure 2: Revised Study Structure

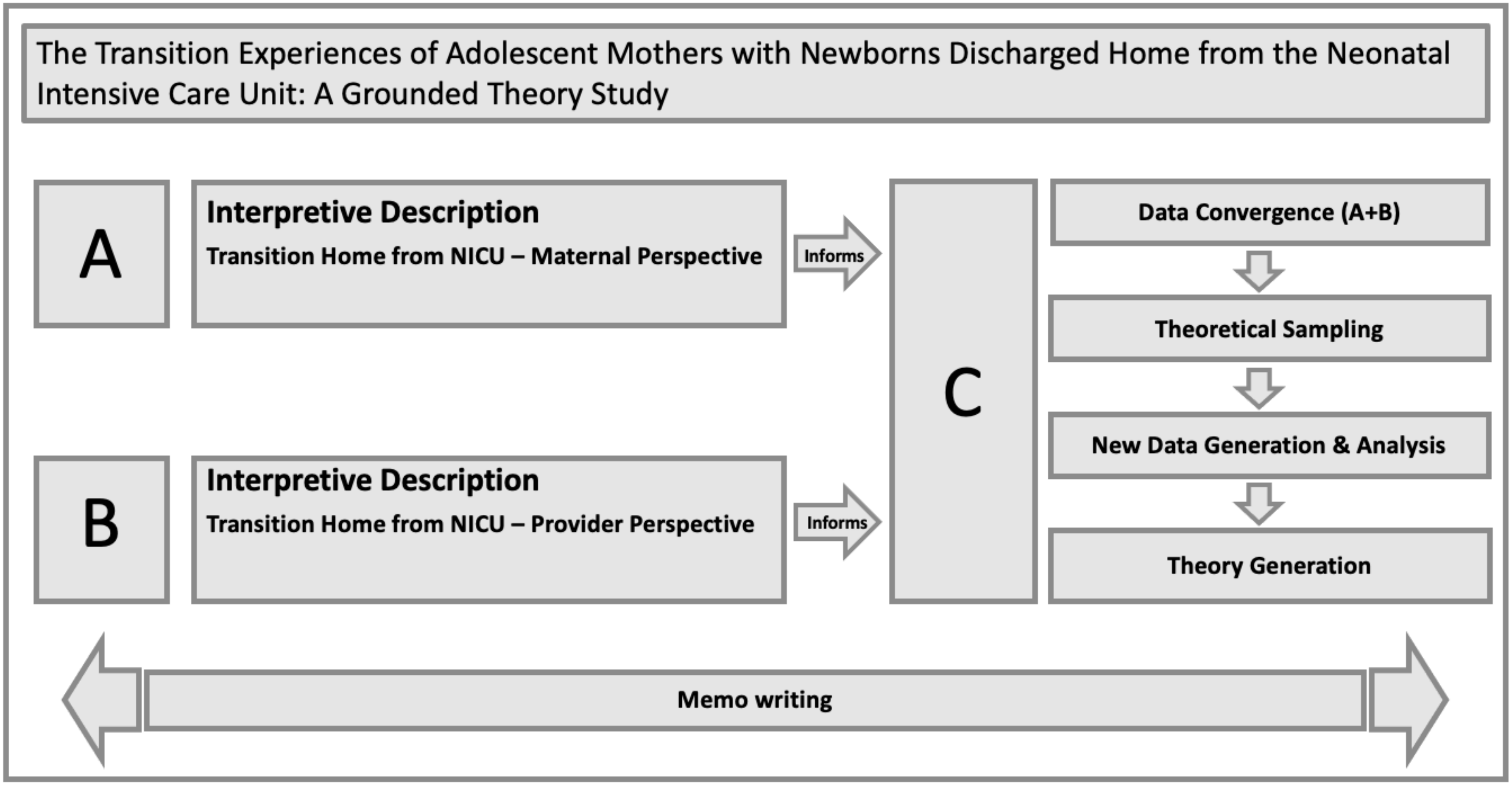
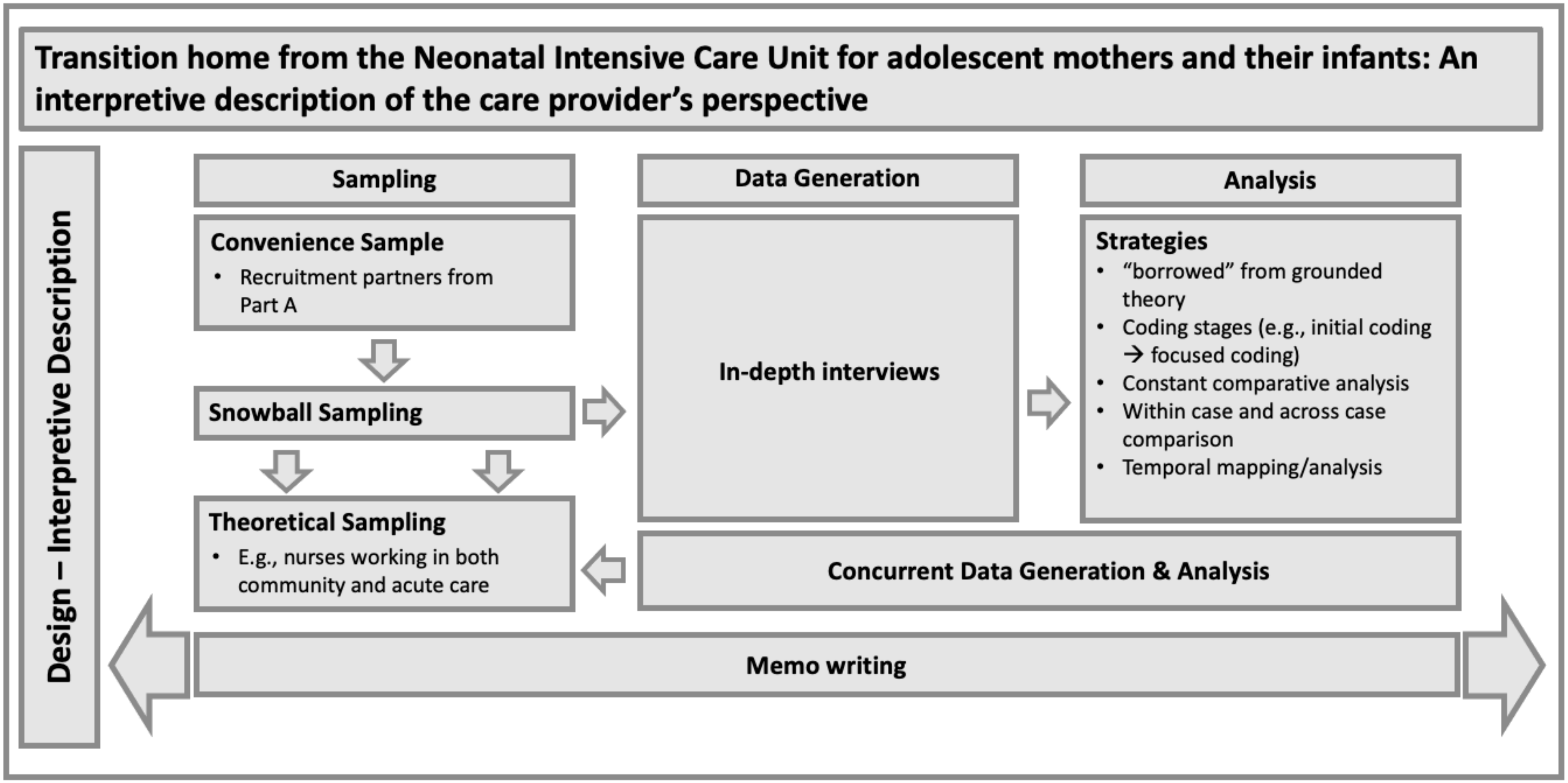


Figure 3: Provider's Perspective Study Structure



CHAPTER TWO

TITLE: The complexity of the NICU-to-home experience for adolescent mothers: Meleis' Transitions Theory applied

AUTHORS: Orr, E., Ballantyne, M., Gonzalez, A., & Jack, S. M.

JOURNAL: Advances in Nursing Science

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NOTE: The manuscript included in this thesis is the final peer-revied manuscript (FPRM) submitted for publication by Lippincott. It is a non-final version of the article published in final form in Advances in Nursing Science (citation above).

Abstract

Quality care for individuals and families during periods of transition is one of the major issues facing health care systems and providers today. The transition-home from the Neonatal Intensive Care Unit (NICU) as experienced by adolescent mothers is poorly understood – placing young mothers and their infants at risk of poor outcomes following NICU discharge. Meleis' Transitions Theory offers a unique theoretical perspective for understanding this transition experience and also serves to highlight the complexity of the NICU-to-home transition for this population of young mothers that is not currently elucidated in the literature.

Keywords: transition-home; adolescent mothers; neonatal intensive care; health transition; transitions theory; women's health; nursing and nursing theory

Statement of Significance

What is known, or assumed to be true, about this topic:

- Quality transitions from inpatient settings to the community are one of the major problems facing health systems today
- Transition is a concept central to the nursing profession with nurses facilitating and providing support to individuals, families and communities experiencing the events, changes, and outcomes associated with transitions.
- Meleis' Transitions Theory is a middle-range nursing theory that integrates the phenomenon of transition into the nursing profession's theoretical knowledge base

What this article adds:

- Transitions Theory is used as a framework for understanding the types, multiplicity and complexity of transitions experienced by adolescent mothers with infants discharged home following admission to the NICU shortly after birth.
- Extending the application of Transitions Theory beyond the situational transition of hospital-to-home allows for a robust and holistic exploration of the transition experience.
- Keeping Transitions Theory at the forefront of the hospital-to-home discourse is important for building disciplinary knowledge and advancing nursing policy and practice in transitional care.

Quality transitions from inpatient settings to the community are one of the major problems facing health systems today. High hospital readmission rates, patient and family dissatisfaction with discharge processes and adverse events post-discharge have prompted leading academic societies of nursing and medicine to recognize the importance of successful care transitions and the need for novel patient- and family-centered approaches to ensure safe hospital-to-home transitions.[1-3] However, this predominantly situational focus on the hospital-to-home transition may contribute to an incomplete understanding of the transition process, thus leading to knowledge and practice that lacks a robust or holistic view of the experience. In this paper we apply Meleis' Transitions Theory,[4] to the example of adolescent mothers with infants admitted to and discharged home from the Neonatal Intensive Care Unit (NICU). By examining Meleis' theory and applying it to this population at risk for poor transitions post-hospital discharge, we highlight the condition of multiple, intersecting and overlapping transition experiences and emphasize the importance of a multi-dimensional view of transition for informing nursing policy and practice related to care transitions.

Background

Meleis' Transitions Theory

The concept of transition is a relatively universal phenomenon, and while frequently used to describe processes of change, the word transition is not simply synonymous with change. Transition most often represents the psychological processes involved in adapting to change associated with developmental stages, alterations in health and changes in social circumstance.[1] Transition is a phenomenon often triggered by critical events and changes in individuals or environments. In health care settings, nurses commonly interact with and support individuals, families and communities experiencing the critical events associated with transitions, and as such, this concept is central to the nursing discipline. Nurses, therefore, need to be aware of the impact of transition experiences on health and well-being. [2] A focus on transition in the nursing profession, "acknowledges universal aspects of nursing, enhances nurses' potential in supporting emerging identities and life patterns, supports nurses' concerns about changing systems and societies, and challenges nurses to develop therapeutics supportive of positive experiences and healthy outcomes".[3]

Accordingly, Meleis' middle-range nursing theory, or Transitions Theory, has been utilized, and widely accepted in nursing research and practice. [4] Transitions theory refines the definition of transition and describes the concept's defining characteristics (see Table 1 for Transitions Theory concepts and contributions). The four types of transitions identified by Schumacher and Meleis, [5] developmental transitions, situational transitions, health-illness transitions, and organizational transitions, highlight the diversity of transition-related circumstances and as these types of transitions are not mutually exclusive, the theory emphasizes the added complexity of multiple transitions occurring simultaneously. [6] The transition experiences of adolescent mothers with infants discharged home from the NICU serve as an example of this complexity.

Adolescent Mothers in the NICU

The postpartum period is a critical time for a woman and her infant. In addition to the physiologic demands associated with the weeks following childbirth, this time-period is characterized by early attachment, infant growth and development, breastfeeding and well-baby care. This is a time where health services are designed to engage new mothers in early-intervention and health promotion efforts to support the optimal health, growth and development of the infant and support the mother in developing sensitive parenting skills and adjusting to the new maternal role. Commonly, these supports may be provided through home visitation programs, well-baby primary care services, parenting groups or specialized clinic services with access to lactation consultants, mental health screening and social service supports. Admission of an infant to the NICU interrupts and complicates this typical postpartum experience for a mother and her infant.

Infants born to adolescent mothers are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a NICU shortly after birth. [7] For adolescent mothers, admission of their infant to the NICU can exacerbate already complex circumstances that include multiple social, psychological and economic difficulties. [7-10] Not only do adolescent mothers often require high need for supportive services to support optimal postpartum maternal and infant outcomes, accessing these services can be difficult due to perceived stigma, lack of trust and programming that does not account for their contextually and developmentally unique needs. [11, 12] Additionally, infants born to adolescent mothers also have an increased likelihood of rehospitalization and emergency department (ED) visits following discharge from NICU, [13] and mothers who parent alone and/or experience more social and economic challenges are more likely to discontinue attendance at follow-up clinics focused on infant neurodevelopment, where participation post-NICU discharge is vital to optimize infant outcomes. [14]

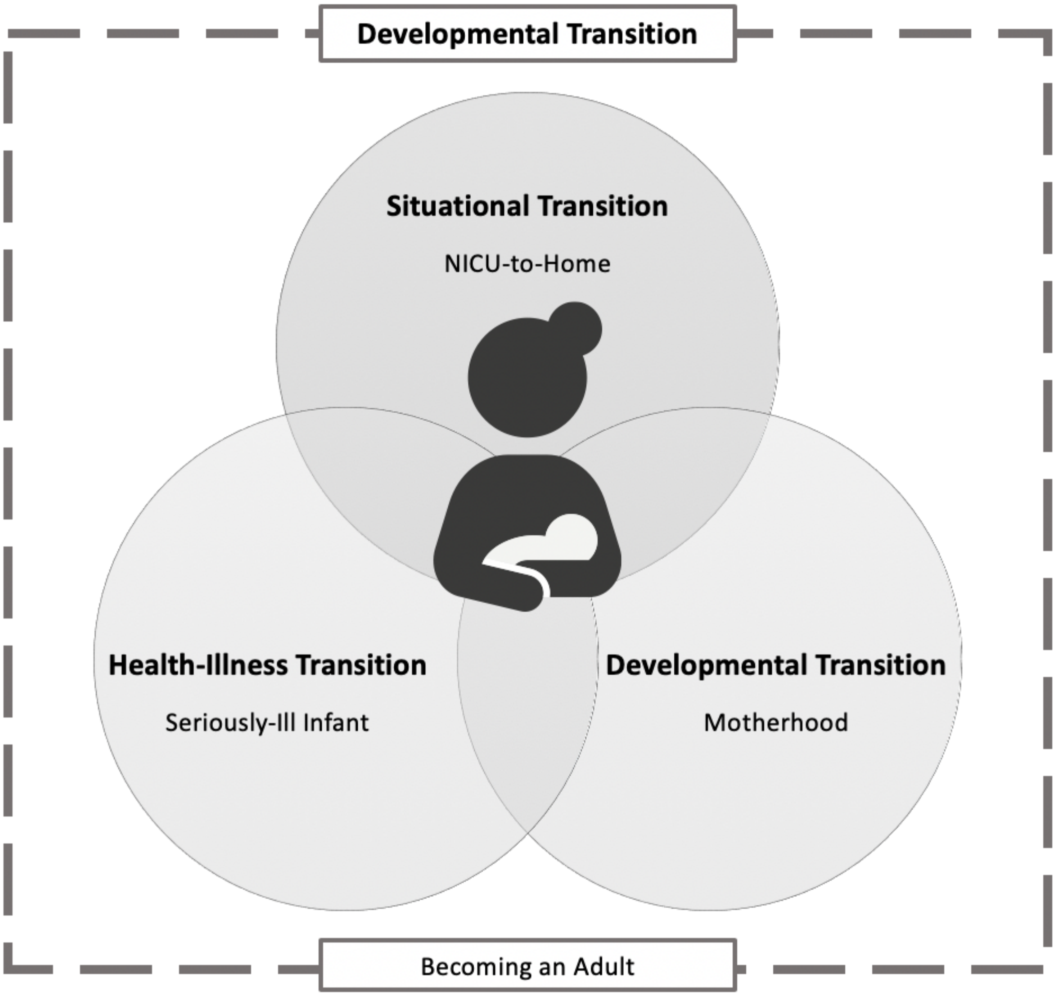
The experience of transition to home following discharge from the NICU has been a topic explored within the health literature that provides an understanding of the experience from both qualitative and quantitative perspectives. [15-22] However, many of the participants in these studies are significantly older than the adolescent age-group and therefore application of these adult-focused findings to the adolescent population would fail to consider the unique developmental stage of the adolescent mother and the relative complexity of her pregnancy and parenting situation.

The use of theory among these studies (or lack thereof) is also a limitation of this body of literature. Where theory, and in this case Meleis' Transitions Theory, can be used to conceptualize the transition experience, establish context and lead to a more comprehensive understanding of the phenomenon being studied, there is little to no theoretical guidance cited within the transition from NICU literature. Adolescent mothers could represent as high as 15% of the NICU parent population; [23] however, the unique experience of the adolescent parent within the NICU – and more specifically their transition-home from NICU, is poorly understood on a number of levels. [24] The application of Meleis' Transitions Theory highlights the importance of understanding this experience as more than a situational-transition from hospital-to-home and instead as a complex phenomenon of intersecting and overlapping transition experiences.

Transitions Theory Applied: Beyond the Situational

Transitions Theory represents a useful framework for understanding the types, multiplicity and complexity of transitions experienced by adolescent mothers with infants discharged home following admission to the NICU shortly after birth. Specifically, these mothers, at the time of discharge from the NICU are experiencing at least four transitions: (i) a health-illness transition – NICU admission; caring for an infant with increased risk of developmental-delay/complex health needs and the associated uncertainties; (ii) a developmental transition – becoming a mother; (iii) a situational transition – discharge home from NICU and notably, these three transitions occur within the context of a fourth transition, (iv) the developmental transition of the adolescent mother to adulthood (see Figure 1). Exploring each of these transitions more deeply serves to highlight the complexity that needs to be considered when a young woman is discharged home from the NICU with her infant.

Figure 1 –Types of transitions experienced by adolescent mothers with infants discharged from NICU



Health-Illness Transition – Parent of a seriously ill infant

Admission to the NICU is a source of stress, anxiety, depression, and grief with emotional and psychological outcomes often lasting well beyond the infant's discharge. [24-27] When individuals and their families experience an acute health-event, receive an unexpected diagnosis or learn they are at risk for a particular condition they are experiencing health-illness transitions. From the moment a mother learns her infant is seriously ill and will require specialized care in a NICU she commences a health-illness transition that is often characterized by uncertainty.[17] Uncertainty is cited as the single greatest source of stress for those affected by serious illness, with uncertainty pervading parents' experiences of a child's serious illness. [28] Parental experiences of their infants requiring specialized care in the NICU are dominated by prolonged periods of uncertainty from NICU admission through discharge-home and beyond. [18, 19, 29, 30] Derived from knowledge in nursing and other disciplines, Michel's [31] middle-range nursing theory of Uncertainty in Illness offers an explanation for the process of determining meaning in the illness experience.

Uncertainty is a major component of an illness experience and is generally perceived as a significant stressor. [32] Uncertainty develops when the patient (or parent experiencing illness of a child) does not form a cognitive schema, or subjective interpretation, for an illness event. A number or variables can impact whether a situation is perceived as uncertain including the stimuli frame (e.g., symptom pattern, event familiarity and event congruency), cognitive capacity and structure providers (e.g., credible authority, social support and education). [31, 33] Uncertainty in Illness theory and the uncertainty variables help explain why this concept dominates parental experiences of NICU admission and beyond. The admission of an infant to NICU shortly after birth is rarely expected thus leading to a situation perceived as both unfamiliar and incongruent with prior expectations (delivery of a healthy newborn). Additionally, for the adolescent mother, immature brain development, mistrust of health systems, lack of social support and lower educational attainment are likely to contribute to more profound and pervasive feelings of uncertainty which can lead to intrusive thoughts, avoidance of social interaction and severe emotional distress. [34]

While Uncertainty in Illness theory further explicates the health-illness transition experienced in parenting a seriously-ill infant or an infant at risk for developmental delay, it still only accounts for one of the transitions the adolescent mother must face when her infant is admitted to the NICU.

Developmental Transition – Transition to Motherhood

Developmental transitions are complex and dynamic phenomena involving predictable, biologically determined stages of growth as well as non-normative, unpredictable events likely to influence health and well-being. [2] Many developmental transitions such as experiencing menopause or becoming a mother, align with health experiences and therefore intersect with the roles and values of the nursing profession. Nursing theorist Ramona Mercer defines and describes the developmental transition to motherhood in her middle-range nursing theory, Becoming a Mother. [35] According to the theory, the transition to motherhood is characterized by a period of reorganization in a woman's life that involves the addition of the mothering role to an established set of roles according to the woman's particular life stage. During this process the mother first learns the expectations of the maternal role and relates to the fetus *in utero*, then begins taking on the role of mother guided by others in the mother's social system, she then makes the new role fit within her existing lifestyle developing unique ways of dealing with the role and eventually integrates maternal identity into her persona. [36]

Becoming a Mother as a theoretical framework for explaining the process of transition to motherhood has been widely accepted by the nursing profession. The theory has been adopted into areas of nursing practice, education and research that encounter women during pregnancy and in the mothering role. The theory has also been advanced by exploring and expanding the theoretical concept for a number of unique circumstances including adolescent motherhood and motherhood in the context of the NICU. [37, 38] For example, the transition to motherhood can be a significantly different experience for adolescent mothers compared to adult mothers with a number of factors including relationships, finances, housing and availability of informal support impacting whether this transition is perceived as positive or negative. [37]

Situational Transition – NICU-to-Home

The NICU environment and the uncertainty associated with NICU admission can have a negative impact on the transition to motherhood, leaving mothers with infants in the NICU feeling disconnected from their infant and "hovering around the edge of mothering". [38] The accounts of the profound experiences of motherhood in the NICU described by Shin and White-Taut[38] underscores the importance of understanding intersecting developmental transitions and health-illness transitions. These transition experiences become woven in such a way that a new experience is created and is unique in that does not exist when one or the other is experienced alone. The complexity of this experience is now compounded when the infant is discharged home form the NICU.

Situational transitions, such as the discharge home from the hospital, have been widely explored in the health literature, with various aspects of the discharge experience or discharge for specific patient populations well documented. Much of the literature related to transition home from the NICU has focused on the description and evaluation of NICU discharge interventions; [22, 39] discharge readiness indicators for infants and parents; [40] and descriptions of the parent experience. [17-19, 25, 41] Kenner with colleagues, through a series of studies conducted with parents of infants following NICU discharge, developed the Transition Model from NICU to home. [42] Based on a qualitative descriptive study asking parents what they were concerned about regarding discharge of their infant from the NICU, five thematic categories of responses emerged: informational needs, anticipatory grief, parent-child development, stress and coping, and social support; these themes represent the five concepts that constitute the proposed theoretical model or framework. [30] The Kenner Transition model is a useful framework to address the information needs of parents prior to discharge from the NICU and has also led to the development of a measurement tool to assess transition challenges among NICU parents. The issue that remains is that the literature on the situational transition from NICU-to-home is often focused on the discharge event rather than the process experienced as one moves from hospital-to-home. This focus on one or two time points in the entire transition (e.g., preparing for and/or discharge from hospital) make it difficult to fully understand what the experience entails and for providers, it is then difficult to target interventions aimed at improving points along this process. Additionally, as outlined earlier, the experience of the adolescent parent in the context of the NICU is poorly understood and it is this developmental transition to adulthood that encompasses all the other transitions happening at this time.

Developmental Transition – Becoming an Adult

The transition experiences outlined above, the transition to motherhood, the health-illness transition of having an infant admitted to the NICU and the situational transition upon the infant's discharge, are, theoretically, experienced by all mothers in the situation where their infant is ill at or shortly after birth. However, the developmental transition to adulthood is a process that overarches these other three transition experiences and is perhaps the most important to understanding the complexity of the experiences of young mothers upon discharge of their infant from the NICU.

Adolescence is marked by significant physical, emotional, intellectual and social changes including the physical transformations of puberty, intense interest in peer activities, novelty seeking, increased risk taking and decreasing dependence on one's parents. [43, 44] While the presence of secondary sex characteristics and engaging in sexual activity gives the appearance of being more mature, the adolescent brain is still developing. The prefrontal cortex is the fastest and largest region of brain development in adolescence, it is responsible for advanced reasoning, including the ability to plan, understand cause and effect, think through scenarios and manage impulses. [43, 45] Knowledge that this area is still developing throughout adolescence serves to highlight a biological component important in the understanding of pregnancy in adolescence, for example, this immature cognitive functioning can lead to distortions in judgement leading the adolescent to believe that pregnancy could not happen to them, or when their pregnancy is confirmed, adolescents may find it difficult to employ abstract decision making or planning for the future. [43, 45] While this is simply one example of how the unique developmental issues that characterize adolescence have an impact on health and related behaviors, it emphasizes the demand for a specialized approach when the individuals in this life stage intersect with the health and social care systems.

The dominant developmental theory proposed by Erikson [46] advances that adolescence beings with puberty and lasts until the late teenage years; adolescence is then followed by young adulthood lasting from the late teenage years until age forty. However, the sociologist Arnett [47] argues that this paradigm no longer fits the normative pattern in industrialized nations and proposes that the transition to adulthood is now long enough to represent an additional period in the life course: Emerging Adulthood. In the theory, Arnett argues that demographic changes in industrialized nations over the past fifty years have altered the nature of development for young people in their late teens and early twenties. The theory's main argument is that Emerging Adulthood is neither adolescence nor young adulthood (the dominant stages proposed by Erikson) but is theoretically and empirically distinct from them both. [47] Emerging Adulthood is defined by "longer and more widespread education, later entry to marriage and parenthood, and a prolonged and erratic transition to stable work". [48] Five distinguishing features of Emerging Adulthood are proposed: identity explorations, instability, self-focus, feeling in-between and possibilities/optimism. [48]

Arnett's theory of Emerging Adulthood proposes the addition of a life-stage to developmental theory that has remained essentially unchanged for over half a century. He offers compelling demographic and empirical evidence for his propositions and clearly explicates the new paradigm. The new developmental stage has been adopted within the nursing and health literature as it is this group that experiences the transition from pediatric to adult care services (typically at age 18 years), a current focus in the fields of pediatrics and transitional care. [49] While the theory describes notable features of an emerging adult on a typical trajectory it is unclear what happens when someone advances their trajectory prematurely – like in the case of a pregnant or parenting young woman. The intersection of the developmental transitions of motherhood and emerging adulthood has not been explicated, leaving many questions about what it means to experience this new life stage as a pregnant and parenting young woman. Regardless of the label given this developmental stage, it is distinct from adulthood, and individuals experiencing this developmental transition should be given specific consideration when this transition experience intersects with the others described above.

The Importance of Intersecting and Overlapping Transitions

Using Meleis' Transitions Theory to explore the transition-home from NICU as experienced by adolescent mothers offers a unique perspective for understanding the issue and serves to highlight the complexity of the transition experience that is not currently elucidated in the existing literature. From Transitions Theory we understand that transitions are periods characterized by uncertainty and disconnectedness, where there are losses of networks and social supports, and therefore individuals experiencing transitions are in a vulnerable state and often require intervention to facilitate healthy transition and enhance healthy outcomes following transitions. [2] What remains unclear though is the possible cascading or compounding effect of these multiple transitions, or the potential health risks or consequences of developmental transitions intersecting with health-illness and situational transitions. Simply combining the concepts from multiple related empirical studies or theories does not create a comprehensive understanding of the unique transition-home phenomenon experienced by adolescent mothers with infants discharged from NICU.

Examining and applying Transitions Theory's concepts emphasizes the importance of understanding the number and types of transitions that may intersect or overlap with the situational transition of hospital to home. In this paper the adolescent mother serves as an example, as she is simultaneously experiencing the transition to motherhood; parenting an infant with complex health needs and risk for developmental delay; transitioning from the critical care environment to home – all within the context of transitioning to adulthood. However, to facilitate healthy transitions in any population this consideration of multiplicity and complexity in the transition experience is important. Exploring each type of transition allows for thinking that extends beyond the concept as simply the situational transition or discharge event, and for nurses, it is this kind of theoretical approach, focused on a robust and holistic definition of transition, that is important for building disciplinary knowledge, advancing nursing practice and keeping Transitions Theory at the forefront of the hospital-to-home discourse.

Moving Forward with a Theory-informed Understanding of Transitions

To extend the disciplinary knowledge base related to transitions and advance transitional care practices, knowledge generating research – informing health care professionals of the distinct circumstances, experiences and needs of individuals across various transitions experiences – is warranted. This theory-informed research can then be translated into policy and practice that facilitates a healthy and holistic approach to care transitions. To continue the example of the adolescent mother with an infant discharged home from the NICU, individually each of the transitions she experiences has been explored to some extent within the health literature, however the unique and often complex intersection of these transition processes have yet to be investigated. This gap in the literature supports the argument for a proposed grounded theory study to explain how adolescent mothers transition-home following discharge of their infant from the NICU. This understanding can then be used to inform practices and policies, beginning in the NICU and continuing beyond the acute care setting, to address the complex biopsychosocial care needs of this unique group of mother/infant dyads.

A holistic approach to transitions, that is theory-informed, may quite possibly be a key-factor in addressing the problem of quality care transitions that faces health systems today. Nurses are in the unique position, having the disciplinary knowledge of Transitions Theory and the frequent encounters with individuals experiencing transitions, to ensure successful hospital-to-home transitions across all contexts.

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Table 1: Meleis’ Transitions Theory

Theory Development	• 3 decades of work by Meleis and colleagues • Extensive review of transitions literature as well as empirical testing of the developing framework [50]
Purpose	To describe, explain and predict human experiences in various types of transitions [4]
Definitions & Concepts	Transition – “a passage or movement from one state, condition, or place to another”[5]. Defining characteristics [51]: a) process, in that transition involves a sense of movement or flow; b) disconnectedness, or a disruption in the associations on which one’s feelings of security depend; c) perception, transition and its attributed significances vary between persons, communities and societies; d) awareness, persons must have some awareness that change is occurring Types of transitions [5]: 1) developmental transitions (e.g., becoming a parent); 2) situational transitions (e.g., discharge from hospital); 3) health-illness transitions (e.g., end of life); and 4) organizational transitions (e.g., introduction of new care technology). Transitions conditions [4]: • Factors that may facilitate or constrain the process of healthy transition • Examples, socioeconomic status, cultural beliefs surrounding transitions and knowledge about transition experiences
Contribution to Nursing Knowledge	Theory-informed nursing research • Exploring transitions experiences among various contexts and populations[4] • E.g., discharge, relocation and care transitions; chronic conditions; hip fracture; medical complexity and end of life Theory-informed nursing interventions • E.g., transitional care interventions, public health nursing models and frameworks for nursing student education. Exemplar References: 1. Fegran, L., Hall, E. O., Uhrenfeldt, L., Aagaard, H., & Ludvigsen, M. S. (2014). Adolescents' and young adults' transition experiences when transferring from paediatric to adult care: a qualitative metasynthesis. International Journal of Nursing Studies, 51(1), 123-135. 2. Joly, E. (2016). Integrating transition theory and bioecological theory: a theoretical perspective for nurses supporting the transition to adulthood for young people with medical complexity. Journal of Advanced Nursing, 72(6), 1251-1262.

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CHAPTER THREE

TITLE: Visual Elicitation: Methods for Enhancing the Quality and Depth of Interview Data in
Applied Qualitative Health Research.

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Abstract

Generating rich data from interviews for a qualitative study can be difficult to operationalize; especially when difficulties establishing rapport, power imbalances and participant factors threaten the interview process and quality of data. The aim of this methods paper is to (a) discuss the value of incorporating visual elicitation tools or tasks within semi-structured or in-depth qualitative interviews to enhance the depth of data generated and (b) provide a specific example of how this is planned and executed within the context of an applied qualitative health research study.

Keywords: Qualitative methods, arts-based methods, qualitative research, data collection, qualitative interviews, visual data

Statement of Significance

What is known, or assumed to be true, about this topic:

- The usefulness of qualitative research evidence often rests on a researcher's ability to generate high-quality or rigorous findings; with the quality of such findings depending largely on the generation of high-quality data.
- The interview is one of the most common ways of eliciting information or co-producing knowledge in in the health, human and social sciences, however, despite the relative simplicity of the interview – from a technical standpoint – the quality and depth of data required to produce meaningful results can often be difficult to operationalize.

What this article adds:

- Common threats to the generation of high-quality data from semi-structured or in-depth interviews including establishing rapport, power imbalances and participant factors are discussed with visual elicitation strategies described to mitigate these threats.
- Considerations and planning required for incorporating visual elicitation tools to enhance semi-structured or in-depth interviews are outlined using an applied health research example.

Recognizing the complex nature of health and health systems has led many practitioners and decision makers to use qualitative research evidence to inform and guide their work.[1] Qualitative research evidence is used to direct clinical or policy decisions; to inform program evaluations; to theoretically develop new interventions or assessment tools; to understand client or community experiences – leading to more empathetic care; to stimulate new ideas; or to validate positions, programs and services.[2] However, the usefulness of qualitative research evidence in many ways rests on a researcher's ability to generate high-quality or rigorous findings; with the quality of such findings depending largely on the generation of data that is rich in detail and leads to a deeper understanding of the phenomenon of interest.[3]

The interview is one of the most common ways of eliciting information or co-producing knowledge in the health, human and social sciences[4] and semi-structured or in-depth interviews are ubiquitous within qualitative health research methods. In-depth interviewing: (a) seeks deep information and understanding (e.g., a way to learn the meanings of participant's actions); (b) relies on open-ended questions; (c) goes beyond common-sense explanations or understandings of events, activities or places; and (d) generates deep understandings – allowing researchers to grasp and articulate multiple views, perspectives and meanings.[5, 6] Researchers use semi-structured or in-depth interviews to study topics about which the participant has had substantial experience. The interviews are usually organized around a set of pre-determined open-ended questions and during the interview the participant talks while the researcher encourages, listens and learns.[6, 7] Interviewing may be perceived as a rather simple form of data generation –

merely a conversation between two individuals. However, the depth and detail required in the data to produce meaningful results and the skill required to generate this rich qualitative data is often underestimated and can often be difficult to operationalize. The use of visual data elicitation tools and techniques, a form of arts-based research methods, in conjunction with more traditional semi-structured or in-depth interview techniques can mitigate some of the threats to generating rich qualitative data.

The aim of this methods-focused paper is to (a) discuss the value of incorporating visual elicitation tools with semi-structured or in-depth qualitative interviews to enhance the richness and depth of data generated and (b) provide a specific example of how this is planned and executed within the context of an applied health research study.

Arts-based Methods and Qualitative Interviews – A Brief Overview

Arts-based research is an umbrella-term and can be defined as "research that uses the arts, in the broadest sense, to explore, understand, represent and even challenge human action and experience".[8] Arts-based research methods "are a set of methodological tools used by researchers across the disciplines, during all phases of social research, including data generation, analysis, interpretation and representation".[9] In health research, arts-based methods are for the most part used in combination with other data collection strategies, particularly questionnaires and interviews; and include visual, literary and performance based strategies.[10]

Within qualitative health research, visual arts-based methods such as photography, drawing, digital storytelling, animation and collage are the most commonly used strategies.[10, 11] Photovoice, for example, is a process of study participants using photography to identify, represent and enhance their community through creating and discussing photos.[12] This visual arts-based method has also been extended and modified in the age of social media using popular photo sharing applications data generation.[13] Poetry is an example of a literary arts-based method that uses repetition, rhythm and rhyme to allow the reader to see and hear the data across new dimensions.[11] Found poetry is a specific example where a poem is created by taking words, phrases or whole passages from other sources such as interview transcripts and reframing them as poetry.[14] This method was used by Reilly and colleagues[14] to distill the findings of a study examining how art-making shaped the trajectories of women diagnosed and treated for breast cancer. Theatre, dance, music and performance poetry are variations of performance-based methods within arts-based research.[10] Research-based theatre has been adopted across a wide variety of academic disciplines including health research and has the potential to engage researchers and audiences in both critical and empathic explorations of health and illness within a live space.[15] For example, Mitchell, Jonas-Simpson and Ivonoffski[16] describe the process of creating a research-based drama about living with dementia. The resulting performance piece presents understanding gained from a decade long program of research and connects it with persons who might benefit most from the research findings.

Most often, health researchers cite limitations of traditional qualitative data collection strategies in communicating the subjective human health experience and the need for alternative methods as rationale for adopting arts-based strategies.[17] In the context of the qualitative interview, arts-based research methods are often employed as a strategy to elicit contributions from interviewees that are difficult to achieve by verbal exchanges alone.[18] The most common elicitation tools are photographs, but other visual tools are increasingly being utilized and include drawings, maps and other visual artifacts.

Visual Elicitation to Mitigate Threats to Generating Deep and Detailed Interview Data

Qualitative health research is a unique sub-discipline of qualitative inquiry; differentiated from traditional qualitative research by its focus on the health-illness continuum and methods employed to accurately capture these phenomenon of interest.[19] Researchers operating within this unique context of qualitative health research are often forced to adapt the methods used in general qualitative inquiry to address factors specific to the health-illness focus of research, for example, limited time to conduct interviews due to pain or patient treatment schedules.[19] Discovering and utilizing innovative ways to enhance the depth of data obtained from qualitative interviews and increase the overall rigour of a study, such as using visual elicitation tools, is an example of the strategic and purposeful selection and adaption of methods for a qualitive health research study.

Incorporating a visual task into a standard semi-structured or in-depth interview can be very helpful for elicitation purposes; allowing participants to go beyond the verbal mode of thinking and connecting with wider dimensions of the experience of interest that may otherwise be disregarded.[20] Visual tools or tasks used for the purpose of enhancing qualitative interviews include viewing and discussing photographs;[21] mapping exercises such as concept maps and mind maps,[22] relational maps,[20] and ecomaps;[23] creating timelines;[24] and other drawing activities[25] (e.g., patients with Chronic Obstructive Pulmonary Disease draw their lungs[26]).

Common threats to the generation of deep and detailed data from semi-structured or in-depth interviews include establishing rapport – or the inability to do so;[7, 27] power imbalance;[28, 29] and participant factors impacting the ability to transform experiences into spoken word or narrative – including language and cognition.[30-32] These threats may be mitigated by introducing visual elicitation methods to facilitate and enhance the traditional qualitative interview.

Establishing Rapport

Developing rapport and engaging research participants in a conversation is central to generating data that are meaningful and useful; in-depth interviews must create an open and interactional space that develops and builds on intimacy and trust.[5, 6, 27, 33] Typically in qualitative health research this rapport needs to happen rapidly, as the nature of the semi-structured interview process does not allow for the development of trust or rapport over time (in contrast to traditional ethnographic research).[7] Even the most skilled interviewer can encounter challenges in creating an environment where this kind of interaction can occur and additional considerations are often required when planning research among certain participant groups – including youth and marginalized individuals where rapport can be particularly challenging.[31, 34] Incorporating visual elicitation methods such as photographs and drawings can make a semi-structured interview more intriguing for participants and ultimately less intimidating.[35] These methods can be useful as a lead-in or icebreaker or can serve as a stimulus for the interviewer, resulting in further questioning and elaboration thus allowing for an enhanced data generation experience and rich qualitative data.[20, 36]

Power Imbalance

The relationship between the researcher and participant in qualitative research interviews is characterized by power imbalance – with the interviewer having the authority to frame the interview and ask the questions – in addition to the presence of potential imbalances involving gender, race/ethnicity, class and education.[29] This power imbalance can threaten the quality of the data generation as participants may employ "problematic interviewee behaviours" (e.g., social desirability) or shift the focus of the conversation completely.[28] Visual elicitation methods situate the research participant as the expert in the interview transaction and can facilitate increased participant authority in the research process – thus enhancing trust and overall engagement.[35, 36] These methods also allow the participant control over how their data are analysed, for example, participants engaged in a drawing activity are subsequently asked by the researcher to describe and explain their depictions, thus avoiding de-contextualization of the drawing or misinterpretation by the researcher.[37]

Participant Factors

Understanding the patient or client experience is central to qualitative health research in the questions posed and methods used – and this understanding can lead to genuinely empathic practices and policy. Certain groups, however, may be difficult to involve as participants in research, such as children and young people, people experiencing cognitive delay or decline or the frail elderly – yet exclusion from research prevents these individuals, as well as the groups they represent, from the benefits of research participation.[38] Visual elicitation tools can enable participation in data generation for a broader range of participants, including those for whom the ability to transform experiences into spoken word (or generate in-depth of detailed data by more traditional methods) may pose challenging.[35] For example, Teachman and Gibson[39] utilized cartoon captioning in a study exploring beliefs, assumptions and experience of children and youth with disabilities. Participants were asked to fill in the speech bubbles above the heads of two characters in a cartoon provided by the researchers; eliciting perspectives that may have otherwise been missed with interview methods alone. Similarly, the use of visual aids or prompts while interviewing may facilitate the expression of feelings and greater depth of data generated among the frail elderly.[32]

Cognitive factors such as those associated with typical developmental stages can also contribute to challenges in generating rich data from interviews. For example, among adolescents the prefrontal cortex (the region of the brain responsible for advanced reasoning) is less developed compared to adults, which could lead to difficulty considering and articulating complex understandings that may be expected in a traditional qualitative interview.[40, 41] Visual elicitation methods have been utilized specifically among youth research participants to mitigate these challenges associated with this typical developmental stage.[20, 41] For example, researchers using a visual storytelling method cite the use of visual images and in-depth interviews as effective in promoting reflection and communication about issues that could otherwise be difficult for young participants to conceptualize or express in conversation alone.[30]

Visual Elicitation Tools to Enhance Qualitative Interviews – Considerations for Planning and Execution.

Developing a qualitative health research study plan or protocol requires careful planning and decision making around choosing a topic, selecting as design, writing a research question and choosing methods that facilitate the research aims (e.g., describe a health or illness related phenomenon).[42] Data generation methods need to allow for the expression of a participant's thoughts, values and beliefs in order to understand how an individual or group experiences the phenomenon of interest – making the interview a method of choice.[42] Anticipating threats to data generation from semi-structured or in-depth interviews and planning strategies – such as visual elicitation tools – to mitigate these threats can save a researcher valuable time and resources while also maintaining the responsibility for high-quality research processes and outputs. In this section we describe the considerations and planning required (Table 1) for incorporating visual elicitation tools to enhance semi-structured or in-depth interviews using an applied health research example (see Table 2 for brief study context). This example is based on a study titled "NICU-to-Home Transitions Study – Understanding the Transition Experiences of Adolescent Mothers with Newborns Discharged Home from the Neonatal Intensive Care Unit (NICU)**".**

A. **Purpose**. The purpose of incorporating visual elicitation tools into the data generation methods of a study can be linked to the anticipated threats to generation of deep and detailed qualitative data, for example, establishing rapport. In the NICU-to-Home study, the population of interest was adolescent mothers making the transition from hospital-to-home after their infant's stay in a Neonatal Intensive Care Unit. Many adolescent mothers have experienced negative healthcare encounters that have contributed to disengagement and mistrust of the healthcare system and health providers.[43] As a research team consisting of nurses and other health professionals seeking to engage young mothers in conversation about their health experiences in the NICU, we needed to consider strategies that would reduce perceptions of stigma and power imbalance on behalf of the participants thus facilitating rapport during the research interview. This served as our purpose for considering visual elicitation tools during the individual semi-structured interviews.

B. **Tool or Technique Selection**. Once the purpose has been identified, researchers can now consider the type of visual elicitation tool or technique that will serve this purpose and contribute to answering the overarching research question. Various visual art forms can be used for elicitation purposes during semi-structured interviews with the most common in health research being photographs, videos and drawings.[11, 17] In the NICU-to-Home study, drawing – specifically timelines and relational maps, were the techniques selected. ***Timelines*** are a visual depiction of significant life events displayed in chronological order that facilitate recollection and sequencing of personal events and help capture temporal dimensions of studied concepts.[20, 36] ***Relational maps*** are an elicitation tool where participants are asked to draw themselves and important people in their lives using distance from oneself to represent importance (with importance diminishing as distance from oneself increases).[20, 37]

Relational maps and timelines were chosen as they may be less threatening than direct dialogue with the researcher and offer a technique to approach sensitive or personal topics.[20, 25, 35] These methods can also be effective at reducing researcher-participant power differentials, an important consideration when interviewing adolescents as they can be easily intimidated and feel dehumanized in the research process as an object of knowledge.[35, 44] Visual methods can also capitalize on a stage of heightened creativity in adolescence, allowing for unique opportunities for validation of youth participant narratives.[45, 46] These visual methods also contribute to the overarching research question, for the NICU-to-Home study, the important relationships in a young mother's life as she transitions from hospital-to-home with her newborn as well as significant time points along this process are highlighted within the timelines and relational maps.

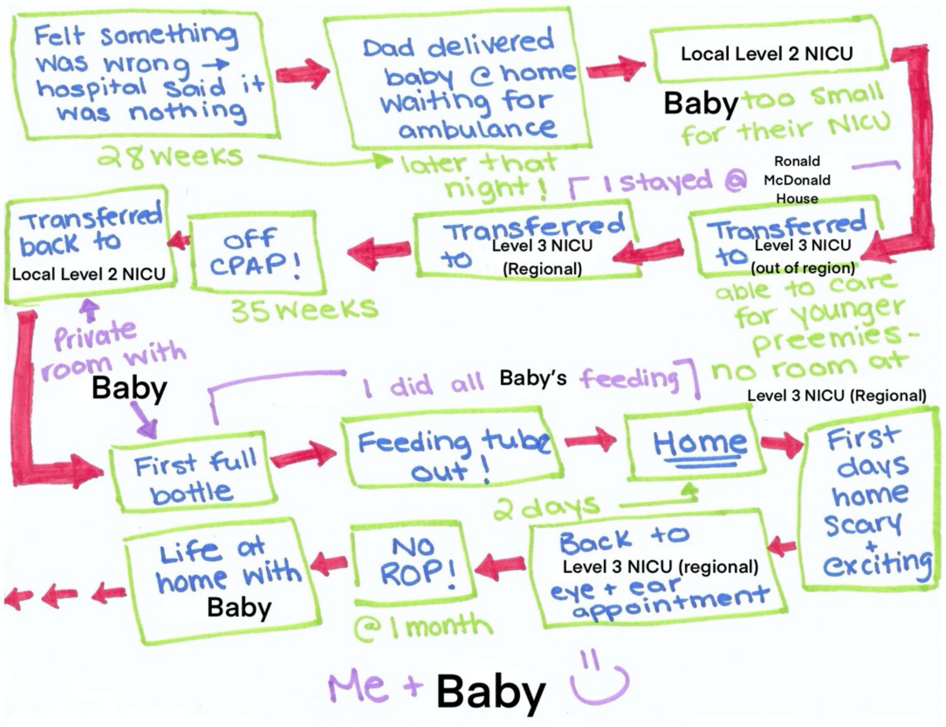
C. **Elicitation Guide**. A clear description of the visual elicitation technique as well as appropriate prompts to guide the subsequent discussion will allow for a smooth integration of these tools into more traditional interview processes. Similar to a semi-structured interview guide that lists a number of open-ended questions with flexibility to probe for deeper exploration,[42] the elicitation guide will lead the participant through the drawing activity and provide areas for the interviewer to question and probe. An elicitation guide for both the timeline and relational map drawing activities was created by the research team for the NICU-to-Home study (see Table 3 for sample relational map elicitation guide). Note that the interviewer provides very little scaffolding for the activity to the participants, therefore allowing them to construct their own representations and allowing for a discussion between the interviewer and participant about what was included and why.

D. Analysis. As visual elicitation strategies are primarily for the purpose of facilitating communication between the researcher and participant, analysis is often conducted within the context of the interview by asking participants to describe and explain their depictions. This is important to avoid de-contextualization of the drawing or misinterpretation by the researcher.[37] The subsequent discussion is then analyzed as text according to the study's analytic design (e.g., qualitative description, reflexive thematic analysis, grounded theory). Additional analysis of the visual data itself can also be completed with content and thematic analyses commonly used in health research using visual methods.[17]

In the example study, participant interviews were recorded and transcribed verbatim thus capturing the discussion of the relational maps and timelines and the elicitation of deep and detailed descriptions of the transition experience. These in-depth interviews – enhanced with the elicitation strategies of timelines and relational maps – are then analyzed as text, much the same as a traditional in-depth interviews, according constructivist grounded theory methodology and the processes outlined by Charmaz consisting of initial coding, focused coding, theoretical coding and memo writing.[6] While elicitation of rich data is the primary purpose of the drawing activities, the creation and discussion of the maps and timelines can facilitate certain analytic strategies. For example, temporal ordering is a coding strategy used in grounded theory analysis to understand the processual nature of a phenomenon,[6] therefore the inclusion of the timeline activity allows the participant to begin this temporal ordering within the context of the interview and the researcher to continue this analysis by comparing across participants and incorporating this ordering into the overall analysis. The maps and timelines also lend themselves well to constant comparative analysis – a strategy central to grounded theory analysis – where individual maps and timelines can be lined up and compared incident to incident and scrutinized for variation in processes and relationships. These visual outputs from the interviews may also serve as starting points for the maps, figures, charts and other visual representations produced while teasing out relationships, processes and ultimately how the resulting ground theory fits together.[6]

E. **Data Representation and Dissemination**. While the purpose of the elicitation tool may be primarily to facilitate the generation of rich interview data, researchers should consider the power of visual data when representing and disseminating the findings (see Figure 1 and Figure 2). Visual methods are powerful knowledge translation (KT) tools. Visual representations of research evidence (e.g., images, art, videos) are largely accessible and therefore facilitate dissemination across broad audiences.[35] Visual outputs have the power to impart knowledge by attracting interest and developing meaningful connections with research findings and therefore hold strong potential for effecting change among knowledge-users outside of academic institutions.[35, 47] For example, timelines outlining the many individual transition experiences of adolescent mothers can be analyzed, synthesised and represented as a meta-timeline or journey-map[48] that communicates salient and systemic issues within the health and social systems these young mothers navigate.

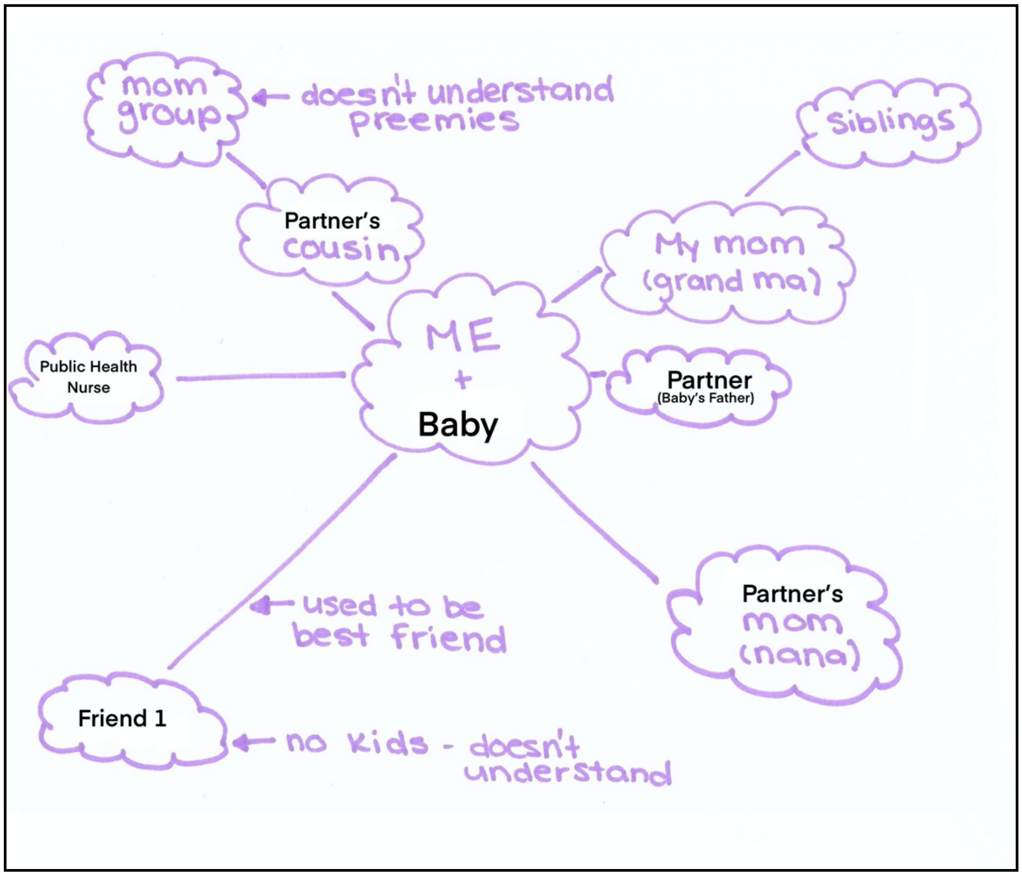
Figure 1: Example Timeline from NICU-to-Home Study



F. Ethical Considerations. Additional safeguards to protect participants will need to be considered when using visual elicitation methods during qualitative interviews. Fundamental ethical values when conducting research with human participants still guide this consideration, however, how the visual tools may influence these values requires careful reflection.[35] Photos and the other visual depictions may identify participants or their environments thus compromising confidentiality. In the example study, strategies to ensure confidentiality include anonymising digital images by removing or blurring identifiers (see Figures 1 and 2 for example de-identification). Ownership of visual outputs must also be considered.[35] In the example study, the participant is considered the owner of their visual depictions with the research team asking for permission to obtain a digital copy for analysis.

Visual methods are also often used to facilitate expression of emotions and tacit knowledge, as such researchers need to safeguard the participant by minimizing potential risks, promoting transparency during the consent process, ensuring ongoing consent throughout the interview process and ensuring a protocol is in place for assessing and addressing emotional distress.[35, 49] To minimize the risk of negative emotional impact as a result of participation in the example study, the research team developed a detailed distress protocol and ensured ongoing consent by asking “okay to continue” at multiple points throughout the interview process.

Figure 2: Example Relational Map from NICU-to-Home Study



Implications for Research and Practice

Integration of visual elicitation tools and techniques into qualitative interview methods by nursing and other applied health researchers can improve the depth and detail and overall richness of their interview data. This can be particularly important when conducting qualitative interviews on sensitive topics or with participants experiencing vulnerability or marginalization as is often the case in nursing research. Qualitative data that is rich in detail and leads to a deeper understanding of the phenomenon of interest can produce more rigorous qualitative research evidence that can then be used in many ways that are important to nursing practice including, informing clinical or policy decisions, understanding client experiences and stimulating new ideas or validating positions, programs and services.[2] Visual methods should also be considered by nurse researchers for the dissemination of research findings as a method that is accessible to knowledge users thus strengthening the potential impact of research evidence.

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Table 1: Visual Elicitation in Qualitative Interviews – Considerations and Planning

Purpose	Identify the purpose of incorporating visual elicitation tasks or tools into the interview. E.g., to facilitate rapport among a difficult to engage participant group.
Tool/Technique Selection	Select the visual elicitation tool(s) or strategy(ies) that will contribute to answering the overarching research question. E.g., Relational mapping to capture the relational networks of study participants.
Elicitation Guide	Integrate the visual elicitation tool or strategy into the interview guide. E.g., Outline the activity for the participant as well as prompts to facilitate the subsequent discussion.
Analysis	Choose an analytic strategy that is congruent with the overall research objectives and design. E.g., Throughout the interview, allow the participant to analyze their depictions for the researcher to avoid decontextualization and misinterpretation.
Representation & Dissemination	Consider how visual data may be used in the representation and dissemination of research findings. E.g., Individual timelines analyzed and synthesized into a meta-timeline or journey-map
Ethical Considerations	Consider the additional ethical safeguards required when using visual elicitation in the research process. E.g., Establish expectations regarding ownership of participant-produced visual outputs.

Table 2: Brief Study Context and Purpose – NICU-to-Home Transitions Study

Example Study: NICU-to-Home Transitions Study – Understanding the Transition Experiences of Adolescent Mothers with Newborns Discharged Home from the Neonatal Intensive Care Unit (NICU)

Background/Context: Pregnant and parenting young women often experience high levels of social and economic disadvantage including difficulty accessing critical health and social care services – leaving them and their infants vulnerable to poor outcomes [50, 51]. Infants born to adolescent women are also more likely to require hospitalization in a NICU shortly after birth [51-53]. An extended NICU stay can disrupt maternal-infant attachment, decrease breastfeeding rates and postpartum engagement with community-based health promotion and early-intervention services – therefore increasing the vulnerability of this already complex mother-infant dyad. The unique social, psychological and developmental context of the adolescent mother combined with the complexity associated with NICU-to-home care transitions underscores the need for an age-specific understanding of their experience and supportive care needs post-discharge. Currently, however, very little is known about specific experiences of Canadian adolescent mothers when they transition-home from NICU.

Purpose: to develop a mid-range substantive theory to explain how adolescent mothers experience transition to home and community following discharge of their infant from the NICU.

Table 3: Sample Interview Guide Using Relational Map Graphic Elicitation Method

Introduction

Interviewer:

Thank you for taking the time to be interviewed today.

Some people find it helpful to use drawings to tell their story, so during our time together we're going create some drawings to help highlight important parts of your transition-home experience.

Relational Map Activity

Before the drawing begins

- Provide printed relational map instructions to mother
- Explain that the purpose of the relational map is to place important people in a picture around themselves with those closest relationships drawn near and those not as close drawn further away – similar to the solar system with the mother being the sun and the people in their life being planets different distances away
- Emphasize that individuals complete this task differently and that there is no right or wrong way to draw their relational map

Relational Map Activity Instructions

In this activity, we are asking mothers to draw a relational map.

In other words, draw a picture of you in the centre of the page, and then show the important people in your life by drawing them on the paper. Draw the people most important or closest to you in the space near you in the picture, and those less important or not as close further away in the picture. Different people draw this in different ways, and there's no right or wrong way to draw your relational map.

Things you might want to consider for your relational map:

- Include important people such as family, friends, care providers (doctors, nurses, social workers), teachers and role models
- Maps could also include people you wish were in your life

- Important people or relationships do not have to be ‘good’ or ‘positive’ to be important in your life – for example bad relationships can still be considered important

You can describe what you are doing while you draw or complete the drawing without talking.
After about 10 minutes, I will ask you to tell me about the map you drew.

Participant Draws Map – after 10-15 minutes ask the participant to describe what they drew

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Potential probes for elaboration during discussion of relational map:

- PROBE – Looking at the map
    - What makes a relationship more or less important to you?
    - What makes each of these people important to you?
    - Is there anyone that you wish were closer to you in this map that is currently further away? Why?
    - Are any of these relationships particularly difficult? Rewarding? Why?
- PROBE – How have your relationships changed since before learning you were pregnant and now?
- PROBE – What (if any) care providers (doctors, nurses, social workers…) have you placed on your map?
    - How have these relationships changed over time?
- PROBE – Has anyone been with you on the entire journey since before learning you were pregnant until now?
- ASK – Is there anything else that you would like to tell me about your relational map that you think is important for me understanding your story?

Concluding the Relational Map Activity

Interviewer:

Thank you for sharing your relational map with me. Do I have your permission to take a picture of this map and we will revisit it when we meet again? I may also use examples of drawings when I write about and/or present my study findings, may I use your drawing in this way? All personal details will be removed or replaced with “fake” names and places.

CHAPTER FOUR

TITLE: Understanding the context of care for adolescent mothers in the Neonatal Intensive Care Unit: An interpretive description of care providers’ perspectives

AUTHORS: Orr, E., Ballantyne, M., Gonzalez, A., & Jack, S. M.

JOURNAL: Prepared for submission to an academic nursing journal focused on qualitative research methods and evidence.

Abstract

Infants born to adolescent mothers have a higher risk of admission to the neonatal intensive care unit (NICU) shortly after birth. The experience of having a critically-ill infant in the NICU has pervasive emotional and psychological outcomes for parents, however, little is known about the experiences of adolescent mothers in the NICU. We used interpretive description methodology to guide an exploration of the NICU context of care. In-depth interviews were conducted with expert providers caring for adolescent mothers in the NICU (n=23) and we asked them to describe how the context of care influences mothers' experiences during a NICU stay. We learned from providers that having a baby in the NICU was perceived as a traumatic experience, impacting maternal-infant attachment, parenting confidence and competence, and maternal mental health. NICU environmental factors and perceptions that adolescent mothers are treated differently in the NICU also influenced this overall experience. Findings highlight the opportunities for strengthened interprofessional collaboration and trauma- and violence-informed care strategies within the NICU to mitigate the negative influence of this experience.

Keywords: Adolescent mothers; intensive care units, neonatal; qualitative interpretive methods

Introduction

Infants born to adolescent mothers are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a neonatal intensive care unit (NICU) shortly after birth (DeMarco et al., 2021; Fleming et al., 2013; Shrim et al., 2011). Admission of their infant to the NICU creates a complex situation as adolescent motherhood is often associated with a range of psychosocial challenges – including health inequities grounded in the social determinants of health. Additionally, adolescents are still developing important cognitive functions, such as advanced reasoning and decision-making, thus making their ability to navigate complex systems such as the NICU particularly challenging (Blakemore & Choudhury, 2006). However, the unique experience of the adolescent mother within the context of the NICU and their transition-home following discharge is poorly understood.

Background

Risks Associated with Adolescent Pregnancy and Motherhood

Pregnancy in adolescence is associated with multiple social, psychological, and economic risk factors. Similar factors are also considered consequences or outcomes of pregnancy and parenting in adolescence, making it difficult to determine the direction of causality in most situations. Risk factors associated with adolescent pregnancy include low socio-economic status (Al-Sahab et al., 2012), adverse childhood experiences (ACEs) and childhood disadvantage (Hillis et al., 2004; Smith et al., 2018), mental health challenges (Vigod et al., 2014), and exposure to violence (Al-Sahab et al., 2012). In addition, health harming behaviours such as smoking and substance use are higher among pregnant adolescents (Wong et al., 2011; Wong et al., 2020); and behaviours seen as protective or preventive are lower among adolescents, including antenatal care rates (Fleming et al., 2013) and breastfeeding (World Health Organization (WHO), 2018a). Additionally, pregnancy in adolescence may contribute to lifelong health disparities for adolescent mothers and their children, including, lower educational attainment, unstable employment, residential instability, and lower levels of social support compared to older mothers (Fleming et al., 2015; Ruedinger & Cox, 2012; Wong et al., 2020); with social determinants of health inequities more likely at the root of poorer health and social outcomes than maternal age alone (SmithBattle & Leonard, 2012).

Social determinants of health inequities and co-existing risk-oriented health behaviours can have a significant impact on the health of the young mother. Additionally, infants born to adolescent mothers are at an increased risk for poor birth outcomes including preterm birth, low birth weight, and congenital anomalies (Chen et al., 2007; DeMarco et al., 2021; Fleming et al., 2013; Shrim et al., 2011); with higher prevalence of poor pregnancy outcomes among adolescents experiencing socio-economic deprivation when compared to more well-off counterparts (Amjad et al., 2019). Most likely related to the abovementioned risks, infants born to adolescent mothers also have an increased risk of admission to the NICU shortly after birth (Fleming et al., 2013; Shrim et al., 2011). For adolescent mothers, admission of their infant to the NICU can exacerbate an already complex situation. In addition to the above-mentioned social, psychological and economic difficulties associated with adolescent motherhood, the NICU environment coupled with the fragile condition of a critically-ill infant are frequent sources of stress, anxiety, depression, and grief for most parents.

Parents’ Experiences of the NICU

Globally, preterm birth is a leading cause of neonatal mortality (WHO, 2018b), and while most infants in high-income nations survive being born early, preterm birth is associated with short- and long-term health problems including neurodevelopmental complications (Chawanpaiboon et al., 2019). In Canada, approximately 11% of infants are admitted to an intensive care unit within their first month of life; with preterm birth, multiple birth, low birth weight, and small for gestational age birth as risk factors (Fallah et al., 2011). In addition to experiencing the critical illness of their infant, parents in the NICU often experience emotional and psychological consequences related to this hospitalization.

In a scoping review of the published research regarding parents’ experiences of the NICU, Roque and colleagues (2017) found stress, anxiety, depression, and psychological distress were common among NICU parents. They noted that parental role adjustment and the NICU environment were frequently identified stressors for parents, with increased levels of stress noted in unmarried, lower income, and younger mothers. Anxiety and depressive symptoms were also greater in parents whose infants were in the NICU compared to other parents; with a lack of perceived social support and reports of increased stress strongly associated with anxiety and depression. The emotional and psychological outcomes discussed in this review are pervasive and continue well beyond the infant’s discharge from the NICU; with studies investigating the prevalence and longevity of these symptoms reporting ill-effects up to seven years post-discharge (Lefkowitz et al., 2010; Schecter et al., 2020; Treyvaud et al., 2014).

Comparable findings were summarized and discussed in a review of qualitative studies exploring parental experiences of the NICU; with common themes of parental stress, difficulty adjusting to the parenting role or altered family roles during the hospitalization, and the lasting impact of the hospitalization on parental mental health (Al Maghaireh et al., 2016). While the experiences of adult-aged parents in the NICU are well documented, the unique experience of the adolescent mother within the context of the NICU is poorly understood. In a review of the literature on adolescent parenting in the NICU, Rosenstock and van Manen (2014) found the majority of studies focused on parental stress and parenting practices among adolescent parents with infants in the NICU (with adolescent parents often only a sub-population within the study sample) and a few studies examining other aspects of the NICU experience, including communication practices, parental needs, and evaluation of various intervention programs. Notably, only one small qualitative study focused specifically on the experiences of adolescent mothers within the NICU (Bocock, 2012). Since the time of Rosenstock and van Manen's review, studies that specifically focus on adolescent mothers with infants in the NICU remain scarce (Griglak, 2020). What we have learned from literature outside of the NICU context is that adolescent mothers often experience health care differently than their adult counterparts.

Adolescent Mothers' Health Care Experiences

In general, adolescents are a relatively healthy population with decreased health care utilization during the teen years (Harrison et al., 2017). When they do access the health care system, adolescents are cautious about revealing sensitive information for fear of judgement and are particularly concerned about privacy and confidentiality (Britto et al., 2010). Pregnant and parenting adolescents require enhanced engagement with the health care system compared to their non-pregnant counterparts; additionally, tailoring of services to meet the unique needs of this sub-group is necessary to mitigate the associated risks (Harrison et al., 2017; Moriarty Daley et al., 2013). However, stigma surrounding young parenting and judgemental attitudes of health care providers toward pregnant adolescents can contravene this engagement (Rice et al., 2019; SmithBattle, Loman, et al., 2020).

Adolescent mothers report negative health care encounters associated with judgemental attitudes by providers toward adolescent pregnancy. An example of this type of negative experience or judgement is the presumption of substance use by the adolescent mother by care providers, leading to fear of involvement of child protection services. In contrast, features of positive experiences included respectful, supportive, and non-judgemental care (Harrison et al., 2017). Labour, delivery, and the immediate postpartum period are critical points of contact with the health care system for adolescent mothers. Nursing care during this time can leave a young woman feeling respected and confident in the maternal role; or judged, disempowered and vulnerable (Erfina et al., 2019; Peterson et al., 2007). While experiences during the postpartum period vary, negative experiences are cited as more memorable and hurtful (Erfina et al., 2019).

Despite encountering adolescent mothers during this vulnerable period, perinatal nurses may lack education specific to the care of adolescent mothers and knowledge of hospital- and community-based resources for adolescent parents (Peterson et al., 2012). Negative health care experiences related to perceived stigma, lack of trust, or programming that does not account for the contextually and developmentally unique needs of the adolescent mother indicate that existing health care and social care service designed to improve maternal-child health outcomes might in fact be difficult for young mothers to access and engage with.

Adolescent Cognitive Development

Among adolescent girls, the presence of secondary sex characteristics and engaging in sexual activity gives the appearance of being more mature, however, the adolescent brain is still developing (Giedd, 2008; Johnson et al., 2009). The prefrontal cortex is the fastest and largest region of brain development in adolescence, it is responsible for advanced reasoning, including the ability to plan, understand cause and effect, think through scenarios, and manage impulses (Weinberger et al., 2005). In the case of pregnant and parenting adolescents, this immature cognitive functioning can lead to distortions in judgement, resulting in the belief that pregnancy could not happen to them, thus resulting in delayed prenatal care; or difficulties with aspects of the parenting role, such as the anticipation of child behaviour that is required for safety/injury prevention (Aruda & Burke, 2013; Daley et al., 2013; Leany, 2013). Knowledge that the brain, and in turn advanced cognitive functions, are still developing throughout adolescence serves to highlight another important component of understanding pregnancy in adolescence and the demand for specialized knowledge and approaches when individuals in this life stage intersect with health care and social care systems.

Purpose & Research Question

Adolescent mothers and their infants are a vulnerable dyad given the many complexities associated with adolescent motherhood and the risk for poor maternal and infant outcomes. This vulnerability may be exacerbated when the infant of an adolescent mother is admitted to the NICU shortly after birth. In this situation, the risk-oriented factors associated with adolescent motherhood intersect with the pervasive emotional and psychological effects of the NICU experience. However, little is known about this intersection, thus often rendering health and social care professionals to be ill-equipped to support these mothers within the NICU, and beyond into the community, to promote optimal growth and development of mother and infant. This article reports on an in-depth analysis of the NICU context of care and, from providers' perspectives, how this context influences mothers' NICU experiences. Data for this analysis were collected as part of a larger study, the NICU-to-home transitions study, exploring the transition experiences of adolescent mothers upon discharge from the NICU. As the NICU-to-home transitions study progressed, it became evident that the experiences in the NICU for adolescent mothers, or where the transition journey began, was central to the overall understanding; thus, warranting additional analysis. The transition home from NICU for adolescent mothers from care providers' perspectives is reported elsewhere (Orr et al., submitted). The experiences of the NICU-to-home transition from the mothers' perspective is also being studied, however, given the need to pivot from in-person data collection with young mothers during the COVID-19 global pandemic, these data are not fully collected and will be analyzed and published in a subsequent paper.

This article addresses the question: what can be learned about the NICU context of care and its influence on the experiences of adolescent mothers from the providers involved in their care?

Methods

Interpretive description was used to guide the methodological decisions for the larger NICU-to-home transitions study, as well as this additional analysis. Interpretive description is an applied qualitative research approach that aligns with the disciplinary knowledge requirements of nursing and other applied health professions in that it emphasizes research questions that are clinically relevant and findings that are application ready (Thorne, 2016). Additionally, interpretive description highlights the role of "thoughtful clinicians" as rich sources of qualitative data in applied health research; such that the perspectives of these experts offer a broader experiential range of diversity or variations as they have seen multiple cases of a phenomenon over time (Thorne, 2020).

Sampling & Recruitment

A purposeful sample of providers involved in the transition experiences of adolescent mothers were recruited for the NICU-to-home transitions study. Specific criteria for inclusion were not prescribed to allow for maximal variation and a broad range of perspectives based on discipline, role and practice setting. Team leaders and/or managers at seven sites across southern Ontario, Canada acted as recruitment partners; these sites included four NICUs and three public health units (PHUs). Partners assisted the research team by distributing recruitment emails to relevant team members and inviting the Principal Investigator (EO) to present at research rounds with a recruitment invitation following the rounds. Interested individuals then contacted the study team and a formal email invitation to participate in the study was sent by the Principal Investigator. We also engaged in a process of snowball sampling, whereby study participants recommend additional potential participants; and with permission, these individuals were contacted by email with an invitation to participate in the study.

An additional sample of public health nurses (PHNs) involved in the care of adolescent mothers was available through a study, concurrent to this study, conducted by co-investigators (SJ, AG). In the British Columbia Healthy Connections Project (BCHCP) process evaluation study, PHNs delivering the Nurse-Family Partnership® (NFP) – a targeted public health intervention program aimed at improving maternal-child health outcomes for young pregnant and parenting adolescent girls and young women through nurse home visiting (Olds, 2006) – were interviewed eight times between 2014 and 2018 (Jack et al., 2015). Questions related to nurses' experiences of providing care for clients who experienced hospitalization of their infant were purposefully added to the seventh cycle of one-to-one PHN interviews to provide an additional sample for this study. This study was approved by the Hamilton Integrated Research Ethics Board (HiREB # 5089) and scientific approval from partnering PHUs was also obtained. Written informed consent was collected prior to scheduled interviews, with a verbal confirmation of consent conducted prior to commencement of questioning.

Data Collection

Data were collected using individual, semi-structured interviews. A semi-structured interview guide was developed to guide the direction of the interview; however, most interviews were free-flowing conversations, rich with detail and specific examples, thus reflecting the participants' expertise related to the topic. Interviews were conducted in-person (n=2) or by telephone (n=15) and were 30-65 minutes in length. All interviews were digitally recorded and transcribed verbatim. Field notes were recorded by the researcher following each interview; these included relevant contextual information as well as initial analytic impressions. An additional six transcripts were part of the data set and represented the nurses from the BCHCP process evaluation who spoke to the experience of supporting a client with a hospitalized infant.

Data Analysis

For this study, data collection and analysis progressed concurrently, with analytic memos informing each subsequent interview and contributing to the overall analysis process. Analysis in interpretive description is inductive, and thus began with immersion in the data set (Thorne, 2016). A constant comparative analytic approach was then applied, comparing similarities and differences both within and across cases; additionally, developing patterns were defined, described and challenged in analytic memos and a process of diagramming was used to explore relationships between developing patterns (Campbell et al., In press; Terry et al., 2017; Thorne, 2016).

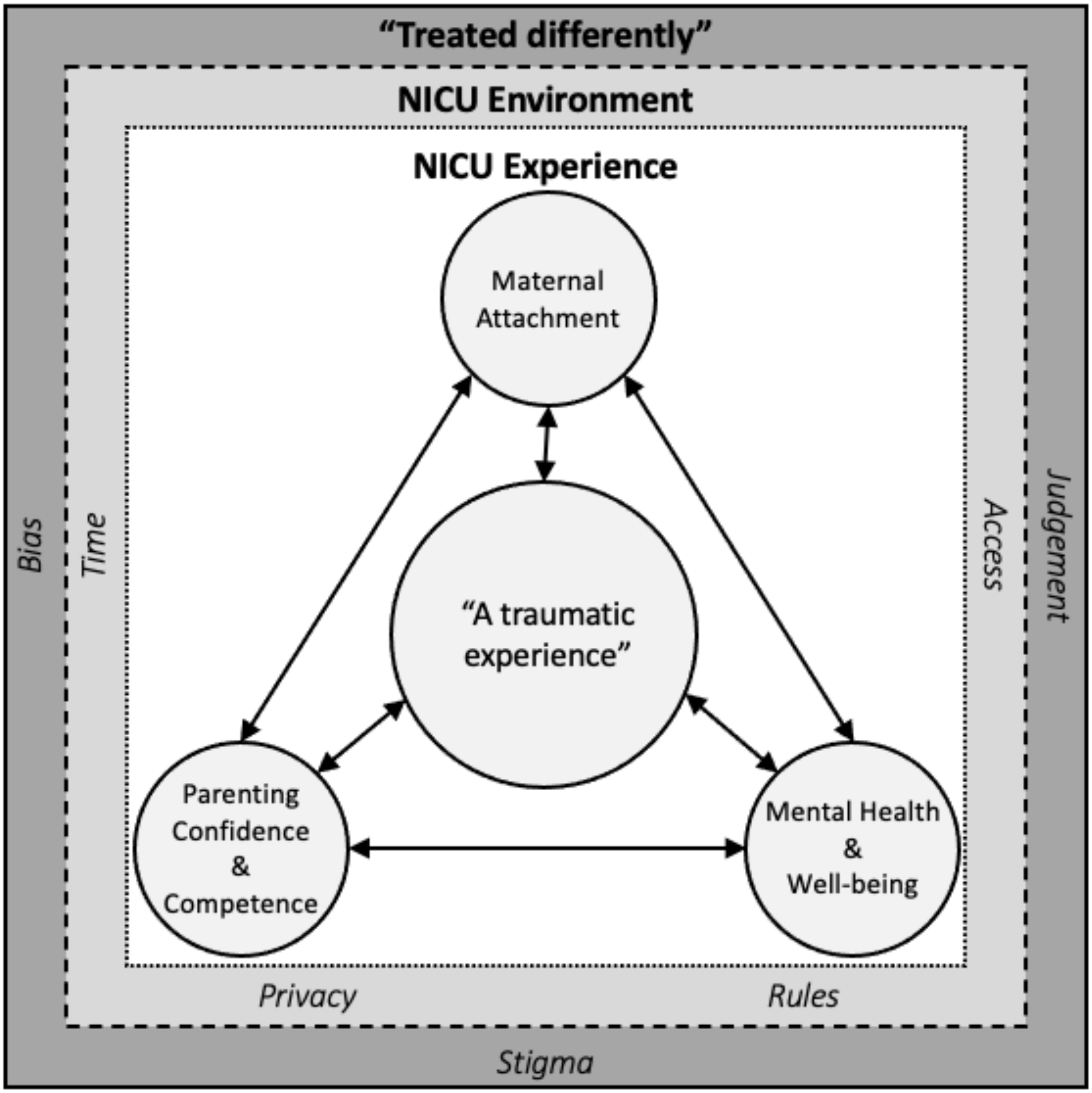
Preliminarily analysis was completed independently by the principal investigator, however, a sample of transcripts were reviewed by the entire research team (SJ, AG, MB). Additionally, developing patterns were discussed as a team throughout the analytic process. To further advance the analytic thinking of the principal investigator and enhance analytic credibility, two sample transcripts and initial analytic insights were presented to a graduate student qualitative research interest group to which EO and SJ are members.

Findings

The results of this analysis represent the experiences of 23 health care and social care providers: 18 registered nurses (RN), three nurse practitioners, and 2 social workers. Participants represented both the NICU setting (n=7; level II and III NICUs) and the community or outpatient setting (n=14; public health programs or neonatal follow-up clinics) and two participants had experience working in both the NICU and community settings. The majority of providers from the community setting were PHNs practicing in Nurse Family Partnership programs across Ontario and British Columbia, Canada (n=11). All participants were women and had at least two years of practice experience; with four providers having over 30 years of clinical expertise (mean, 17 years; standard deviation, 8.9 years; range, 2-31 years).

What we learned from the providers interviewed for this study was, first and foremost, that having a baby in the NICU was perceived as a traumatic experience for the young mothers they cared for. The providers' accounts also spoke to the impact of this experience on these young women's lives – especially as they navigated new motherhood in the NICU. Also present in these providers' accounts was the influence of the NICU environment on how the NICU was experienced by young mothers. Consequently, our findings are presented in such a way that we first present the participants' descriptions of the NICU experience and its impact for young mothers and then present the perceived influence of NICU contextual factors on this experience – particularly how being “treated differently” often encompasses the entire NICU experience for young mothers. Figure 1 is a visual representation of the findings that also demonstrates how each of the patterns described below are interconnected, thus, highlighting the complexity of the NICU experience for adolescent mothers.

Figure 1: The NICU Context of Care and its Influence on the Experiences of Adolescent Mothers



NICU Experience and its Impact

Provider participants consistently spoke to the profound impact of the NICU hospitalization for their young mother clients. This experience was commonly described as traumatic and was seen to impact maternal-infant attachment, parenting confidence or competence, and maternal mental health or emotional well-being.

"A Traumatic Experience"

Many of the providers referred to the NICU experience as traumatic or traumatizing for all mothers; as this NICU nurse explained, "I think anyone who gets admitted to the NICU it's very much a bit of a traumatic experience." Among those who did not specifically label the experience as "traumatic", they instead described the types of emotional or psychological responses associated with traumatic events – such as fear, anxiety, and grief – among the mothers they cared for. One provider reflected on their 35-year career working in the NICU and how few parents were unaffected by the NICU experience – regardless of age or circumstances surrounding the infant's need for care:

> And that's the other thing that I've felt my whole career ... if you have a baby, you remember forever having the baby in an intensive care unit. And so, whether your baby was born really preterm or the baby had transient tachypnea and was not particularly sick ... I think that it is just as traumatic … it doesn't matter how sick you were, forever you will remember that you had a child in the NICU, and that's traumatic.

While the NICU providers recognized the traumatic nature of having one's infant admitted to the NICU in general, it was typically the PHNs who discussed the importance of the intersection between a stressful stay in the NICU and young mothers' previous experiences of trauma. These intersecting experiences were perceived as contributing to exacerbated levels of stress during an already complex parenting experience. For many of the PHNs in this study, their clients had experienced various forms of trauma and violence across their lifespan including interpersonal and structural racism, child abuse and/or neglect, and intimate partner violence. The fear and uncertainly of the NICU was experienced as another threat to which these young mothers had limited or inappropriate strategies to cope, as this PHN described:

> A lot of the NFP clients, you know, they've gone through some kind of trauma. So, dealing with all that social piece, and then on top of that if you were to have the NICU experience, depending on how that journey was … is an added stress to their life.

The potential for the NICU experience to re-traumatize vulnerable clients was similarly described by another PHN, however in this case the NICU was seen as having the potential to mitigate the experience of trauma. In the example described, the actions of an NICU nurse altered how the NICU was experienced for one young client when compared to another:

> She didn't have a great experience in NICU. So then that really traumatized her from all the other traumas. Right. But then I had another girl who had a beautiful experience in NICU, like the nurse was just ... she was just doing all sorts of cute little things with her. And just like adoring the baby and giving them lots of praise. And they loved that nurse. So they had such a great experience that they felt so much confidence going into parenting. Right. So, I think that's important.

This above quote also highlights the importance of understanding the potential impact of starting one's parenting journey in the NICU, especially if it is experienced as traumatic.

Impact on Attachment. Providers were very aware of the negative impact of separation of mother and infant when the infant's condition warranted NICU intervention shortly after birth; with both NICU and community providers describing the effects on parental attachment regardless of age. However, adolescent mothers were often seen as needing more support to overcome this separation and its potential impact on attachment; including support in establishing an emotional connection with their infant as well as tangible support overcoming situational, social, and economic forces that perpetuate the initial separation following delivery as the mother becomes a “visitor” of their infant in the NICU:

> I think one unique challenge, because of the forced separation there - it's getting [adolescent mothers] to commit to come back for the variety of reasons while baby's admitted ... the importance of them being there as often as they can [especially for] attachment, baby's physical stability and growth and development. So quite often there's a little bit more health teaching that has to go into that to encourage them to be there [in the NICU] because I guess just developmentally, they might not be ready to commit that amount of themselves without a lot of extra support.

Additionally, the skill and expertise with which the NICU nurses provided care to their patients was also seen as restricting or inhibiting the developing bond between mother and infant, as this PHN observed:

> So, I can only imagine ... [the young mother has] to sit there and watch someone else do it [provide infant care] with such confidence. You know, kind of watching the nurses do everything for [their infant] that I can't help but wonder if that impacts their bond or the attachment with their baby from the beginning.

In the NICU providers’ reflections on supporting younger mothers, they recognized the unique needs of this group within the NICU context; for example, younger mothers were seen to need more teaching related to basic parenting skills to increase attachment. However, this type of support, or practicing in such a way that included mothers and supported attachment with their infants was often viewed as difficult to operationalize in the NICU context.

Impact on Parenting Confidence and Competence. Beyond identifying opportunities to promote maternal-infant attachment, the NICU experience was perceived to impact the development of parenting knowledge and skills that served to support new mothers' confidence and competence in the transition to the maternal role. As analysis progressed, a paradox became evident; NICU providers understood the importance of focusing on maternal role attainment, but had difficulty integrating mothers into the care of their infant in meaningful ways that supported this growth:

> I think [there are] a lot of expectations that parents will be able to competently perform tasks like checking the baby's temperature or changing the diaper or calming the baby down. But we don't always step back to think, "Have we really walked a parent through how to do this when their baby is intubated or really sick?" You know, there's a bit of that fear, I think, from parents and I'm not sure we're always good at coaching them through it.

This impact on developing the maternal role was viewed as particularly challenging for "the younger ones more than the older moms." These challenges were perceived to be related to the busyness of the NICU as well as individual nurses' comfort and skill partnering with parents to provide care.

Challenges were also perceived to be related to the high level of needs, observed in or expressed by younger mothers, with respect to increasing parenting knowledge and skills when compared to adult-age mothers. Development of parenting capacity was not seen as a priority in the context of these young mothers lives as they were experiencing other life challenges such as poverty, mental illness, and experiences of poor parenting practices from their own childhood. Supporting this level of parenting need within the NICU was seen as a consistent challenge across NICU providers and something that could only be done in "an ideal world, if staffing was wonderful." Ultimately, this was problematic because, parenting skills and mothers' abilities to provide care for their infants were often the criteria by which providers judged the competency of a mother within NICU, as this NICU nurse highlighted:

> [Adolescent mothers] are placed in the NICU environment. It's very sterile. It's very regimented in what happens when … and [adolescent mothers] don't necessarily know what to do ... it's reflected poorly upon them in charting, and to the physicians.

The feelings of detachment from their infant, lack of confidence in the parenting role, and feelings of judgement based on parenting competence contribute to a vulnerable state for young mothers in the NICU and likely contribute to the NICU being experienced as traumatic. Maternal mental health or emotional well-being has a similar relationship within the overall NICU experience; such that the experience is perceived to affect young mothers' mental health and pre-existing mental health challenges can contribute to how hospitalization in the NICU is experienced.

Impact on Mental Health or Emotional Well-being. Young mothers' experiences of pre-existing mental health issues or the onset of perinatal mood disorders were described as a particular challenge by providers in the NICU. Social workers in the NICU saw supporting mental health or emotional well-being as a significant component of their role and nurses relied on social workers to provide this type of support for families. The NICU was also perceived to exacerbate experiences of mental health challenges for mothers of all ages, something NICU nurses felt ill-equipped to manage, as this NICU nurse describes:

> Yeah, I think that's not just the young ones, I think that's for everybody. And the push is not just the mental health issues, it's mental health issues when, you know, you've just had a baby, you're stressed and that kind of thing. It's just heightens

> everything. I honestly don't think we do great with that … I think one of the things we probably don't do as well as we could is supporting moms with mental health issues.

Many of the PHNs in this study were employed in programs that start working with clients early in pregnancy and provide regular support until the infant is two years of age; with weekly home visits in the initial postpartum period. These PHN participants, noted a need for emotional support in their young clients when infants were admitted to the NICU; often continuing their "home visits" in the NICU to provide this support to clients. Even mothers that were seen as coping well with other NICU related challenges (e.g., attachment and parenting) were often seen as struggling emotionally, as this PHN described:

> This mom did so well in the hospital. I can't even think of something that was really challenging except for what was going on emotionally. So, I did long visits sometimes at the hospital with her. But I was mostly supportive, listening and, you know, supportive guidance with her and reassuring her ... where you wouldn't do that in a home where mom brings home a baby, you would reassure the mom with the care. But this was more mostly emotional.

One PHN, who also worked in the NICU, described providing similar support to their clients in the NICU because they knew, from the NICU perspective, that this type of support can be lacking given the other demands on nurses' time in the NICU environment.

When pre-existing mental health challenges or the emotional impact of the NICU was not recognized or addressed, mothers often received the label "difficult," thus creating tensions with the care team and a breakdown in the therapeutic relationships between providers and parents. Mental health challenges left unaddressed, and perceptions of judgement were also perceived as contributing to ineffective coping upon discharge, prolonged emotional distress, and the overall assessment of the NICU experience as traumatic, as this PHN described witnessing in one of their clients:

> That's all she thinks about what she thinks of her labour and birth experience. So, she is pregnant with her second baby ... and I guess this is all she keeps talking about. So, I don't know if it's some kind of like a post-traumatic stress ... reflecting on their experiences and that fear and that worry of things happening again and feeling that judgement.

The provider accounts also spoke to the influence of the NICU environment, as part of the care context, on how the NICU was experienced by young mothers.

Influence of NICU Environment on the NICU Experience

From the providers' perspectives, the NICU environment had a significant impact on how care was experienced by young mothers; in some cases, environmental factors were seen as escalating or exacerbating the NICU's negative impact on maternal-infant attachment, parenting confidence, and maternal mental health. These factors included the fast-paced nature of care in the NICU and the lack of time for providers to assess for and then address social or emotional needs outside of hands-on care of the infant, the lack of privacy available in NICU spaces, the rigidity of rules especially related to infant care and visiting, and the accessibility of the NICU especially related to transportation and out-of-pocket costs.

"Time is not fair in the NICU"

Providers described the high degree of critical illness among infants in the NICU environment which required health care professionals to prioritize their time and actions to addressing the mostly physical health needs of the infant. This reality often then meant that less time was available to address other social or emotional needs of the family or any needs outside of “keeping those [on a ventilator] babies alive.” These needs included emotional support for parents, health teaching and even the interpersonal connection required for developing a therapeutic relationship with the mother and family, as this nurse described:

> And time in the NICU is not fair. I have the skill set and the ability to help these moms, but with all of the other constraints and the acuity that's happening, you just you can't do it. And I think that's a really hard spot to be in as a nurse and a provider, because we're not providing these families, especially young families, with the care they deserve.

The lack of time was also described around the time of discharge from the NICU. Despite discharge being perceived as a time of heightened anxiety for parents, with needs for parenting confidence and social emotional support at their peak, this time was also particularly seen as difficult to prioritize, as this NICU nurse described:

> And so it makes discharging effectively really difficult when you're [so busy] they kind of just don't get seen as an important thing in a way ... like it's important to go home but the process and getting them there somehow doesn't seem as important so much as the actual outcome.

Privacy

Many providers described limited opportunities to maintain family privacy in the NICU as a factor that contributed to the negative NICU experiences. This decreased privacy faced by mothers was seen as impacting the development of trusting relationships between parents and staff, contributing to the emotional toll of the NICU, and eliciting the general feelings of discomfort in the environment. Additionally, a PHN described the impact that witnessing others’ suffering or grief had on their clients:

> And I think they often see a lot of other things happen in the NICU that even if their baby's stable another baby they've gotten to know may not be. And so, I think just there's a whole lot of feelings that come with that. The guilt that

> someone else other than them struggled more in the NICU or just a feeling of fear, right ... stuff that they have to get off their chest and process a little bit.

Private rooms were viewed as the remedy for a number of issues related to privacy, however, communal spaces such as parent lounges and waiting rooms were perceived as potentially “hostile” for younger mothers, where there was potential for judgement from other families and visitors. Some providers also felt that private rooms contributed to feelings of judgement “because people are watching them all the time,” especially with health care providers’ expectations of near round the clock parental presence.

Rules and Routines

From the provider perspective, rules and routines in the NICU were experienced by parents as overly rigid and often contributed to restrictions on their level of comfort in the NICU and feelings of exclusion from their infant’s care. Visiting rules seemed to particularly impact young parents and other non-traditional family relationships. Visiting rules varied across the units represented by the providers in this study; for example, one unit limited visitors to parents and grandparents of the infant, where another did not limit who could visit but how many individuals could visit at a time and when (maximum of 2 individuals, but only parents within certain hours). NICU visiting guidelines were often a reflection of more traditional families (2 parents) or more traditional support patterns for women in the postpartum period (mother and her mother). These rules or guidelines demonstrated a lack understanding of the different types of support systems women may have outside of more traditional definitions; this was perceived as impacting the adolescent parents specifically:

> I know a lot of [adolescent mothers] ... their supports aren't necessarily immediate family. So, it may be friends, cousins ... what not. And here in our NICU there are specific visiting guidelines, so only parents and grandparents. So, I have seen that being a bit of a barrier where perhaps a friend is a support person ... exceptions are of course made, but I think that's a potential barrier to some of these girls and not feeling confident or having that assertiveness to say 'this my support ... I don't have a relationship with my mom ... blah, blah, blah'. So that sort of thing.

When questioned on this idea that support people in the NICU had to be parents or grandparents one provider reflected: “I mean, it doesn't ... in my mind it doesn't matter who ... what the relationship is ... if you've got a sort of a formal relationship through family, it's who is your best support.”

Rules and routines in the NICU also governed when care was provided (e.g., feedings, diaper changes, etc.) as well as the availability of staff to provide support. For staff, these routines maintained order in an otherwise chaotic environment. However, when reflecting on how they were received by parents, providers often reflected on how rules or timing of care could limit parents’ connection with their infant and promote the notion that parents are outside their infant’s circle of care. As this NICU nurse reflected:

> Like we only do things at certain times and it's like, 'oh, well, they always do this at this time on this day of the week and so they can't come right now'. [To staff] that’s understandable that they do those things. But I think to a family, it's kind of like, okay but that's their biggest need right now like they need to speak to that person. And so, I think sometimes there's rigidity around our routines and what we do, which I think can impair that trust, because I think that it sometimes doesn't feel to families like we're really family-centred. I think we say that we are. But in a lot of ways, I'm sure it doesn't feel like that to families.

Tailoring schedules or processes within the NICU to meet parents’ needs was seen as an exception rather than the norm, and parents that did not fall in line with the routine missed out on care or teaching opportunities, conversations with the NICU team, or were labeled as “disengaged.” The challenges with strict routines, especially related to timing of care and ability to engage with their infant, was seen to significantly impact parents with issues accessing the NICU; an issue perceived by providers as common among younger parents.

Factors that Limit Maternal Access and Engagement

Providers recognized that access to the NICU is a perceived challenge among many parents, but especially younger mothers or those representing other marginalized groups (e.g., newcomers to Canada). Access to reliable or affordable transportation to travel to the hospital on a regular basis was a perceived barrier that was observed to limit mothers' ability to spend regular or extended periods of time with their infant in the NICU. Most NICUs deliver care to families across large geographic regions and therefore many parents need to travel, sometimes significant distances, to be with their infant in the NICU. Younger mothers often did not have access to their own vehicle and therefore relied on rides from family members or friends or used public transit. Several providers shared that when this barrier was not recognized by NICU staff as an issue of access, it often became a point of judgement, as this social worker account highlights:

> I think travel is a really big one because here in [region] we have one centralized NICU now. And I know staff will say, like, you know, 'this mom ... she hasn't been coming in...', but is she is not able to get in? Does she not have money for a cab? She doesn't drive. She lives 45 minutes away from the hospital. How is she going to get there and how can we support her in getting there? I think that's a really big barrier.

Costs associated with visiting the NICU, such as food and drinks, were also perceived barriers to accessing the NICU that resulted in mothers spending less time with their infant; time that could contribute to maternal-infant attachment and development of parenting skills.

While ways to address these more tangible barriers to access, such as food, transportation, and parking, were discussed by providers, only a few recognized that the mother's perception of the NICU environment as unwelcoming or threatening in general may serve as an invisible barrier, as this NICU nurse described:

> Sometimes I think we do see families that maybe don't visit as much as we think that they should. And I think for a lot of families, that can be because they just may not even feel comfortable in the environment. They may not feel like they're welcome there. So, we might see that they're more absent than we would quote "expect them to be" with their infant in the NICU.

This understanding of the more psychological factors to accessing the NICU was seen as critical, especially for those experiencing mental health challenges, past experiences of trauma, and feelings of stigma as an adolescent parent in this environment.

"Treated Differently"

Physical and emotional separation leading to poor maternal-infant attachment, difficulties establishing parenting confidence and competence, and challenges with mental health or emotional well-being including potential for (re)traumatization is likely common, to a certain degree, among all mothers with infants in the NICU – with differences and distinctions observed across all demographic variables – not simply age. Even the providers in this study, who described scenarios and circumstances where the NICU experience was more challenging for younger parents, noted that this was not always the rule without variation. However, one common thread throughout the providers' accounts was that younger mothers' experiences of stigma or judgement – whether actual or perceived – served to underscore the entire experience of the NICU for this group. So, younger mothers may have similar experiences to adult-aged mothers on all of these levels previously described, but they also had to experience the age-related stigma and judgement.

Providers from both the NICU and community reflected on examples of young mothers being treated differently, and more negatively, compared to other mothers due to ageism. As this nurse who worked both in the NICU and as a PHN described:

> I've found as well ... just kind of the treatment of some of the younger girls is not necessarily the same as if they were a 30-year-old, educated individual ... [they are judged on their] outward appearance, involvement on their phones, the way they even interact with the babies.

Providers often observed implicit bias against younger mothers during staff handover or other staff-to-staff interactions with a common example of such bias being the qualification of a young mother's progress or success as being good "for their age." Providers also felt bias was present in nonverbal behaviours of staff or the perceived warmth offered some mothers versus those that appeared "rough" or "edgy."

From the providers' accounts, it was also clear that young mothers were often aware of this staff bias and/or differences in treatment based on their age. The result was an increase in mother's feelings of detachment from their infant and decrease in confidence in the parenting role, as one PHN described:

> So, [the NICU staff] would make comments to her about how the baby would be really fussy when the mom was around to the point where [the young mother] kind of stopped coming to visit the baby because they felt so uncomfortable and judged. And then they got judged for not coming to see the baby enough either.

This finding of stigma or bias against younger mothers was not viewed as a NICU exclusive problem; but a general societal judgment that motherhood should look a certain way. These societal views, however, impacted the way young mothers experienced hospitalization of their infant in the NICU, thus compounding the aforementioned effects of the NICU environment and leading to an NICU experience that is considered traumatic with consequences on maternal-infant attachment, parenting competence and confidence, and maternal mental health.

Discussion

To our knowledge this is the first study to ask NICU and community-based care providers about how the NICU context of care influences adolescent mothers' experiences of hospitalization of their infant in the NICU. In this study we were able to capitalize on the abundant knowledge and skill of these expert clinicians, who provided insight into the complexity of adolescent mothers' NICU experiences. We learned that the NICU care context, and how it is experienced, can have a significant influence on the adolescent parenting journey and that tailored approaches to reduce this impact, and set the course for post-NICU success, are likely required.

Reducing the impact of the NICU experience for young mothers

NICU and community providers want to contribute to the optimal health and development of the mother/infant dyads for whom they provide care, however, the impact of the NICU hospitalization serves as a significant barrier. The NICU experience was perceived to impact maternal mental health, parenting capacity, and maternal-infant attachment. Central to this issue was that providers in the NICU often had the knowledge and skills required to provide care that could limit this impact; however, the way care was delivered in the NICU limited the potential for success when faced with complexity or increased need – such is the case with adolescent mothers. Thus, findings suggest expanding the NICU interprofessional team to include members that are skilled in addressing complex social, emotional, and psychological needs could serve all parents experiencing the NICU better.

Expanding the NICU Interprofessional Team

NICU providers in this study, were experts in working as part of an interprofessional team and often relied on one another's knowledge and expertise to care for infants and families in the NICU. For example, nurses relied on the expertise of social workers to address social factors when they arose. The mental health impacts experienced by parents, both in the NICU and beyond discharge, have been extensively documented and were also a significant aspect of adolescent mothers' NICU experience (Beck & Woynar, 2017; Hynan et al., 2015; Treyvaud et al., 2014). Building on the interdisciplinary strengths of the NICU, additional layers of emotional support for parents, beyond nurses and social workers, are warranted. Hynan and colleagues (2015) describe best practices for supporting the emotional well-being of parents while in the NICU and mitigating the potentially traumatic NICU experience; these include, incorporating mental health professionals (psychologists, psychiatrists, and psychiatric nurses) as part of the NICU interprofessional team. These mental health professionals would be responsible for providing emotional support, screening for emotional distress, education, and psychotherapy for families. These professionals could also offer educational and emotional support for the NICU health care staff; as moral distress has become relatively ubiquitous with among NICU practitioners (Thorne et al., 2018).

Beyond mental health practitioners, the findings of this study point to the potential role that PHNs can play in supporting parents in the NICU. Many public health programs aimed at supporting healthy families focus on facilitating early attachment between mother and infant, teaching positive parenting strategies, navigating health and social services, and promoting healthy growth and development among infants and children. Recognizing PHNs as experts in these areas and integrating them into the NICU interprofessional team could support parents who have greater needs for developing parenting capacity and confidence as well as those who require additional layers of social and emotional support. The additional benefit integrating PHNs within the NICU interprofessional team would be the anticipatory guidance and continuity of care that these nurses could provide as parents transition home from the NICU; an important ingredient in post-NICU success (Fairless et al., 2020; Purdy et al., 2015). However, NICU and public health nursing collaboration remains relatively unexplored (Voie et al., 2018).

Despite the potential of additional supportive roles within the NICU, the stigma and judgement encountered by adolescent mothers as they interact with the health care system, including in the NICU as our analysis suggests, may contravene any benefit. As noted in a review on adolescent mothers' experiences of stigma, parenthood can be a positive transformative period in the lives of young women, however this potential can be rendered ineffective in the presence of stigmatizing interactions and low expectations from providers – such as those encountered in the NICU (SmithBattle, Punsuwun, et al., 2020). Adopting the principles of trauma- and violence-informed care (TVIC) within the

NICU could reduce feelings of judgement or discrimination, support the establishment of strong therapeutic relationships between parents and staff, and limit the traumatising effect of the NICU experience.

Trauma- and Violence-Informed Care in the NICU

A ‘trauma-informed’ approach refers to the delivery of health, social, mental and behavioural services, that accounts for possible experiences of trauma (Harris & Fallot, 2001; Knight, 2019). Expanding on this concept, trauma- and violence-informed care draws attention to forms of interpersonal and structural violence that individuals may experience (Public Health Agency of Canada (PHAC), 2018). The inclusion of structural violence is important because social structures within the NICU, such as visiting guidelines or transportation requirements, can reinforce inequities resulting in an uneven distribution of resources that could eventually lead to harm for the mother and/or her infant (Burton et al., 2020).

There are four, inter-related principles of a trauma- and violence-informed care approach which could be applied within the NICU: (1) understand trauma and violence on peoples’ lives and behaviours; (2) create emotionally and physically safe environments; (3) foster opportunities for choice, collaboration, and connection; and (4) provide a strengths-based and capacity building approach to support client coping and resilience (PHAC, 2018). Adopting a trauma- and violence-informed care lens in the context of the NICU, where providers understand the life circumstances of the mothers they care for, would help to acknowledge and reduce implicit bias toward adolescent mothers displayed by staff and the stigmatization experienced by young mothers. This approach could also lead to a recognition of the traumatizing effects of the NICU environment as well as efforts towards mitigation of these impacts; therefore, helping reduce harm related to re-traumatization from past exposure to violence and ACEs (Al-Sahab et al., 2012; Hillis et al., 2004). Additionally, strengths-based approaches or care would aim to see and understand the whole family – mother/infant and support persons – with the goal of understanding what is functioning well and what supports are needed to optimise functioning (Gottlieb & Gottlieb, 2017). This approach to care, that is non-judgemental and tailored to each mother/infant's unique circumstances could see the formation of trusting relationships between NICU staff and adolescent mothers, leading to engagement in care and overall parenting confidence moving forward (Quosdorf et al., 2020).

Adopting universal trauma precautions such as trauma- and violence-informed care, can improve system responses for everyone – not just those with trauma histories, as staff are equipped and organizations are more responsive to the needs of all people (Public Health Agency of Canada, 2018). Integrating trauma- and violence-informed care principles in the NICU could reduce the influence that the environment has on the NICU being experienced as traumatic (e.g., attention to issues of privacy and addressing rules that represent violent structures). Additionally, equipping NICU nurses and staff with trauma- and violence-informed knowledge and opportunities for skill development, similar to public health nurses working within mother/infant programs, could lead to strong therapeutic relationships between NICU staff and parents; necessary to mitigate the impact of the NICU experience and support maternal-infant attachment, parenting confidence and competence, and maternal mental health and emotional well-being. Specific examples of trauma- and violence-informed care principles in action in the NICU are outlined in Table 2. Public health nurses working within mother/infant programs are trained in trauma- and violence-informed care.

Strengths and Limitations

A strength of this study is perspective of the expert clinician. The voice of clinicians or providers can often go unrecognized when exploring phenomena experienced by patients or clients; however, providers can provide significant insight into the diversity and variation of health experiences on account of having seen many cases over time (Thorne, 2016). Additionally, providers in this study represent both the NICU and community setting, this is an important source of triangulation given the diverse perspectives of the NICU (i.e., providers internal and external to the NICU context). While the findings of this study provide a rich understanding of the NICU experience for young mothers, to develop and extend what was learned from this study, the experiences of young mothers, from their own perspective, need to be investigated. Additionally, the inclusion of other providers, beyond nurses and social workers, could further enhance analysis.

Participants in this study often avoided the term “adolescent” in their accounts of mothers’ experiences in the NICU because of the strict age boundary associated with the term; they favoured the term young mother and often discussed factors beyond biological age (e.g., cognitive development) in this definition. This could lead to some confusion as strict boundaries are often required when quantifying an experience, but the edges of these boundaries are softer when speaking qualitatively about a group and their experiences. Defining young motherhood is a potential direction for future conceptual work.

Conclusion

This analysis presents critical insights into the NICU experiences of adolescent mothers from the perspective of providers involved in their care. Understanding these experiences serve as an important foundation for improving care for adolescent parents both in the NICU and as they transition to home a community. Based on the traumatic nature of the NICU experience for many parents, NICU nurses have the opportunity to lead the adoption of trauma- and violence-informed care principles within the NICU; leading to reduced harm experienced by parents, especially young mothers, while providing safe and responsive care to all NICU families. In efforts to support parenting competence and confidence, maternal-infant attachment, and emotional well-being of young mothers in the NICU; conceivable collaborations between NICU nurses and public health nurses require further exploration.

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Table 1: Actions Supporting Trauma- and Violence-Informed Care (TVIC) Principles in the NICU

TVIC Principles	**Actions supporting Trauma- and Violence-Informed Care in the NICU**
Understand trauma and violence on peoples' lives and behaviours	• Provide staff education on trauma, violence, and its effects with a specific focus on the families and communities the NICU serves • Provide staff education related to the principles of trauma- and violence-informed care • Promote staff understanding of the parent/family experience of the NICU through sharing resources, workshops, and listening to the voices of parents
Create emotionally and physically safe environments	• Ensure welcoming and comfortable physical environments with an emphasis on both physical and emotional safety • Perform a trauma walk-through of the NICU and surrounding spaces • Provide access to food, water and basic personal care items for parents in the NICU • Review policies and procedures to ensure alignment with trauma- and violence-informed care principles
Foster opportunities for choice, collaboration, and connection	• Support parents' choice in determining their support person in the NICU • Create routines based on parents' preferences where possible rather than unit/provider preference (e.g., care routines, rounds) • Encourage models of care that focus on hands-on care by parents with support by nurses and NICU staff
Provide a strengths-based and capacity building approach to support client coping and resilience	• Support parents in recognizing their own strengths and self-care strategies • Provide sufficient time and resources to support meaningful engagement between NICU staff and parents

CHAPTER FIVE

TITLE: Transition home from the Neonatal Intensive Care Unit for adolescent mothers and their infants: An interpretive description of care providers' perspectives

AUTHORS: Orr, E., Ballantyne, M., Gonzalez, A., & Jack, S. M.

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Abstract

Pregnancy and parenting in adolescence and the transition home following the hospitalization of an infant in the neonatal intensive care unit (NICU) are two relatively complex phenomena; and while each have been consistently explored within the relevant literature, little is understood about their intersection. Using interpretive description methodology to guide our exploration, we conducted in-depth semi-structured interviews with 23 expert providers caring for adolescent mothers involved in NICU-to-home transitions to describe this process in their practice. A constant comparative analytic approach was applied as well as a process of iterative diagramming. Findings suggest that successful NICU-to-home transitions for adolescent mothers, or mobilizing forward, relied strongly on understanding the impact of the NICU experience, establishing therapeutic relationships, and facilitating supportive partnerships between the NICU and mothers, and the NICU and supportive services post-discharge. Findings highlight the opportunity for more integrated models of care within the NICU and extending into the community, to address the complex biopsychosocial care needs of this unique group of mother/infant dyads.

Keywords: Adolescent mothers; intensive care units, neonatal; transitional care; qualitative interpretive methods

Background

Adolescent Mothers and the Neonatal Intensive Care Unit

Experiences of pregnancy and parenting in adolescence are associated with maternal factors including lower educational attainment, housing instability, exposure to violence (Al-Sahab et al., 2012), adverse childhood experiences (ACEs)(Hillis et al., 2004; Smith et al., 2018), mental health disorders (Vigod et al., 2014), and higher rates of smoking and substance use (Fleming et al., 2015). Furthermore, this constellation of factors contributes to poorer health and social outcomes among adolescent women and their children, with social determinants of health inequities more likely at the root of negative outcomes than maternal age alone (SmithBattle & Leonard, 2012). However, even when controlling for significant sociodemographic factors, infants born to adolescent mothers (age < 20 years) are at an increased risk for preterm birth, low birth weight, and congenital anomalies, making these infants more likely to require hospitalization in a neonatal intensive care unit (NICU) shortly after birth (DeMarco et al., 2021; Shrim et al., 2011).

The experience of a critically-ill infant in the NICU environment is a frequent source of stress, anxiety, depression, and grief; with subsequent need for increased social and professional support for all-aged parents (Caporali et al., 2020; Hynan et al., 2015; Soghier et al., 2020). Additionally, these emotional and psychological outcomes are pervasive and continue well beyond the infant's discharge from the NICU; with studies reporting ill-effects up to seven years post-discharge (Beck & Woynar, 2017; Treyvaud et al., 2014). For adolescent mothers, these emotional and psychological outcomes associated with the NICU experience intersect with the social, psychological, and economic difficulties associated with adolescent motherhood. Therefore, for an adolescent mother, admission of their infant to the NICU exacerbates an already complex situation. Mothers less than 20 years of age make up approximately 15% of the NICU parent population (de Jongh et al., 2012; Walsh & Goser, 2013) and while the experiences of adult-aged parents in the NICU are well documented (Al Maghaireh et al., 2016), the unique experience of the adolescent mother within the context of the NICU is poorly understood. This gap in the knowledge base was highlighted in a review by Rosenstock and van Manen (2014); with little addition to the literature since this review was completed. This void is perhaps most profound when seeking to understand how adolescent mothers experience the transition from hospital to home and community following discharge from the NICU.

Transition home from NICU

In general, transition to home post NICU discharge has been explored within the health literature. These studies range in focus from preparing for or facilitating discharge among infant/parent dyads (Boykova, 2016; Lopez et al., 2012); describing the development, implementation and evaluation of discharge programs or interventions (Brodsgaard et al., 2015; Garfield et al., 2016; Toral-Lopez et al., 2016), and documenting parental perspectives, experiences, or emotional responses related to discharge and transition-home both qualitatively and quantitatively (Aydon et al., 2018; Enlow et al., 2014; White et al., 2017). Adolescent parents, however, are not the focus of these discussions; additionally, many of the participants in these studies are significantly older than the adolescent age-group. So, while it is possible to apply adult-focused findings to the adolescent population, failure to consider the unique developmental stage of the adolescent mother and the relative complexity of her pregnancy and parenting situation could lead to care that is un-informed and unable to meet her needs and the needs of her infant.

Another limitation of the NICU-to-home transition literature is the principal focus on the situational transition of hospital-to-home; without considering other transitions that overlap and intersect with this transition (Orr et al., 2020). Meleis' middle-range Transitions Theory helps both researchers and practitioners understand that transitions are periods characterized by uncertainty and disconnectedness, where there are losses of networks and social supports, and therefore individuals experiencing transitions are in a vulnerable state and often require intervention to facilitate healthy transition and enhance healthy outcomes following transitions (Meleis, 2010). Importantly, Transitions Theory describes four types of transitions: (a) developmental (e.g., becoming a parent); (b) situational (e.g., discharge from hospital); (c) health-illness (e.g., illness recovery); and (d) organizational (e.g., structural reorganization) (Schumacher & Meleis, 1994). Recognizing the diversity of transition-related circumstances, and as these types of transitions are not mutually exclusive, the theory emphasizes the added complexity of multiple transitions occurring simultaneously (Meleis et al., 2000). Thus, transition experiences of adolescent mothers with infants discharged home from the NICU are an example of this complexity; while navigating the situational transition of coming home from the NICU, an adolescent mother is simultaneously experiencing the developmental transition to motherhood; the health-illness transition of parenting an infant with complex health needs and/or risk for developmental delay; all within the context of the complex developmental transition to adulthood (Orr et al., 2020).

Problem, Purpose & Research Question

The unique social, psychological and developmental context of the adolescent mother combined with the complexity of NICU-to-home care transitions, underscores the need for an age-specific understanding of these experiences and supportive care needs post-discharge. This understanding could inform practices and policies, beginning in the NICU and continuing beyond the acute care setting, to address the complex biopsychosocial care needs of this unique group of mother/infant dyads and to ensure focused and holistic care. Therefore, to begin to understand this complex phenomenon, we explored how providers caring for adolescent mothers involved in NICU-to-home transitions view this process in their practice. We asked: what can be learned from providers' perspectives about the experience of transitions from NICU to home for adolescent mothers? The provider perspective in applied health research, acknowledges that expert practitioners are a significant source of qualitative data related to a particular phenomenon on account of having seen many cases of the phenomenon over time (Thorne, 2016). The experiences of the NICU-to-home transition from the mothers' perspective is also being studied, this study remains ongoing.

Methods

Designed to meet the unique knowledge needs of applied disciplines, in particular the pragmatic aims of applied health research, interpretive description was used to guide the methodological decisions for this study (Thorne, 2016). The nursing disciplinary orientation was applied in the interpretive phase (Thorne, 2016). This approach leads to findings that are relevant to the discipline and ready for application within the applied health context versus those that are too abstract or theoretical to be meaningful.

Recruitment

Following ethical approval from the Hamilton Integrated Research Ethics Board (HiREB # 5089) and scientific approval from partnering Public Health Units (PHU), we recruited providers involved in the transition experience for adolescent mothers. Recruitment partnerships were established at seven sites; four NICUs located in southern Ontario, Canada and three PHUs covering the same geographic area. Partners distributed recruitment emails to relevant team members; interested participants then received a direct email invitation from the Principal Investigator (EO). The study was also presented at both NICU and PHU research rounds with a recruitment invitation following the rounds. A process of snowball sampling elicited referrals from study participants, who, with permission, were contacted by the Principal Investigator with an email invitation to participate in the study.

Study participants

To represent provider perspectives inclusive of the transition process, the intended participants for this study were interprofessional team members involved in the care of adolescent mothers and their infants both in NICU and community settings. Specific criteria for inclusion were not prescribed to allow for a broad range of perspectives based on discipline, role and practice setting. Providers were included if they self-identified as a health care or social care provider having had experience supporting adolescent mothers with an infant in the NICU. Findings for this study are grounded in the professional experiences of 23 health care and social care providers. Of these 23 participants, the majority were registered nurses (RN) (n=18) and nurse practitioners (NP) (n=3); 2 participants were social workers (SW). Participants represented both the NICU setting (n=7; level II and III NICUs) and the community or outpatient setting (n=14; public health programs or neonatal follow-up clinics) and two participants had experience working in both NICU and community settings. The majority of providers were from southern Ontario; however other regions of Ontario and Canada were represented. All participants were women and had at least two years of practice experience; with four providers having over 30 years of clinical expertise (mean, 17 years; standard deviation, 8.9 years; range, 2-31 years). About three-quarters of the participants (n=16) held a bachelor's degree and the remaining participants held master's degrees. Partial demographic data was missing for one participant.

Participants represented two groups based on recruitment and data collection strategies; 17 were recruited and interviewed for the sole purpose of this study, while six additional participants were part of a purposeful extension of the sample to include public health nurse (PHN) participants from the British Columbia Healthy Connections Project (BCHCP) process evaluation (Jack et al., 2015). In the BCHCP study, PHNs delivering the Nurse-Family Partnership® (NFP) – a targeted public health intervention program aimed at improving maternal-child health outcomes for young pregnant and parenting adolescent girls and young women through nurse home visiting (Olds, 2006) – were interviewed eight times between 2014 and 2018. As co-authors of this study (SJ, AG) were also lead investigators of the BCHCP process evaluation, questions related to nurses' experiences of providing care for clients who experienced hospitalization of their infant were purposefully added to the seventh cycle of one-to-one PHN interviews to provide additional data for this study reported here.

Data collection

Individual, semi-structured interviews were used as our data collection approach. Written informed consent was collected prior to the scheduled interview, with a verbal confirmation of consent conducted prior to commencement of questioning. Interviews were scheduled at a mutually convenient time and were conducted in-person (n=2) or by telephone interview (n=15). Researcher field notes were recorded following the interviews and included relevant contextual information as well as initial analytic impressions. Participants received CAD$15 gift cards as a token of appreciation.

Interviews ranged from 30-65 minutes in length, and all were digitally recorded and transcribed verbatim. A semi-structured interview guide was developed to guide the direction of the interview; however, most participants reflected freely on their experiences supporting adolescent mothers both in the NICU and the community, touching on the challenges encountered by providers as well as the perceived challenges to mothers with little prompting. All providers were asked to imagine the ideal support for mothers transitioning home from NICU – whether a program, role, or resource – and to describe what this support would look like.

Six nurses from the BCHCP process evaluation (of the 12 interviewed) spoke to the experience of supporting a client with a hospitalized infant; these transcripts were included in this study to further extend the understanding of this type of support for vulnerable young mothers while in the NICU and in transition home.

Data analysis

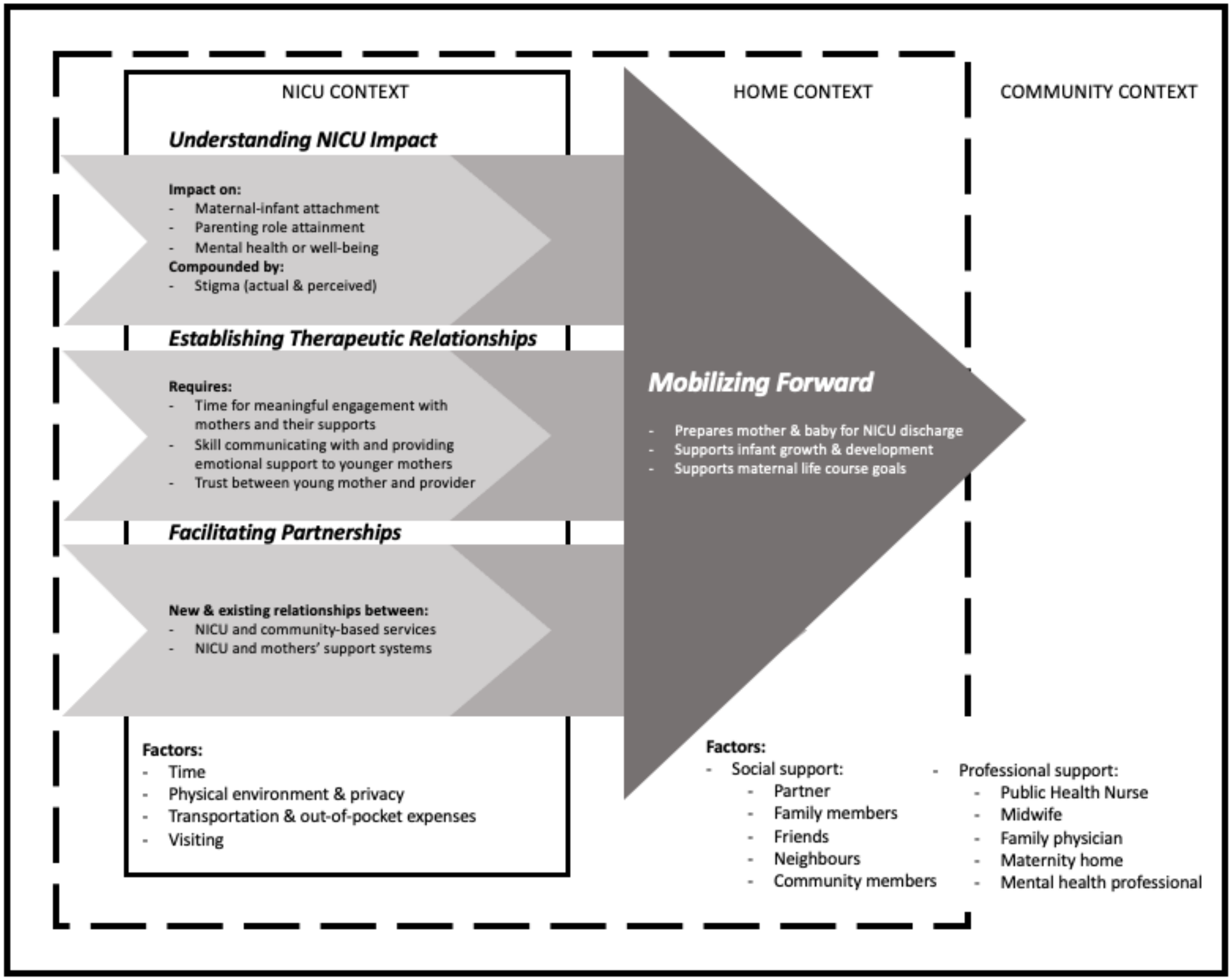
We used a concurrent data collection and analysis approach, with data analysis commencing following completion of the first interview. This approach informed the recruitment of participants practicing in specific roles related to the NICU-to-home transitions, (e.g., nurses who practice both in the NICU and the community and hospital-based public health liaison nurses). Consistent with interpretive description, the analytic process was inductive and began with immersion in the data set (transcripts were cleaned by listening to the audio recording, then transcripts were read and re-read to fully familiarize oneself with the data). A constant comparative analytic approach was then applied, comparing similarities and differences both within and across cases; with the intent of our applied research question remaining at the forefront (Thorne, 2016). Developing patterns were defined, described and challenged in analytic memos and relationships between patterns were explored through a process of diagramming (Campbell et al., In press; Terry et al., 2017; Thorne, 2016). Primary analysis was completed independently by EO however, a sample of transcripts were reviewed and discussed among team members (SJ, AG, MB), and developing patterns were discussed as a research team throughout the analytic process.

Findings

Providers interviewed for this study offered critical insights into the NICU-to-home transition experience for adolescent mothers. Their ability to see their own practice through the eyes of these mothers entering their care, both in the NICU and community, displayed a deep level of compassion and concern for this population. What we learned from providers, regardless of where they encountered young mothers along the NICU-to-home continuum, was that their overall aim was to keep their patients/clients moving forward – whether in health or broader life course goals – throughout the NICU hospitalization and beyond discharge. Thus, our findings are structured in such a way that we first highlight the providers' goal of successful NICU-to-home transitions for adolescent mothers or *mobilizing forward*, then we illustrate each of the patterns from our analysis that support this overarching goal *understanding impact*, *establishing therapeutic relationships* and *facilitating supportive partnerships*, and finally we explore the influence of NICU, home, and community contextual factors related to successful NICU-to-home transition. *Mobilizing forward* is depicted in Figure 1 and illustrates the relationships between the described patterns as well as the overall directionality of our findings.

It is also important to note for the analysis, that participants often avoided the term "adolescent" when speaking of the mothers they supported because of the strict age boundaries associated with this term (typically 13-19 years). Both NICU and community providers preferred the term "young mother" and cited multiple factors, beyond biological age, that contributed to this classification (e.g., social, emotional, and cognitive, development, as well as levels of social and economic support contributed to their determination). From the providers' perspective the term young mother generally includes young women and girls ages 15-24.

Figure 1: Mobilizing Forward



Mobilizing forward

Providers consistently spoke to their role in supporting the transitions from NICU to home and community for the young women they cared for. The overarching goal across the providers' accounts was "*mobilizing forward,*" or making progress toward certain health and life goals for both mother and infant. For the NICU nurse, these goals were often connected to the health or stability of the infant in relation to readiness for discharge from the NICU, for example achieving a goal weight for the infant, establishing a specific feeding method, or intake volume. Mobilizing forward from this perspective was also associated with the ability of the mother to care for their infant. While NICU nurses did not ignore the importance of safe and supportive home environments prior to discharge from the NICU, ensuring these were in place was primarily the role of the NICU social worker. For example, this NICU social worker explained the importance of ensuring social support for younger mothers as discharge from NICU approached:

> To make sure that they have the supports when they leave right ... so they have a good support system at home and in the community who can assist them moving forward. Especially in the home. Right. Or close to the home. And if they're living on their own. You know 'who is going to be living in the house with you? Who's going to be supporting you? Who's going to be assisting you?' Kind of talking to them about postpartum and isolation and moving them toward understanding that you kind of need to have a support system to move forward.

The variances in what *mobilizing forward* looked like to providers or how this was achieved were not just appreciated across disciplinary perspectives (i.e., between nursing and social work); nurses in distinct roles or programs also described this overall goal differently. For example, PHNs and nurses involved care post-NICU discharge (e.g., neurodevelopmental follow-up) had a broader and more long-term perspective of successful transitions when compared to NICU nurses. These nurses were concerned with outcomes including infant growth and developmental milestones and general health and life course markers for mothers. One PHN, who worked in a home visiting program, explained:

> So, we care about [mothers] too, so getting them mobilized with their schooling, their work, whatever they need is really important for their mental health, and for everything. Right? So, we really work on their parenting skills, obviously. Right? But also getting mom mobilized so she can move on with life and get out of that cycle of poverty.

These distinctions underscored an important characteristic of *mobilizing forward*, that it was multifaceted and involved the consideration of a variety of complex aspects to be successful, including infant health, growth and development, parenting capacity, social and economic support, and general life course factors. What also became apparent across the analysis of this pattern, was that the success of *mobilizing forward* relied on specific actions taken by health and social care providers both in NICU and community settings. These actions included: *understanding* the impact of the NICU experience for young mothers, *establishing* therapeutic relationships with these patients/clients, and *facilitating* supportive partnerships that connected the NICU with the home and community. These actions, and how they support mobilizing forward, will be considered in follow paragraphs.

Understanding Maternal Impact

Providers consistently raised the issue of the profound, and predominantly negative, impact of the NICU hospitalization for young mothers; so much so, that a separate analysis describing how the NICU environment is thought to influence the care and supports provided to adolescent mothers from the provider perspective was warranted (Orr et al, 2021, submitted). Providers described a stay in the NICU as “a traumatic experience” for parents. Based on their extensive experiences, providers spoke specifically to the impact of the NICU environment and the overall hospitalization experience on maternal-infant attachment, confidence and competence in the parenting role, and maternal mental health or well-being. These impacts were in addition to, or in some cases compounded by, experiences of actual or perceived judgement or stigma from the care team as well as others within NICU (including other families and visitors).

Understanding Maternal Impact for Mobilizing Forward

From the providers’ perspective, the hospitalization of one’s infant in the NICU is such a profound experience that *mobilizing forward* required an acknowledgement of this impact for support to be effective, as this provider summarized, “these girls, they recognize, and they see somebody that supported them in a really tough time.” Community providers also spoke to the impact on the mother’s mental health post-NICU, in particular the anxiety felt related to the infant’s well-being. They also described the impact on the development of parenting skills and confidence as well as bonding with their infant beyond the NICU stay:

> Well, I think it affected their confidence in terms of their own abilities to take care of these little babies. Because I think these young women already struggle with that and are judged by so many random people just by you know their look and their age. And I think in some part it affects their bond or their attachment with their babies from the beginning.

Providers also recognized the need to tailor their support in such a way that accounted for the impact of the NICU. A PHN described this kind of tailoring:

> And then parents get really fixed on the routine of being in the NICU. Right. So, they're feeding every three hours, you know. You know, they're used to looking at their vitals all the time and, you know, anticipating a spell. So then when they do go home, especially when I do see a family that had a baby in the NICU and had that public health experience like a home visit. You know, they're really fixed on that routine still. So, when they're home and the babies now doing really well and, you know, you're trying to normalize the care that they're doing at home.

We learned that providers also rely on strong therapeutic relationships to mitigate the impact of the NICU experience. However, these relationships were often difficult to establish, particularly with adolescent mothers.

Establishing Therapeutic Relationships

There was a pattern across providers' descriptions of the NICU-to-home transition that highlighted the importance of establishing therapeutic relationships with the mothers; a process that required both time and skill and centred around trust. Many providers, from both the NICU and community, described the increased length of time it took to establish a therapeutic relationship with an adolescent mother; something that NICU providers felt could not always be prioritized above the tasks of providing physical care to critically-ill infants, as this NICU nurse described:

> Sometimes you're so busy, you don't necessarily have, you know, maybe the half hour that she needs to sit and talk, because if you've got three babies and they're due [to feed] every two hours, like you're on your feet the entire time.

Different factors supported developing skill or expertise engaging with young mothers. Public health nurses often reflected on specific training, such as motivational interviewing or trauma- and violence-informed care that became part of their practice and ability to connect with their clients. The skill of establishing therapeutic relationships was also seen as developing with practice over time:

> So, I really know that vulnerable client and how to engage them …I really make sure it's trauma informed, too … that's really important because some of these girls have ... for being so young, have such traumatic histories, with sexual assaults ... so much trauma. Right. And I think it's just nice to have like been around.

It is possible that these skills may be lost or undervalued in the high-tech, fast-paced, medically focused environment of the NICU. Alternatively, NICU nurses are skilled at working within an interprofessional team and have the resources, such as social workers, available when their individual skills may be limited. Having someone else on the team with the skills to connect with young mothers and provide psychosocial care may contribute to NICU nurses perceiving this type of care as not within their role:

> I think it's sort of perceived as not being an ICU nurse's job in a way. I also think we don't necessarily ... there might be a discomfort among nurses in engaging in that kind of conversation or care because maybe we feel like we don't know how ... so maybe people feel like they don't know how to ask families in that situation what they need, how we can help them. Maybe there's also a lack of understanding about what is out there to help serve these families ... like in the community. But I do think it's a little bit of 'oh that's not my job', you know?

The difficulty with leaving the more challenging therapeutic relationships to other interprofessional team members, such as social workers, is that nurses in this context are then unable to develop or practice these interpersonal skills themselves. Where encouraging strong interpersonal skills, across all team members, could decrease the discomfort providers feel when working with mothers and families that are more challenging to engage in a therapeutic relationship. Consequently, as providers become more comfortable with these interpersonal skills, the perception of judgement for young mothers in the NICU may be relieved as they witness being treated similarly as adult aged mothers.

Trust was seen as central to establishing any therapeutic relationship, but no single element was perceived as more vital than trust when providing care specifically to adolescent mothers:

> Honestly, I think that [trust is] one of the most important things that can happen, because I think we see the effect when it doesn't happen. [If trust is not established], I think it really feels like you're working upstream the rest of the time … I think that's really essential, especially for a young parent who may already have experienced, who knows, comments through the pregnancy or a sense from others that this was not a good thing, that they were expecting a baby.

This account from a NICU nurse also highlights, as discussed prior, that establishing trust can be difficult to operationalize in the NICU context where adolescent mothers feel judged, stigmatized or even traumatized by the experience. From one PHN's perspective, young mothers viewed the NICU as a "hostile environment" and mothers had to enter the "nurses' house" to be with their baby – when compared to the home visiting context where the nurse is a guest in the young mother's home and trust can be established more easily related to this more balanced relationship.

A significant barrier to establishing therapeutic relationships, in either context, was the parents' past relationships with child protection services or the perception that letting a care provider engage in a therapeutic relationship was only for the purpose of reporting to child protection. While not exclusive to the role, NICU social workers spoke specifically to this challenge:

> lots of times there's that barrier of that defensiveness sometimes of 'why are you talking with me' and 'are you just here because you are thinking I'm not capable to take care of this baby?' And so, getting over that hurdle and normalizing things that 'I'm here as a social worker here, a hospital social worker to provide you with support during your baby hospital stay just like I am for that baby in the bed next to you'. And, not making it about the fact that I'm seeing you because you're an

> 18-year-old mom. I'm seeing you because you are a mom who's had a baby who needs to be in special care nursery.

Some providers were able to skillfully navigate this and other barriers, while others felt that despite their best efforts, they were unable to connect with some mothers; leaving the providers worried about the consequences of the inability to engage with an adolescent parent, “so I think my challenge too is not having a ... the ability to have a better relationship with them and often, as they leave, [I]think, oh, my heavens, I hope their family doctor is on top them.”

Establishing Therapeutic Relationships for Mobilizing Forward

The ability to connect on a therapeutic level with adolescent mothers was also seen as essential to *mobilizing forward*. From the providers’ perspective, trusting therapeutic relationships moved young women forward in their health and life journeys because they felt supported in their NICU experience:

> We're there to care for all of them, not to take away control of their baby's care from them. I think that's really essential, especially for a young parent who may already have experienced, who knows, comments through the pregnancy or a sense from others that this was not a good thing, that they were expecting a baby. I think we have to work extra hard in those situations to develop that rapport.

Additionally, providers believed that adolescent mothers remained engaged in supportive programs and services post-NICU when they trusted the individuals connecting with them, “I think building a trusting, supportive, therapeutic relationship with [adolescent mothers] is really, really important to engaging them and to help them want us to come back right?”

Strong therapeutic relationships with understanding of the impact of the NICU experience contributed to *mobilizing forward* and NICU-to-home transition success.

However, these actions or this process was made easier when there was an effort to establish new relationships, or foster existing ones, with the aim of supporting young mothers in the NICU and beyond post-discharge.

Facilitating Supportive Partnerships

A third pattern across the providers' perspectives was that parents, and especially young mothers, faced several challenges during the transition home that pointed to a system that is disconnected, with numerous potential gaps that place the young family at risk of poor health and social outcomes. Recognizing and marshalling existing supportive relationships or facilitating new partnerships – that bridged the NICU and home/community divide – were seen as important in closing these gaps and supporting NICU-to-home transition success.

The need for partnerships was particularly clear as providers described the NICU discharge process or the context in which NICU discharges took place. Discharges were described as happening very quickly and were often accompanied by the pressure of managing other patients or overall unit bed-flow; new admissions would regularly drive the need for more stable patients to be discharged or transferred to a lower level of care. An NICU RN described this pressure and how ensuring parents were prepared for discharge became less of a priority within this context of competing demands:

> We had 72 [infants] for 68 beds last week … So how do you have time to adequately prepare a young adolescent mom and potentially her partner for discharge when you're putting out fires left, right and center, like you just need to get them out … if they're going home, make sure they have the referrals if they need them and then 'bye'. 'You have a car seat - cool - see ya'. It's awful. But that's what happens.

The pressure at discharge was not just felt by the providers but was also perceived to be felt by the parents; especially as the expectations related to their involvement in their infant's care increased.

Perspectives surrounding discharge, however, represented a large amount of variation in our analysis; with some providers speaking to a more organized and supportive discharge process. These accounts predominantly represented units designated for infants with less intensive care needs and included extra time “rooming-in” (round the clock care by parents in preparation for home) for adolescent mothers and referrals to supportive services in the community. However, a provider with experience in an NICU follow-up clinic setting still noted significant variation across different NICUs (albeit with similar levels of care designation) with regard to their discharge preparation processes:

> I'm not bashing [the NICUs]; it is just their resources and their focus ... But, you know, a baby that comes home from one level II community nursery [compared to a baby that comes to follow-up] from another ... there's huge variations in what their focus at discharge is.

The void of established pathways and/or therapeutic partnerships between NICU and community-based providers such as PHNs was evident in NICU providers' expressed sentiments of “hoping for the best”; as if there was no way of knowing if these families would succeed once discharged and that they were being released into an unknown system where there is just “hope” that families, especially those from marginalized groups – including young mothers, would be able to navigate successfully:

> Because honestly, I don't know how [the young mothers] do when they get home. We just hope that things go well for them and we never hear from them again.

> And you just hope that everything that they've learned when they were in the hospital, they're able to manage it at home.

Similarly, another provider shared:

> So, I think a lot of it's kind of like, you know, tell them what they need to know to get through these next four days and then the doctor will tell them everything. And probably not ... they probably go to their doctor for their well-baby [check-up] or whatever checkup and the doctor's like 'Okay, great. Yeah. So all's well.' And they still go home with no answers and no idea what they're doing ... and it's a little bit scary.

In contrast, when describing an NICU discharge that went well for her young mother client, this PHN emphasized the importance of partnering with community providers early and throughout the discharge planning process. In this case the PHN was brought into the NICU circle of care to help prepare her young client for discharge:

> I just had one that was discharged from NICU and we had a beautiful discharge conference, right? With [child protection services] and with the father of the baby and his mother, the client and her mother, and myself, everybody was there. So, I asked a lot of questions about, about the feeding, the preparation of the formula ... and all that kind of stuff. So that really helps when we are transitioning them. So, we know what to look forward to as far as whatever the concerns they had in NICU.

However, when probed about other experiences supporting clients in the NICU, this partnership between NICU and public health was more of an exception rather than a normal occurrence; a response that was echoed by other community providers. One PHN expressed that if the NICU staff were provided with inter-agency opportunities to learn more about public health nursing roles and services provided to their more vulnerable mothers, that partnerships could be facilitated in the future – despite seeming unrealistic:

> [Speaking to relationships between NICU and NFP] Realistically, I know that would never happen, but I think it's a nice thought. I know like even for me going between the two, like public health and hospital, I still get jabs from everyone saying, 'hey, you're not a real nurse, you have the cushy job'. So, they're not keen

> on public health to begin with. But I don't know ... I think honestly, more education surrounding these young moms, the higher risk and nature of health equity as well, because that's a big piece that I think the hospital staff is missing.

The potential for partnership between NICU and public health programming aimed at supporting mothers in the postpartum period was also emphasized by community providers that did not have pre-existing relationships with the mothers prenatally, but who are trying to connect with them and provide postnatal support:

> And we've had this discussion many times at our different tables of how to engage families while they're still in hospital so that we're a known support with a face to a name that families feel comfortable engaging with prior to leaving the hospital ... and just sort of have that soft transition in place before they're discharged as opposed to, you know, really relying on follow up after discharge, just start building the relationship, because I think the sooner that we can be involved and have face to face with a family

Thus, our analysis highlights a paradox in the NICU-to-home transitions experience for adolescent mothers. That is, NICU providers want to feel better about the support given to young families post discharge, rather than simply hoping for the best; and community providers were hoping to provide this type of support but needed to feel invited into this circle of care earlier in the NICU hospitalization – certainly as discharge plans were being made. Unfortunately, this type of coordinated support and NICU-community partnership was often only realized if the mothers themselves initiated it, as this PHN explained:

> The only way that I knew they were being discharged was that the moms tell me. And I'm always like 'have you got any word?' like that ... cause I know it's kind of a day by day process. I would say to them like 'if they tell you you're going home like let me know' so then we can ... I can plan to follow up with them very quickly in the community.

Facilitating Partnerships for Mobilizing Forward

Partnerships between the NICU and home or community were, from the providers' perspective, a core ingredient in mobilizing young mothers forward. NICU providers that understood the impact of the hospitalization for young mothers and who were able to establish therapeutic relationships still recognized the importance of partnership as part of *mobilizing forward*. This was seen as most successful when pre-existing home and community supports were identified and incorporated into the NICU circle of care:

> We have lots of moms who come in who are involved already with the Nurse-Family Partnership Program. And so that's really great because they're already working with the public health nurse during the pregnancy and they already have established that support network.

Even social support persons such as friends or family members were seen as vital – especially since the support of the NICU staff ends with discharge:

> Like maybe whoever is going to help, because usually there's somebody at home helping that teenager. Right. Like whether it's the mom, or grandma or partner or whoever. So just to engage them with the whole process of all the teaching that needs to go on. And it would be nice for [PHNs] to know what they've been taught too. So, if we got a copy of that, that would be really nice. So, we could reinforce that kind of stuff, too, at home.

As providers discussed the ideal support for adolescent mothers transitioning home from NICU, the 'who' of such a support system was discussed less specifically than the 'what'; and the 'what' most often included the concept of facilitating a partnership that starts in the NICU and continues beyond discharge. As this NICU provider described:

> So, I think having a person that can kind of talk the NICU talk and engage with the families while they're there and do some preliminary teaching, preliminary like I don't even want to just say teaching, but engaging with the family and even just speaking about life after the NICU and then actually be able to visit them at home once they're home. I think that would be so amazing. And that to me, like having a person that basically goes from the NICU stage to your home, like the

> same person that knows the family really well and maybe could work with the family like even after a year or something would be so amazing.

For public health providers that were already involved in young women's lives antenatally, they felt they were already providing a version of this ideal support, however NICU providers needed to recognize this existing support and tap into it to promote successful transition, as one PHN explained:

> I was like it would never happen, but having a relationship between the teams ... meeting us, getting to know us, getting to know our programming ... if there was a client and they were comfortable with the hospital calling and saying, 'hey, [nurse] I have blah, blah, blah in the nursery, do you want to come in and visit them?' Realistically, I know that would never happen, but I think it's a nice thought.

NICU, Home and Community Contextual Factors Influencing Mobilizing Forward

Mobilizing forward post-NICU for adolescent mothers, is the culmination of *understanding* the maternal impact of the NICU hospitalization, *establishing* therapeutic relationships and *facilitating* supportive partnerships between providers that can continue beyond the NICU and bridge the NICU and home/community divide. *Mobilizing forward* also requires a consideration of the influence of NICU, home, and community contextual factors related to successful NICU-to-home transition (see Figure 1).

NICU Context

From the provider perspective, the NICU environment can contribute to, and even escalate, the negative impact of the NICU experience for young mothers. Providers described the decreased privacy faced by mothers and how this can impact the development of trusting relationships between parents and staff. Additionally, the close proximity to other infants and families or the use of communal spaces such as lounges and waiting rooms (where privacy can be difficult), was also seen as contributing to the emotional burden experienced by mothers – as witnesses to others' suffering or grief. All of which can contravene *mobilizing forward*.

Provider participants also described the acuity (or high level of critical illness) of the NICU environment and the subsequent lack of staff time affecting the overall NICU experience. One provider, who had roles both within the NICU and as a PHN in the community described a tension between knowing how much she *could* support mothers in the NICU based on her knowledge and skill acquired from her PHN role, but that this was hampered by the NICU environment and demands placed on nurses' time in this context.

For many young mothers, access to reliable or affordable transportation to the hospital on a regular basis and then costs such as meals while staying at the hospital were common barriers that were perceived to limit mothers' ability to spend extensive and regular periods of time with their infant in the NICU, time essential for attachment and developing parenting skills and developing maternal role identity. While it was noted that this barrier was not exclusive to young parents, participants indicated that this was not always recognized by NICU staff as an issue of access and instead became a point of judgement.

Visiting rules or restrictions were another element of the NICU context that impacted the overall NICU experience and ultimately *mobilizing forward*. Based on providers' accounts, NICU visiting guidelines were often a reflection of more traditional families (2 parents) or more traditional support patterns for women in the postpartum period (mother and her mother). These rules or guidelines demonstrated a lack understanding of the different types of support systems women may have outside of more traditional definitions; this was perceived as impacting the adolescent parents specifically.

When the NICU care context was perceived to be negative or traumatic, or when the abovementioned factors were seen to undermine a young mother's parenting confidence or attachment to their infant, this was perceived to impede the *mobilizing forward* efforts and ultimately transition success. For example, providers caring for mothers post-NICU discharge described developmental transition difficulties such as trouble adjusting to the maternal role, as well as health-illness transition challenges such as ongoing mental health concerns including anxiety and depression, and fear of ongoing stigma. Additionally, when barriers such as cost or access were not addressed in the NICU, these were seen to continue post-discharge and had an impact on participation in neurodevelopmental follow-up and engagement with other supportive services for mother and infant, thus impacting the situational transition from hospital-to-home as well as the health-illness transition for the infant.

Home and Community Context

From the providers' perspectives, factors in the home and community that related to successful transitions from NICU to home – or *mobilizing forward* – centred around the relationships within these settings available to support young mothers and their infants during their time in the NICU and post-NICU discharge. These relationships were both social, including partners, family members, friends, and neighbours/community members, as well as professional, including midwives, family physicians, lactation consultants, PHNs, maternity home workers and mental health professionals. Recognizing the limits this type of support was another essential aspect of understanding the home and community context. An NICU social worker described the importance of identifying sources of social support as well as situations where the inclusion of more professional support may be needed; noting that there is significant range of support needs among the younger parent population. Importantly, when the NICU was able to recognize these support networks in the home and community – both social and professional – and facilitate partnerships that extended beyond the NICU, *mobilizing forward* was considered more likely to be successful.

Discussion

The purpose of this study was to explore what can be learned about the NICU-to-home transition experience for adolescent mothers from the expert providers that care for this population. Improving care transitions is a global priority (World Health Organization, 2016). With an increased focus on quality transitions from inpatient settings to the community – to curb costs associated with readmission rates, emergency department use, and adverse events post discharge (Health Quality Ontario, 2020) – our analysis adds to the available understanding of the NICU-to-home transition with a unique focus on adolescent mothers. Additionally, our discussion contributes to the evolving conversation of how to best support healthy transitions and, more specifically, on how tailored approaches can more meaningfully address the unique needs of the individual and overall transition success. The main element related to transition success in this study was the ability to partner with young mothers, their individual social support systems, and supportive services in the community.

Partnership in the NICU

Providers in this study consistently spoke to the importance of facilitating supportive partnerships as a core ingredient in mobilizing adolescent mothers forward in their health and life journeys. This finding was driven by the fact that the majority of community provider participants in this study deliver a targeted public health intervention program, the NFP home visiting program (Dawley et al., 2007). As NFP nurses, these PHNs understood the importance of partnering with young mothers and their support systems to promote optimal health and social outcomes for mother and infant. Importantly, these nurses also had the knowledge and skill to operationalize these partnerships. For NICU providers in the current study, while understanding the importance of partnership as a core principle of Family Centred Care (FCC) (FCC is the guiding framework for care and treatment most NICUs (Dennis et al., 2017), partnership appeared challenging to operationalize, especially with adolescent mothers. This finding of difficulty practicing according to the principles of FCC is supported by a recent review of parents' and nurses' experiences of partnership in the NICU context (Brodsgaard et al., 2019). Similar to the findings of the current study, this review concluded that successful relationships between parents and nurses depended on being respected and listened to, establishing trust, and allowing parents to develop competencies while negotiating roles. Furthermore, a study of former NICU families and their experiences of FCC found that perceived staff judgement and a lack of meaningful relationships with nurses contributed to unmet needs of partnership in care (Sigurdson et al., 2020). Together these findings point to a need to better operationalize the principles of FCC.

Family Integrated Care in the NICU

One shift that is currently occurring in NICUs in North America, is the implementation of the Family Integrated Care model (FICare) (O'Brien et al., 2013); a model of NICU care, based on FCC principles, that requires extensive parental participation in their infant's care and bi-directional communication with the NICU team (Hall et al., 2017). In addition to improving important infant outcomes such as weight gain and breastmilk feeding; evaluations of FICare have demonstrated decreases in parent stress and anxiety and improvements in parental confidence and role attainment (Broom et al., 2017; O'Brien et al., 2018). FICare was also perceived to require less hands on-care by nurses, thus leading to more time spent educating and supporting parents (Broom et al., 2017). FICare could go a long way in establishing supportive partnerships with young families, while also empowering parenting capacity that extends well beyond the NICU hospitalization (Hall et al., 2017; O'Brien et al., 2018). However, parent participants included in studies of FICare interventions are significantly older than the adolescent parent population, with mean participant ages over 30 years reported in the pilot study as well as subsequent evaluations of the intervention (Benzies et al., 2020; Broom et al., 2017; O'Brien et al., 2013); thus, further research evaluating FICare is warranted among adolescent parents. Additionally, strategies to reduce the actual and perceived stigma young mothers experience as they encounter health care and social care systems, including the NICU, need to be incorporated into any intervention aimed at promoting partnership, otherwise the effects of stigma could impede any benefit from such interventions (SmithBattle, 2020).

Partnership Beyond the NICU

While facilitating partnerships between parents and NICU staff is important, we learned from providers in this study that partnerships also need to extend beyond the NICU to ensure adolescent mothers are successful in their hospital-to-home transition experiences. While there exists a wide range of programs and services available to mothers and infants post NICU discharge, parents are often left to navigate these unfamiliar, complicated and fragmented systems alone (Murch & Smith, 2016). Parents become caught between systems with different priorities and funding models that are not built to handle complexity, thus leading to inequities in what is offered.

This problem was highlighted by our providers' accounts; NICU providers are not equipped to support the complex needs of the adolescent parent in the NICU and preparing for home, and community providers – who are equipped – are not brought in to the NICU circle of care to help fill these gaps. The literature supports the need for an integrated approach to NICU-to-home transitions with NICU and community providers having equal responsibility to pursue collaborative relationships with each other; understanding each other's languages, systems, and constraints (Murch & Smith, 2016).

Integrated Care

Integrated care approaches are being recognized as promising solutions to support transitions from hospital to home and community; with integrated care believed to be most effective among populations with complex care needs (Brown & Menec, 2018). Integrated care strategies may operate horizontally and or vertically. Horizontal integration links similar levels of care, for example community-based health and social services; where vertical integration links different levels of care, for example primary care and specialist or tertiary care (Valentijn et al., 2013). The findings of this study suggest both horizontal and vertical integration are needed to support the NICU-to-home transitions for adolescent mothers. This is supported in the integrated care literature where strategies reflecting both levels integration are often needed to counteract fragmentation of services within a health system (Axelsson & Axelsson, 2006; Valentijn et al., 2013).

The shift toward integrated care for NICU patients and families will require adopting shared goals and an integrated care culture across all levels involved in the integrated system (Valentijn et al., 2013). An example of such a shift in NICU practice is evidenced in a position paper calling for neonatal health care providers to accept the responsibility to address social determinants of health inequities among infants and families requiring neonatal intensive care (Horbar et al., 2020). In lieu of the traditional neonatal practice of *follow-up*, which focuses primarily on medical conditions and assessment of neurodevelopment post-discharge, authors propose *follow-through*, an approach focused on partnership between health professionals, families and communities to meet social as well as medical needs of infants and families. Adopting *follow-through* as a philosophy in the NICU could serve as a foundation to a more integrated approach to the care of NICU patients and families both within the NICU and beyond post-discharge.

Some features of integrated care initiatives include care coordination between care settings, use of individual care coordinators, home visits, and co-location of staff (e.g., community providers in the hospital) (Brown & Menec, 2018). Promising NICU initiatives that incorporate some of these features include, (1) the Calgary Neonatal Transitional Care Program, that uses Clinical Nurse Specialists to deliver neonatal follow-up, in the home setting, post NICU discharge (Lasby et al., 2004); (2) the Transition Home Plus program, that incorporated supportive services both before and after discharge from the NICU including social worker support post discharge, a home visit by a Neonatal Nurse Practitioner, and integration with primary care providers post-discharge (Liu et al., 2018); and (3) the Coached, Coordinated, Enhanced Neonatal Transition, a pilot intervention using a nurse navigator role, including care coordination up to 12 months post NICU discharge (Esser et al., 2019). Missing from these models, however, is the partnership with PHNs that that have the specific knowledge and skill related to navigating supportive services in the communities that the families live, as well as the expertise establishing relationships with adolescent mothers and mobilizing their support networks. Additionally, the presence of a provider who has an established therapeutic relationship with a young mother prior to the NICU (i.e., that begins antenatally) and who is providing support through home visits in the postpartum period and beyond (such as the Nurse Family Partnership), is valued by community and hospital stakeholders alike for the more seamless transition from community to hospital and back to community. This constant provider ensures that while the infant's medical needs are met in the NICU, someone familiar to the mother and family remains available to attend to their social, emotional, and educational needs.

Strengths and Limitations

While the findings of this study provide a rich understanding of NICU-to-home transitions for young mothers, they represent providers' perspectives of the phenomenon. Even though some participants had over 30 years of clinical expertise and spoke to supporting multiple cases of NICU-to- home transition; to continue to develop and extend what was learned from this study, the transitions experiences of young mothers, from their own perspective, needs to be investigated. The mother's perspective is especially important in understanding contextual factors in the NICU, home, and community that facilitate mobilizing forward. Many of the PHNs in this study were employed in programs that start working with clients early in pregnancy and provide regular support until the infant is two years of age; as such they can truly speak to the transition experience – as they are present both prior to hospitalization in the NICU and post-discharge. Participants in this study also identified several community providers/services that supported young women post-NICU discharge, including family physicians, midwives, and maternity homes. Providers in these roles/programs were not captured through participant recruitment, therefore, future study could explore how these programs/services facilitate NICU-to-home transitions for young mothers.

Conclusions

In this study, providers involved in the care of young mothers offered a critical look into the complexities of ensuring a safe and healthy transition-home for this population of mother/infant dyads. Analysis revealed key ingredients to support the goal of a successful NICU-to-home transition. However, this way forward was considered by providers to be idealistic or unrealistic within the current NICU and community structures, with only exceptional cases able to navigate successfully. Findings suggest that integrated models of care, focused on meaningful partnerships between and across systems, could ensure *mobilizing forward* for all families who experience hospitalization for their infant shortly after birth – and especially those most at risk.

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CHAPTER SIX

The overall purpose of this thesis was to explore the phenomenon of NICU-to-home transitions for adolescent mothers experiencing hospitalization of their infant shortly after birth. As described in the introductory chapter and presented in the chapters that followed (chapters 2-5), this thesis included an exploration of transition experiences from a theoretical perspective, an inquiry into data generation practices suited for the population of interest, and the results of knowledge generating research on NICU-to-home transitions from the perspective of health care and social care providers. In this final chapter, the findings from these four distinct manuscripts are integrated and summarized through a discussion of key contributions, implications of this work, and recommendations for research, policy, practice and education. While strengths and limitations are discussed within each of the individual manuscripts included in this thesis, additional strengths and limitations across the entire thesis will be discussed in this final chapter. This chapter will conclude with a description of knowledge translation plans for this body of work and final concluding thoughts.

Key Contributions

Findings from this thesis include key contributions to theory, methods, and knowledge related to the transition home from NICU for adolescent mothers as well as the broader nursing disciplinary knowledge base.

Theory

Chapters 1 and 2 of this thesis outline the exploration and critical examination of theory conducted at the outset this work. This work identified an important gap in the

NICU-to-home transitions literature, in that most inquiry on the topic is focused solely on the situational transition from the hospital setting to the home or community setting, and thus proposed a more comprehensive approach to understanding transitions that includes consideration of the other types of transition that may influence situational care transitions (e.g., developmental transitions, health-illness transitions, and organizational transitions). For adolescent mothers specifically, this more holistic theoretical perspective underscored the potential complexity of overlapping and intersecting transitions for this population, such that for an adolescent mother, at the time when her infant is discharged from the NICU, she is simultaneously experiencing (a) the transition to motherhood; (b) parenting an infant with complex health needs and risk for developmental delay; and (c) transitioning from the critical care environment to home; these transitions are all happening within the context of (d) transitioning to adulthood. This perspective was an important contribution to the theoretical literature in that it provided a specific example of Transitions Theory (Meleis, 2010) application, where multiple overlapping and intersecting transitions experiences exist; as well, it outlined the importance of including Transitions Theory in the current care transitions discourse. This theoretical lens also served as a foundation for both the exploration of using arts-based methods to explore young mothers' experiences of care and transition described in Chapter 3 (acknowledging the developmental factors at play during qualitative data generation with adolescents) and the knowledge generating research described in chapters 4 and 5 (addressing the adolescent-focused gap within the NICU-to-home transitions literature).

In addition, the work contained within this thesis adds to the wider nursing disciplinary knowledge base by demonstrating how deduction from theory can inform research and practice more broadly in the form of situation-specific theory. Deduction from theoretical work is an important step in the development of situation-specific theories, or theories that reflect clinical practice with specific populations or fields of practice (Im, 2021). The body of work included in this thesis outlines the initial steps in the development of a situation-specific theory explaining how adolescent mothers transition from NICU-to-home; (a) deduction from Transitions Theory and other nursing and developmental theories serve as a foundation for (b) induction from qualitative research exploring NICU-to-home transitions for adolescent mothers. With additional induction from future data generation and analysis of the mothers' perspectives of NICU-to-home transitions, a situation-specific theory can be developed. Situation-specific theories can be more applicable to nursing practice in that they incorporate the diversity and complexity of a particular population or field of practice, while respecting the original theoretical perspective (Im, 2021). This commitment to first exploring relevant theories at the outset of the research efforts, then incorporating this theoretical knowledge throughout the entire thesis process, thus leading to further theorizing, is a major contribution of this work within the nursing disciplinary knowledge base.

Methods

Chapter 3 of this thesis is a published manuscript exploring the issue of generating rich data from qualitative interviews when difficulties such as establishing rapport, power imbalances, and participant factors threaten the interview process and quality of data.

Each of these factors were potential challenges for interviewing adolescent mothers in this thesis study, however, the inclusion of arts-based drawing techniques served to mitigate these challenges, and it was posited that use of these strategies would result in an information-rich dataset and an overall positive interview experience for those interviews conducted. Unfortunately, the pause in data generation with mothers related to the global COVID-19 pandemic (March 2020 – ongoing), limited the ability to include findings generated through the use of these types of visual elicitation. Additionally, the knowledge translation potential of incorporating drawings, specifically timelines, in qualitative data generation remains unrealized. Despite this, the methods-based paper remains a key contribution of this thesis work.

In addition to the contributions made to the arts-based data generation methods literature, the prepared manuscripts in chapters 4 and 5 also serve to advance qualitative research methods related to, (a) the various sources of rich qualitative data in applied health research and (b) the use of diagramming as a method to facilitate and enhance qualitative analytic processes. First, each of these papers focus on the perspectives of health care and social care providers as a source of qualitative data related to the NICU-to-home transitions experiences of adolescent mothers. When the purpose of applied research is to harvest shared experiential knowledge so that it can sensitise providers or inform care, there is a role for providers as a rich source of qualitative data (Thorne, 2016). The data generation and analyses presented in chapters 4 and 5 capitalized on the fact that provider-participants had seen many cases of the NICU-to-home transition experience over time, and thus were able to spot variations and speak to patterns that may not be realized in interviews with mothers alone.

Second, the manuscripts in chapters 4 and 5 each include a figure or model to help represent the findings; particularly these visual representations aid in demonstrating the interconnections between the patterns or themes described in the text as well as elements of directionality arising from the analysis. Using graphics to illustrate major patterns or themes developed during analysis for an at-a-glance review is common in qualitative research (Miles et al., 2020), however, using graphics or drawings can also be an important component of the qualitative analysis process. Reflexive thematic analysis (RTA) incorporates thematic mapping or use of visual aids as part of the analytic steps of RTA (Braun et al., 2019). These tools are to enhance the researcher's ability to identify and understand potential themes in relation to each other, and the overall dataset; yet this step is rarely explicated in the literature, resulting in little guidance on how to advance analysis using diagrams. The graphics displayed in chapters 4 and 5 were the result of an iterative process of diagramming, whereby developing patterns and relationships were drawn and then re-drawn throughout the data analysis process. Concurrent with defining and organizing patterns through written analysis, the process of diagramming served to advance the depth of interpretation beyond description, a critical factor of interpretive descriptive studies (Thorne, 2016). Additionally, diagramming not only resulted advancing the interpretation of the written findings but the final display provided a visual framework for the reader to further understand the findings that are otherwise difficult to convey in writing.

New Knowledge

A lack of understanding of transition home from NICU for adolescent mothers combined with the complexity of overlapping and intersecting transition experiences, described in the introduction to this thesis, warranted knowledge generating research. The findings presented in chapters 4 and 5 of this thesis contribute to a deeper understanding of this experience from providers' perspectives. The general experiences of adolescent mothers in the NICU care context, with the exception of a small (sample size = 4) master's thesis (Bocock, 2012), have not been described in the health literature. Therefore, the findings presented in Chapter 4 are a novel contribution to this knowledge base. These findings are important because they contribute to a better understanding of the challenges encountered by young mothers within the NICU context that can then lead to more empathic care and/or interventions reflective of the impact of the NICU hospitalization on young mothers. Similarly, understanding NICU-to-home transitions for adolescent mothers was a gap within the literature, specifically research using qualitative methods and that approached the topic of transition holistically, as a process rather than a time-point (i.e., the date of discharge), was lacking. Thus, the findings presented in the preceding chapter represent another significant contribution to both the nursing knowledge base as well as the broader hospital-to-home transitions literature.

Implications and Recommendations

This thesis work has important implications and recommendations for research, policy, and nursing practice and education; the following sections will discuss each of these areas in turn.

Research

The findings of this thesis suggest a number of implications for further research related to NICU experiences and NICU-to-home transitions for adolescent mothers; first and foremost, these experiences need to be explored from the mother's perspective. Additionally, the COVID-19 global pandemic has highlighted a need to explore virtual methods for qualitative data generation – in particular adapting arts-based methods within these approaches.

The Maternal Perspective

This thesis work addresses important gaps in understanding adolescent mothers' experiences of the NICU as well as transitions from hospital-to-home for these mother/infant dyads. However insightful, these findings are from the perspectives of health care and social care providers working with young women experiencing NICU hospitalization of their infant. From the available literature we understand that parents in the NICU experience stress, anxiety, depression, and psychological distress (Roque et al., 2017) and that symptoms of post-traumatic stress disorder are present among NICU parents well beyond discharge of their infant (Schecter et al., 2020). We also know that parents experience the NICU differently based on different factors; for example, older parents, with higher levels of education, perceiving respect and understanding from health personnel, and higher levels of support from family or friends are more satisfied with their NICU stay (Hagen et al., 2019). Findings presented in Chapter 4 may suggest that younger parents experience greater psychological symptoms in the NICU related to pre-existing mental health concerns and socio-economic factors associated with adolescent pregnancy. Our findings also suggest that lower levels of satisfaction with NICU care may be related to perceived stigma from care providers and bias against young pregnancy and parenting. However, without the unique voices of adolescent mothers, speaking to their NICU experiences, why adolescents experience the NICU differently remains relatively unknown.

Recommendation. It is important to understand adolescent mothers' experiences of the NICU. Qualitative research focused on deepening our understanding of how mothers experience the NICU is an essential starting point for understanding NICU-to-home transition experiences for this group.

Stigma in the NICU

From providers' perspectives, stigma is central to understanding the experiences of adolescent mothers in the NICU. This is problematic because experiences of stigma can have significant clinical implications for young mothers and their infants by compounding mental health issues and creating barriers to accessing care for fear of being judged or losing custody of their children (Recto & Champion, 2018; SmithBattle, 2020; SmithBattle et al., 2020) Understanding the significance of stigma in the health and social care experiences of pregnant and parenting adolescents could help reduce further marginalization of this group by understanding their lived experiences and specifically the impact of stigma. The Young Parent Stigma Scale (YPSS) measures several dimensions of stigma that may aid in understanding NICU related stigma, including internalized stigma, enacted stigma, anticipated stigma, racialized stigma, and felt stigma (Rice et al., 2019). Measuring stigma within the NICU, especially whether stigma correlates with some of the factors suggested in Chapter 4 as contributing to the NICU experience; for example, parenting confidence or competence, maternal-infant attachment, and maternal mental health, would help with understanding this experience from the adolescent mother's perspective. Additionally, exploring staff attitudes or beliefs related to adolescent pregnancy and parenting is also important in addressing the potential for marginalization among these NICU parents. The positivity toward teen mothers-revised (PTTM-R) scale assesses attitudes toward adolescent mothers and may be useful in assessing interventions designed to address stigma in the NICU (Kim et al., 2013).

Recommendation. It is important to understand the experiences of stigma in the NICU for adolescent mothers. Collecting data on young mother's experiences of stigma in the NICU as well as staff beliefs related to adolescent pregnancy and parenting could inform NICU staff education and practice guidance needs in reducing perceived stigma in the NICU.

Evaluating Trauma- and Violence-Informed Care in the NICU

Throughout this thesis work, the association between adolescent pregnancy and multiple social, psychological, and economic risk factors have been highlighted; these include experiences of trauma (e.g., childhood disadvantage (Smith et al., 2018), adverse childhood experiences (ACEs) (Hillis et al., 2004), and reported physical or sexual abuse/violence (Al-Sahab et al., 2012). In the findings of this thesis research, we also learned from providers that having a baby in the NICU was perceived as a traumatic experience, impacting maternal-infant attachment, parenting confidence and competence, and maternal mental health. As outlined in Chapter 4, findings highlight the opportunity to introduce trauma- and violence-informed care strategies within the NICU to help mitigate the negative influence of this experience as care that is not trauma- and violence-informed has potential to retraumatize and may negatively affect future service use engagement (Public Health Agency of Canada (PHAC), 2018; Sinko et al., 2020). Evaluation of service delivery interventions, such as the adoption of trauma- and violence-informed care strategies in NICU education and practice, is an important aspect of intervention research. Sinko et al. (2020) have developed and evaluated a self-report measurement tool, the trauma-informed care grade or *TIC Grade*, that would allow organizations advancing the provision of trauma- and violence-informed care to measure their efforts among youth recipients of care/services. Thus, using the *TIC Grade* tool pre/post implementation of trauma- and violence-informed care strategies in the NICU (such as those outlined in Chapter 4, Table 1) could help measure the perception of the NICU as traumatic and evaluate the success of interventions to limit this perception.

Recommendation. NICUs implementing trauma- and violence-informed care can measure success using the *TIC Grade* self-report measure for assessing perception of quality of trauma-informed care. This measure could also help identify areas where further staff training or organisational support are needed in providing trauma- and violence-informed care in the NICU.

Family Integrated Care (FICare) for Adolescent Mothers

Family Integrated Care (FICare) is a model of neonatal care based on the principles of Family-Centred Care (FCC); a guiding framework for most care in NICUs, FCC is centred around the core tenets of respect and dignity, information sharing, and participation and collaboration in care (Dennis et al., 2017). In the FICare model intervention, parents are taught to be involved in all possible aspects of their infant's care with the goal of promoting parent-infant interactions and building parent confidence through parent-staff partnerships (Family Integrated Care, 2020). As noted in the discussion of Chapter 5, FICare with adolescent parents could support the types of relationships required for successful NICU-to-home transitions. FICare could also be important in addressing the potential negative impact on the NICU experience for adolescent mothers described in Chapter 4, as this model of care is associated with improved parental stress and anxiety as well as parenting confidence and role attainment (Broom et al., 2017; Cheng et al., 2021; Hall et al., 2017; O'Brien et al., 2018). However, FICare has not been evaluated in the adolescent parent population. Importantly, mothers included in the model's evaluation were older (mean maternal age is 31), married (>90% married), and well-supported by family or other social supports (O'Brien et al., 2018) – thus limiting transferability to adolescent mothers. Therefore, the intervention, while promising, warrants evaluation among this group.

Recommendation. Interventions, such as FICare, can support the parenting confidence and competence of young mothers in the NICU. However, prior to broad implementation among adolescent parents:

a. FICare needs to be adapted for use with young mothers;
b. a pilot study evaluating acceptability of this intervention among key stakeholders (e.g., mothers, families, staff) and feasibility of the intervention needs to be conducted; and

c. a trial measuring the effectiveness of FICare with adolescent mothers on important mother/infant dyad outcomes, including breastfeeding, parental stress and anxiety, and parenting confidence, should be completed.

Adolescent Focused Transitional Care

While FICare may support an improved NICU experience and the facilitation of NICU staff-parent partnerships, findings presented in Chapter 5 suggest that partnerships extending beyond the NICU are an important ingredient in perceived NICU-to-home transition success. Additionally, throughout this thesis the unique and often complex needs of adolescent mothers have been emphasized; yet this is an element missing from most discharge frameworks or interventions in the literature that are aimed primarily at supporting parents' feelings of readiness for discharge. In a recent integrative review of transition home from NICU for extremely premature babies, Green et al. (2021) identify knowledge and skill among community health professionals related to post-NICU care as a missing research focus; citing that pediatric and community services may not fully understand the ongoing needs of NICU-graduates. And while this is likely true, the paradox highlighted in the findings of our research is that community providers, particularly public health nurses (PHNs) in targeted home visiting programs such as Nurse-Family Partnership (NFP), are skilled at working with the complex needs of adolescent mothers – suggesting that collaboration between NICU and community is what needs to be achieved to best support the adolescent mother/infant dyad.

Recommendation. Findings of this thesis, combined with maternal perspectives, should inform the development and evaluation of an adolescent focused NICU-to-home transitions framework aimed at improving key outcomes such as maternal-infant attachment, parenting confidence and competence, and maternal mental health. Development of this framework should include key stakeholders involved in the NICU-to-home transition process, including PHNs from both targeted and universal home-visiting programs (Aston et al., 2014), infant-development programs, primary care clinicians, specialty adolescent clinics, and maternity homes.

Arts-based Data Generation within Virtual Interviews

This thesis identified opportunities for advancing arts-based data generation in qualitative applied health research, particularly incorporating visual elicitation tools within face-to-face, semi-structured or in-depth qualitative interviews to enhance the richness and depth of data generated. These tools were suggested to be especially valuable in circumstances where difficulties establishing rapport, power imbalances and participant factors (such as cognitive development) threaten the interview process and quality of data. However, the COVID-19 global pandemic has changed the research landscape; with public health restrictions in many countries significantly limiting the ability to conduct in-person research, thus leading researchers to shift methods toward virtual modes of data generation (Lobe et al., 2020; Nind, Coverdale, et al., 2021).

Videoconferencing applications for online interviews and focus-groups have become the “socially distant” versions of traditional in-person qualitative methods, with researchers adopting these methods even pre-pandemic to gain access to larger populations of participants, to save costs, and support research among geographically diverse groups (Gray et al., 2020; Lobe et al., 2020). The evolving literature related to the adoption of virtual interviewing suggests similar quality to in-person data generation (Deakin & Wakefield, 2014; Gray et al., 2020; Lobe et al., 2020; Nind, Meckin, et al., 2021), however there is limited guidance on how elicited drawings or other co-produced arts-based methods fit within these virtual methods, where the researcher and participant occupy different physical spaces; promising examples include delivering arts-based resources to participants or adapting approaches to ensure objects or supplies can be found in participants' homes (Meckin et al., 2021). Additionally, common videoconferencing platforms (such as Zoom and Microsoft Teams) offer whiteboard applications, where participants can collaborate on digital drawings similar to a physical, classroom or office whiteboard. However, guidance on use of such applications, or other virtual drawing applications, for qualitative interviews using drawings for elicitation purposes has not been described. Shifting research methods online also requires the researcher to carefully consider the issue of digital divide, or the inequalities that may exist across individuals and groups related to access and used of information and communication technologies (Aissaoui, 2021; Lai & Widmar, 2021). Attention to this issue can ensure potential participants are not excluded from research based on access to internet and related technology and that research plans do not magnify inequities or lead to further marginalization (Nind, Coverdale, et al., 2021).

Recommendation. Shifting arts-based data generation methods online using videoconferencing platforms, particularly co-produced drawings such as timelines and relational maps, requires further exploration to determine appropriate processes and practices that are effective while also mindful of equity issues and the digital divide.

Policy

This thesis work has some important implications for health policy, primarily at the unit and organizational level, but findings also contribute to integrated care conversations occurring at the systems level.

Unit-based policy

Support from the NICU leadership level is required to address many of the challenges adolescent mothers face both in the NICU and when transitioning from hospital-to-home. An example of a unit-based policy identified as problematic through this research is parent visiting rules or the restriction of visiting to certain individuals (e.g., only parents and grandparents). NICU visiting policies are generally intended to limit the risk of acquired infection among vulnerable infants (Tan et al., 2018), however, as identified in the findings presented in Chapter 4, these rules seemed to reflect more traditional parenting and support patterns, thus leading to potentially discriminating practices toward those on the margins of these views of support persons for mothers with infants in the NICU.

Recommendation. NICU visiting guidelines often reflect more traditional families (2 parents) or more traditional support patterns for women in the postpartum period (mother and her mother). Strict enforcement of visiting guidelines by NICU staff could be viewed as structural violence, marginalizing those with family support patterns different from the norm. Flexibility needs to be built into unit-based visiting policies to ensure equitable access to maternal social support systems throughout the NICU stray and to reduce feelings of stigma from NICU staff among adolescent mothers.

The high level of critical illness in the NICU environment, contributing to a perceived lack of staff time for establishing relationships with parents or supporting needs outside of the physical needs of the infant, was seen as affecting the overall NICU experience and the perception of the NICU environment as hostile for some parents. An example of unit-based policy that could ameliorate this tissue of time not being fair in the NICU (as described in Chapter 4) is one that accounts for the needs of the mother-infant dyad when planning nursing care requirements. Many NICUs use an hours per patient day (HPPD) calculation to allocate nursing resources for a particular day. HPPD is a measurement of the average number of hours needed to care for each patient on a given unit (Welch & Smith, 2020) and helps unit leaders make decisions related to bed availability and staff-patient ratios. NICU based HPPD often takes into consideration the unique clinical care requirements of NICU patients affecting nursing resource utilization including patient acuity, surgical or other procedures, and obstetrical responsibilities (Baranowski & Conway, 2011). However, HPPD rarely (if at all) takes into account maternal or family factors that may affect resource utilization (e.g., supporting mental health issues or coordinating social services) as well as the additional time and resources required for admissions and discharges (Fike & Smith-Stoner, 2016). When care is allocated by infant needs alone, the result is less nursing time for parents with high social or emotional needs, thus leading to the potential of the NICU admission being experienced as traumatic. Support from NICU leadership and likely broader organizational policy related to resource allocation is needed to support adequate nursing care for vulnerable NICU families.

Recommendation. Allocation of nursing resources in the NICU is often based on infant factors alone, making it difficult to support families with high social and emotional needs. Units need to account for maternal and/or family factors when creating resource allocation guidelines to support nurses in providing optimal family-centred care.

Organizational Policy

Support for parents is increasingly recognized as a priority within pediatric care settings and is linked to improved clinical outcomes among both children and their parents (Davidson et al., 2007; Doupnik et al., 2017; Foster et al., 2018). Findings of our study suggest that the NICU is a traumatic experience for most parents, with the literature suggesting long-term psychological effects (Al Maghaireh et al., 2016; Roque et al., 2017; Schecter et al., 2020). Recommendations for supporting parental mental health in the NICU includes layered levels of emotional support for all parents in the NICU, with targeted care for those at risk or experiencing distress (Hynan et al., 2015). Part of this layered approach is the inclusion of mental health professionals (e.g., mental health nurses, psychologists, and/or psychiatrists) as part of the NICU team. Our findings support this layered approach, especially as the mental health needs of certain parent populations (e.g., adolescent with a pre-existing mental health diagnoses) may benefit from specialized care, beyond the scope or time demands of NICU nurses and social workers, and that is co-located in the NICU. Co-location of services is important as this can decrease barriers to referral for providers, increase access for parents, and reduce stigma associated with mental health services (Briggs et al., 2007; Venkataramani et al., 2017). Organizational support is required to prioritize parental mental health and the co-location of parent-focused mental health services within pediatric acute-care settings.

Recommendation. Supporting maternal mental health during the NICU hospitalization can have a significant impact in reducing the psychological effects of this experience. Additionally, co-location of providers or services that support mental health within the NICU can decrease barriers to accessing these services and reduce stigma associated with mental health challenges.

Organizational support would also be required to support intraprofessional collaboration, (i.e., collaboration between nurses in different roles), particularly between nurses in different systems/settings (e.g., NICU nurses and PHNs). As identified in our findings, this type of collaboration is an important ingredient in mobilizing adolescent mothers and their infants forward in their NICU-to-home transitions, but this was difficult to imagine in practice. Nursing teams often operate as part of broader interprofessional teams – collaborating with physicians, dieticians, pharmacists, occupational therapists and other health professionals, as well as social care providers – when planning and delivering care for their clients. Additionally, intraprofessional collaboration happens between nurses within a team but across different levels and roles (e.g., nursing students, registered nurses, registered practical nurses and nurse practitioners or direct clinical care nurses and clinical leaders) (Ma et al., 2018). However, the same conditions that make it difficult for mothers to navigate the systems involved in NICU-to-home transitions (i.e., different locations, different funding models, different aims of care etc.), create challenges for NICU nurses and PHNs to collaborate in caring for these mother/infant dyads. The result is that organizational and system structures prevent nurses with expert knowledge and skill from meeting the needs of their patients/clients. Incorporating PHNs into the NICU circle of care early in the NICU stay would enhance collaboration between these two expert nursing teams and could support the provision of care for the mother-infant dyad instead of the primary focus on the infant. PHNs as part of the care team could also support the continuity of care perceived as important in the transitions from NICU-to-home (Fairless et al., 2020). For public health programs, such as NFP, that are already engaged with mothers prior to NICU admission, stakeholders from the acute care system (e.g., obstetrical programs and NICUs) could serve on community advisory boards to ensure connections between programs are facilitated and strategies for collaboration are outlined for when programs intersect.

Recommendation. Nurses in acute care settings and community or primary care settings have specific knowledge, skills, and expertise that could benefit patients/clients as they cross these care boundaries. Organizations should support intraprofessional collaboration between nurses, across care settings, for the benefit of the patient/client.

While individual actions – related to how providers engage with the people for whom they provide care – are required to create emotionally and culturally safe environments, organizations are responsible for supporting a culture of learning and capacity-building essential to creating these safe environments for all (Public Health Agency of Canada (PHAC), 2018). Organizational actions to support implementation of trauma- and violence-informed care in the NICU include: supporting trauma- and violence-informed care training or education for all staff; conducting a trauma walk-through of the unit to identify and address access issues and parent experiences of the physical environment, including privacy concerns and addressing both physical and emotional safety (National Center on Substance Abuse and Child Welfare, 2015); allowing time and space for the development of therapeutic relationships between staff and parents; exploring services and interventions that support parents, including social and emotional needs; and supporting clinical supervision, peer support, and self-care programs for staff.

Recommendation. Organizations need to be aware of what structural policies or attitudes result in discrimination or systemic violence (e.g., visiting policies) and then need to work toward change that recognizes the impact of violence on people's lives and well-being, reduces harm, and improves care and services for all. Specific actions at the organizational level to support implementation of trauma- and violence-informed care principles in the NICU are outlined above.

Healthcare and Social Care Systems Policy

The abovementioned collaboration between NICU nurses and PHNs, in an effort to provide tailored or needs-based care to adolescent mother/infant dyads as they transition home from NICU, is an example of professional integration within an integrated care framework (World Health Organization (WHO), 2016). Integrated care is often synonymous with coordinated care or seamless care and is associated with safe and efficient care for patients with complex care needs (Brown & Menec, 2018). Many of the issues raised by providers in this thesis work point to the fragmentation (versus integration) of the health care and social care systems that NICU parents have to navigate. Partnerships that cross traditional organizational and professional boundaries can mitigate this fragmentation and lead to improved outcomes for families (Valentijn et al., 2013). Discussion of health systems integration is beyond the scope of this thesis; however, our findings highlight the disconnected or patchwork nature of the health care system in Ontario.

Nursing Practice and Education

Throughout this thesis work the distinctiveness of the adolescent mother is highlighted however, findings also suggest that a fine balance must be achieved between tailoring care to unique, adolescent-focused, needs and perpetuating bias toward pregnant and parenting young women and girls. Nursing education and practice rooted in the principles of trauma- and violence-informed care can help to avoid missteps and lead to more adolescent-friendly care.

Trauma- and Violence-Informed Care in Nursing Education and Practice

Trauma and violence are pervasive in society and as such, many of the people encountered in health care and social care systems will have histories of trauma and violence (Public Health Agency of Canada (PHAC), 2018). Additionally, childhood disadvantage, adverse childhood experiences (ACEs), and experiences of violence are associated with adolescent pregnancy and motherhood (Bekaert & SmithBattle, 2016; Hillis et al., 2004; Smith et al., 2018); highlighting the importance of trauma- and violence-informed education and practice among providers caring for pregnant and parenting adolescents. Trauma- and violence-informed care education with health professionals and educators can lead to: (a) a better understanding of the link between violence, trauma, behaviour, pain and substance use; (b) changes in practice, including active listening and empathy, less use of jargon, and less judgement across care encounters; and (c) changes to the organization or practice setting, including changes to the physical environment or additional staff training initiatives (Wathen et al., 2021). However, our findings suggest that education and practice of these principles vary across nursing roles. For example, the PHN providers in this study spoke to trauma- and violence-informed training as well as application in practice, but this was not the case among NICU nurses. This suggests trauma- and violence-informed care principles may be a missing piece in undergraduate nursing education; this was also highlighted in a review of trauma-informed education in the health sciences (Li et al., 2019). Additionally, frequent training or "booster shots" of content and application strategies are likely required to sustain practice within a trauma- and violence-informed framework (Wathen et al., 2021, p. 8) – suggesting trauma- and violence informed education should be tailored to specific nursing practice settings (such as the NICU) and re-visited frequently to build on or boost the foundational learning in undergraduate education.

Recommendation. Pregnant and parenting adolescents are a unique sub-set of the adolescent patient population and require nurses that understand the complex nuances of caring for this population. Broadly, education focused on social determinants of health across the lifespan and trauma- and violence-informed care principles provide a foundation for appropriate and sensitive care for adolescent mothers and infants. Specifically, nurses in practice settings that care for pregnant and parenting adolescents should advocate for policies and processes that are in line with trauma- and violence-informed care principles, placing an emphasis on physical and emotional safety, client choice, and client-strengths.

Adolescent-friendly Care

Trauma- and violence-informed care principles can help to shift stigmatizing attitudes among nurses and other health care and social care providers, thus leading to physically and emotionally safe care and improved system responses to the needs of all people, not just those experiencing trauma and/or violence (PHAC, 2018; Wathen et al., 2021). These principles also provide a foundation for safe and equitable care for adolescents; however, care that is acceptable to the needs of adolescents can also be realized by understanding what it means to provide adolescent-friendly care. Adolescent-friendly care should be accessible, acceptable, equitable and effective (WHO, 2009). Findings of our research suggest that adolescent-friendly care is possible within the context of the NICU but is not always operationalized. Supporting parents with the costs associated with the NICU stay or arranging travel can lead to accessibility of the NICU. Ensuring privacy and confidentially for parents as well as engaging in strategies that reduce stigma or judgement among NICU staff can lead to care that is acceptable to adolescent parent. Improved services or support within the NICU to address psychosocial needs of adolescent mothers can enhance the appropriateness of NICU care for adolescent mothers. Finally, care in the NICU could be more effective for adolescent mothers if health care and social care providers are able to dedicate sufficient time to work with adolescent mothers and have the required knowledge and skills to work with adolescents.

Recommendation. Together with trauma- and violence-informed care principles, the characteristics of adolescent-friendly care should be incorporated into nursing education and practice within the NICU and other nursing areas where adolescents are among the client-population.

Addressing Stigmatizing Behaviours

Nurses have the ethical responsibility to safeguard human rights and promote equity; this includes refraining from judging, labeling, and stigmatizing behaviours towards persons receiving care (Canadian Nurses Association, 2017). A tool for addressing stigma toward adolescent parents may be useful for nurses who care for young mothers in their practice to recognize stigmatizing behaviours in their practice setting. The ACTS (Acknowledge-Create Circumstance for Reflection-Teach-Support) script is a structured communication framework developed to address peer attitudes and stigma in relation to substance use during pregnancy and helps nurses initiate conversations with their peers in the NICU about women who use substances from a place of curiosity rather than blame or anger (Marcellus & Poag, 2016). For example, when witness to disrespectful or judgemental language among staff, the ACTS script provides concrete language for nurses to initiate conversations aimed at combatting stigmatizing behaviours (Recto et al., 2020). The ACTS tool could be adapted to the adolescent pregnancy and parenting context to provide a concrete and practical approach to addressing attitudes and stigma among nurses in the NICU.

Recommendation. Adapting the ACTS structured communication framework to the adolescent pregnancy and parenting context and incorporating the tool into nursing education and practice could be a promising intervention for addressing stigma toward adolescent mothers in practice settings where adolescent parents are part of the client population.

Strengths and Limitations

There are some overall strengths of this thesis work. Specifically, this is the first study to explore the NICU-to-home transition experiences for adolescent mothers, it also adds to a very limited knowledge base of adolescent mothers' experiences of the NICU. Additionally, the application of Transitions Theory throughout the research process leads to findings that are relevant to the nursing disciplinary knowledge base by laying the groundwork for a situation-specific theory that could guide further nursing research and inform practice. The sampling strategy for this thesis work, with the inclusion of providers from both the NICU and community setting and the addition of NICU-to-home related interview questions within the British Columbia Healthy Connections Project process evaluation, created a maximum variation sample that allowed for the identification of patterns across the NICU-to-home care continuum. This triangulation of data sources served to enhance the overall credibility of the findings.

This study had to pivot as a result of the COVID-19 global pandemic, thus leading to the focus on providers' perspectives presented in chapters 4 and 5. This was a limitation of the overall thesis because, as outlined in Chapter 1, this was not the original study plan. Therefore, sampling of providers may have been different had this perspective been the focus at the outset of the study, for example, a greater emphasis on sampling other providers involved in the care of adolescent mothers (e.g., midwives, pediatricians, and community-based social workers) may have strengthened the findings. Additionally, the voices of mothers will be important for informing and challenging the recommendations from this thesis work.

Another limitation is that the majority of PHNs included in this study (n=11, 73%) were nurses delivering the NFP program. As a targeted home visiting program (Aston et al., 2014), NFP is delivered to a specific population of mothers based on risk (characteristics such as maternal age and degree of socioeconomic disadvantage determines eligibility for this intervention). Therefore, these providers' perspectives may not be reflective of the experiences of PHNs working in universal home visiting programs; where relationships with mothers are typically initiated in the postpartum period and there are fewer or less frequent visits with families in comparison to NFP. The importance of therapeutic relationships described in the findings of this thesis may be related to the number of nurses representing the relationship-based aspect NFP, however, this pattern was also observed in the accounts of NICU providers as well as PHNs delivering other home visiting programs. Additionally, the therapeutic relationship is described as foundational to home visiting programs aimed at supporting mothers and families, both targeted and universal (Aston et al., 2015).

Quality Considerations

Thorne (2016) offers a set of criteria by which studies adopting interpretive description methodology may be evaluated; these include epistemological integrity, representative credibility, analytic logic, interpretive authority, moral defensibility, disciplinary relevance, pragmatic obligation, contextual awareness and probable truth.

Considering each of these criteria for this thesis research can also serve to highlight its overall strength.

Epistemological Integrity

Epistemological integrity is the alignment of the methodological decision-making (e.g., research question, methods, and analytic processes) with the assumptions of the chosen research design (Thorne, 2016). For this thesis research, epistemological integrity was achieved by asking questions and applying methods consistent with interpretative description. This is evidenced through clear explanations of study methods as well as presenting findings that move beyond description of the phenomenon (e.g., what is happening) toward interpretation (e.g., highlighting patterns, relationships, and variation) but without purporting formal explanation (e.g., prediction and causation).

Representative Credibility

Representative credibility is the consistency of the study findings or claims with the way in which the study was sampled (Thorne, 2016). As this thesis research examined the provider's perspective of the NICU-to-home transitions for adolescent mothers, it was important to ensure that this perspective was clearly communicated through discussion of sampling procedures and descriptions of study participants, and not to imply that findings represent the maternal perspective in any way. Inclusion of providers from both the NICU and community as well as different disciplinary perspectives (e.g., nursing and social work) helped increase the variation of perspectives included within the provider sample, however, conclusions are presented based on these perspectives within the study context and do not claim to represent the experience of others.

Analytic Logic

Analytic logic is the degree to which the reasoning of the researcher is explicit throughout the research process (i.e., from scaffolding through to knowledge claims) (Thorne, 2016). This thesis demonstrates analytic logic in several ways; first, importance of this research was established through a thorough review of the literature as well as a critical examination of relevant theory; second, methodological decision making was clearly described throughout the thesis work and resulting publications – including the impact of the global pandemic on study procedures; third, reflexive and analytic memos as well as diagrams created throughout the research process serve as artifacts of the reasoning process used in this thesis; fourth, frequent consultation with the thesis committee and with a graduate student qualitative research interest group helped to advance analytic thinking and ensure developing patterns were adequately defined, described and challenged; and finally, findings were presented in such a way that interpretive claims were grounded in the data, with the inclusion of direct quotes, thus affording the reader access to the researchers line of reasoning.

Interpretive Authority

Interpretive authority in qualitative research is the assurance that a researcher's interpretations are external to their own biases or experience (Thorne, 2016). Recognizing the role of the researcher as the research instrument in qualitative research, reflexive journaling was an important aspect of maintaining interpretive authority in this research. Journaling allowed the researcher to explore assumptions and challenge interpretations throughout the research process. Presenting early theoretical work at a disciplinary-specific academic conference and preliminary analysis at a graduate student qualitative interest group meeting also served to check the developing findings of this thesis against various disciplinary viewpoints, thus contributing to sound interpretive description findings. Additionally, having a thesis committee with expertise in public health, child development, neonatology, and pediatric rehabilitation, helped to expand the researcher's thinking beyond the NICU (the student researcher's primary nursing background) and to genuinely explore both contexts involved in the NICU-to-home transition (i.e., hospital and community).

Moral Defensibility

Moral defensibility is the impetus within applied qualitative research to generate knowledge with the purpose of informing practice (Thorne, 2016). This thesis was explicitly designed to inform practice in the NICU and in the community related to NICU-to-home transitions for adolescent mothers. As outlined above, this work has important implications for nursing practice including the adoption of trauma- and violence-informed care principles in the NICU context and intraprofessional collaboration between NICU nurses and PHNs during the NICU-to-home transitions process.

Disciplinary Relevance

Disciplinary relevance is the obligation for research products in the applied and practice disciplines to make a contribution to the disciplinary knowledge base. While not exclusive to the nursing discipline, transition is a central concept to nursing research, education, and practice (Chick & Meleis, 1986). This thesis work is underpinned by nursing theory, including Transitions Theory (Meleis, 2010), Uncertainly in Illness

(Mishel, 1990), and Becoming a Mother (Mercer, 2006); it also contributes foundational work for the development of a situation-specific theory to guide nursing practice related to transition home from NICU for adolescent mothers – thus contributing to the nursing knowledge base (Im, 2021).

Pragmatic Obligation, Contextual Awareness, and Probable Truth

The products of qualitative research need to demonstrate consideration for the social and historical contexts within which they were produced. This involves the researcher being aware of (a) the implications of their findings on practice, or pragmatic obligation; (b) the social construction of research findings, or contextual awareness; (c) and the possibility that even knowledge claims that meet the best truth criteria may prove untrue, or probable truth (Thorne, 2016). This thesis work demonstrates careful attention to situating findings within the context from which they were generated, and the limits of these findings are clearly stated.

Plans for Knowledge Translation

The findings of this thesis work, as outlined in the preceding sections, have implications for research, policy, practice, and education; therefore, knowledge translation strategies are important to ensure key stakeholders, clinicians, and decision-makers are aware of the findings and how they may be practically applied in various settings. The theoretical work highlighted in Chapter 2 was presented at local academic and national maternal-child focused conferences prior to publication in an academic nursing journal. The article presented in Chapter 3 was also published in an academic nursing journal, with each publication being featured by the editor on the publication's blog (Chin, 2020a, 2020b). Dissemination using Twitter has also increased the visibility of these publications to a global audience.

This study also relied on partners from local NICUs and Public Health Units for study recruitment. These partners represent key-stakeholders in the dissemination of the findings of this thesis work, in particular the results presented in chapters 4 and 5. Findings will be shared during research rounds and team meetings at the seven sites involved in recruitment for this study. Additionally, findings and implications will be summarized into clear, concise, and visually appealing one- to two-page information sheets and distributed provincially through the Public Health Nursing Practice, Research, and Education Program (PHN-PREP) network. PHN-PREP is a team of nurses, researchers, and public health leaders, involved in the mobilization of evidence and resources to support home visiting program teams; collaborating with this group will facilitate the sharing of findings across the public health programs involved in caring for and supporting young mothers.

An important by-product of the diagramming process in the analysis of qualitive data is the strength of such visuals in disseminating research findings. The graphic representations of the findings presented in chapters 4 and 5 will not only be included in the submitted manuscripts but will be central to presenting these findings back to stakeholders, at academic conferences, and using social media platforms such as twitter.

Conclusion

This thesis makes a significant contribution to the nursing knowledge base; theoretically through the exploration of transitions theory, in advancing arts-based elicitation methods in qualitative interviewing, and in enhancing understanding of NICU-to-home transitions for adolescent mothers. This research represents the first studies to explore NICU-to-home transitions for adolescent mothers from providers’ perspectives, also adding to a very limited literature base on adolescent mothers’ experiences of the NICU in general. Findings of this body of work can inform NICU care that is both trauma- and violence-informed and adolescent-friendly. They can also inform care-transition pathways reflective of the complex needs of adolescent women and their infants. Findings can also be used conceptually, enabling decision makers and clinicians to understand client experiences, provide empathy, attain insight into contextual issues and stimulate new ideas about common problems thus leading to increasingly beneficial care (Jack, 2006).

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